
UNIT 5 DISABILITY AND FEMINISM

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5.1 INTRODUCTION

Disability challenges our fundamental notions of reality, the world, culture, and most importantly, our own bodies. Disability has been historically viewed as a physical or mental limitation affecting an individual. Spinal cord injury, cerebral palsy, blindness, deafness and speech disorders, amputation, mental retardation, autism, etc. are some examples of disabling conditions. Current perspectives move beyond viewing disability as an individual limitation to looking at it as a social issue that is the outcome of social discrimination and stigmatisation.

More importantly, women with disabilities suffer the triple discrimination of being women, being disabled, and being poor. In this unit, key feminist concepts of gender roles, body image, sexuality, and care are used to analyse the impact of disability on women. Beginning with an understanding of the concept of disability, you will read more specifically about disability in India, its relationship to questions of gender, and the inter-relationships between disability and feminism. Through a feminist perspective, we will question and challenge dominant assumptions about disability so that we arrive at a more comprehensive understanding of the inter-play between gender and disability.

5.2 OBJECTIVES

After completing this unit, you should be able to:

- Broadly define the concept of disability;
- Describe a range of discriminations faced by people, particularly, women with disabilities;
- Explain the relationship between feminism and disability; and
- Identify the major feminist disability scholars and describe their important contributions to making disability an agenda of the feminist movement.

5.3 INTRODUCING DISABILITY

After women, disabled persons represent the largest minority group in society particularly in the light of the fact the chances of developing a disability increase exponentially as one grows older. Thus, in a way, everyone is only temporarily able-bodied in the course of the lifespan. Furthermore, accidents and injuries are a major source of injury. Therefore, disability is not a unique experience of particular individuals labelled as disabled but of each one of us at some point in our lives.

Disabled persons are also not a homogeneous group: type and degree of disability, gender, class, caste, race, ethnicity, sexuality, residence, and other cross-cutting social, economic, political and cultural factors frame the experience, perception, and understanding of disability as a phenomenon involving multiple forms of oppression. But what is a disability and what does it mean to be disabled in the first place? Disabilities may be congenital or from birth. For instance, most mental retardation is congenital. Malnutrition and micronutrient deficiencies may result in disabling conditions in children in the form of stunted physical and mental growth. When disabilities are acquired later in life due to accidents, injuries or advancing age, they may be characterised by episodic upsurge of symptoms and/or progressive degeneration. Many mental illnesses like schizophrenia, multiple sclerosis, and Alzheimer disease fall in this category. A disability may be static such as the loss of limb due to an amputation. Then there are also hidden and visible disabilities. Diabetes and epilepsy are hidden disabilities while leprosy and blindness are visible conditions. One of the bones of contention in defining the concept of disability is how to conceptualise the disabling consequences of diseases, particularly chronic diseases, within the disability paradigm. In parts of the world conditions like diabetes, cardiovascular disease and HIV/AIDS are legally recognised as disabilities, while in other places including

India, the legal regime on disability is more restrictive and only recognises a handful of physical, sensory and mental impairments as disabilities. Nonetheless, irrespective of the conditions recognised as disabilities, a disability, generally, has two components, i.e. the medical limitation and social prejudice, which often gets translated into discriminatory behaviour towards the disabled person. In legal documents and policy statements, disability is defined in terms of what qualifies for public assistance.

Now that you have a broad understanding of the concept of disability, let us look more specifically at disability in the Indian context.

5.4 DISABILITY IN INDIA

Persons with disabilities are the most neglected and disempowered section of the population. Due to their marginalised status, they are denied the fundamental civil, political, social and economic rights that are the prerogative of all citizens in a democracy. The plight of women with disabilities is even worse, since they have to confront the double oppression of gender and disability. Indeed not only are they a socially invisible category but their plight is worse than both men with disabilities and other non-disabled women.

Conservative estimates show that 18.49 to 21.92 million persons suffer from some form of disability in India accounting for 1.8 to 2.1% of the total population (census of India 2001)¹. Using a wider definition of disability which includes conditions like diabetes and cardiovascular disease, the World Health Organisation (WHO) estimates that 6%-10% of the population suffers from identifiable physical or mental disability. That comes to over 70 million persons in India. It should be noted that estimates of the total number of persons with disabilities in a country vary depending on the definition of disability used, degree of impairment, survey methodology including use of scientific instruments for identification and measurement of the disabling conditions. Such phenomena as war, ethnic conflict, HIV/AIDS, industrial injuries, and road accidents are increasing the number of disabled persons. Ironically, enhanced life expectancy has increased manifold the incidence of old age-related, chronic disease induced disabilities worldwide as well.

Historically, there has been a deep-rooted cultural antipathy to persons with disabilities. Throughout the ages, the disabled have been looked down upon with disdain, almost as if they were sub-human. They have been portrayed as medical anomalies, helpless victims and a lifelong burden for family and society. Even in religion and mythology, negative characters were attributed some form of deformity, be it Manthara, the hunchback in the *Ramayana* or Shakuni,

the “lame” of the *Mahabharata*. Indeed, the law of karma decreed that being disabled was the just retribution for past misdeeds. Such constructions of the disabled by the non-disabled has the dual effect of not only justifying the complete marginalisation and disempowerment of a whole population group, but also leads to the internalisation of such negative stereotypes by the disabled themselves. This acceptance translates into passivity, dependency, isolation, low self-esteem, and a complete loss of initiative. Pity, segregation, discrimination, and stigmatisation became normalised in the management of persons with disabilities. Needless to say the plight of women with disabilities is even worse.

Instead of giving rights to disabled citizens and empowering them, a culture of charity and welfare has been systematically promoted in India since the colonial period. Medical rehabilitation including distribution of assistive aids and appliances, special schools, vocational training in low-end occupations and sheltered employment, have been the pillars of state policy for the disabled. Furthermore, electoral politics of caste and gender have pushed the disabled to the margins of the political landscape making them a weak political constituency. They have in fact been systematically disenfranchised by the political system. Things began to change marginally after 1981 (International Year of Disabled Persons) when the issue of disability was opened up at the national level. The changing international climate focussing on human rights and empowerment of marginal groups impelled the government to make some policy changes such as token reservations in educational institutions and employment. But real progress in the form of concrete legislation to deliver the promise of equality of opportunity and social justice only came in 1995 with the passage of the Persons with Disabilities (Equal Opportunities and full Participation) Act. Other legislation soon followed. One of the positive outcomes of economic liberalisation and globalisation has been the introduction of a view of disability as a human right and development issue rather than simply a matter of charity and welfare. This perspective is slowly entering deliberations primarily due to the efforts of voluntary groups like the Disability Rights Group in Delhi (a cross-disability coalition of NGOs working in different parts of the country, playing a pivotal advocacy role) that lobbied with the government both for passage of the 1995 legislation, and for the incorporation of disability in the 2001 Census.

In the following section, let us attempt to draw some connections between what you have read above, i.e. disability in India, and questions of gender.

5.5 GENDER AND DISABILITY IN INDIA

How a person with a disability experiences the condition and is perceived by others is largely dependent on whether s/he is male or female. For instance, Michelle Fine and Adrienne Asch point out that women with disabilities experience “sexism without the pedestal” (1988, p.1) , i.e. they are doubly disadvantaged because not only do they experience disability- linked discrimination but they experience sexism without any of the recompense that non-disabled women may claim as wives and mothers. Men with disabilities also experience a similar assault on their masculinity. For a more detailed discussion on the relationship between masculinity and disability, refer to the unit entitled ‘Disabled Masculinity’ (Block 2, Unit 3 in MWG 004).

The 2001 Census estimates that there are over nine million women with disabilities in India constituting 3.5% of the population. Some researches estimate that there are over 35 million women with disabilities in India (Bacquer & Sharma, 1997). Others put the figure at 20 million, 98% of the disabled are illiterate: less than 1% can avail healthcare and rehabilitation services (ActionAid, 2003, p.15). But these statistics are only the tip of the iceberg when it comes to gauging the level of neglect, isolation stigma and deprivation that characterise their lives. The majority of women with disabilities in India suffer the triple discrimination of being female, being disabled and being poor.

While being a man and being disabled are very incongruous, being female and being disabled also implies a certain level of continuity as both are to varying degrees associated with notions of weakness, passivity, and dependence. But the likeness is only superficial because a disabled woman is also considered incapable of fulfilling the normative feminine roles of homemaker, wife and mother. Then, she also does not fit the stereotype of the normal woman in terms of physical appearance. Since women embody family honour, disabled girls are kept hidden at home by families and denied basic rights to mobility, education, and employment. They are less likely to be given in marriage than disabled men. Doubts around the capacity of women with disabilities to be sexual partners, homemakers and mothers abound. They are not considered capable of performing household chores, efficiently, having meaningful sexual relationships or producing and rearing healthy children. Under these circumstances, they may be married off to older already married or men in poor health. In short, women with disabilities do not have the same options of marriage and motherhood as non-disabled women. Being nurturing and caring are core characteristics of normative constructions of femininity, but women

with disabilities are themselves in need of care. This inversion reduces them to the status of being lesser than women.

Being powerless, isolated and anonymous, women with disabilities are extremely vulnerable to abuse and violence. In addition, help in activities of daily living like dressing, eating, and other bodily activities, renders the disabled woman more vulnerable to abuse both at home and in institutions. She will be less able to defend herself in a risky situation because she may not be able to run or scream for help. Then, persons with developmental disabilities may be too trusting of others and hence may be easier to trick, bribe or coerce. They may not understand differences between sexual and non-sexual tactile behaviour. Persons with speech and hearing difficulties may have limited communication skills to report abuse. Furthermore, since disabled persons are often taught to be obedient, passive, and to control their behaviour, this will render them easy victims

Women with disabilities face violations of their rights at every level. They are considered a financial burden and social liability by their families; they are denied opportunities to move outside the home, and have access to education; they are viewed as asexual, helpless and dependant; their vulnerability to physical, sexual and emotional abuse is enormous; their aspirations for marriage and parenthood often denied; they grow up ensconced within the walls of home or special institutions isolated and neglected with no hope of a normal life. A poignant picture of their plight is depicted in the recent Bollywood movie *Black* in which social class and family compassion are only partially successful in alleviating the life of the female protagonist who has multiple disabilities.

Although a rights-based approach has entered the disability rights movement, the specific concerns of women with disabilities have not yet found a place neither in the government policies and programmes nor in the voluntary sector. Legislation is a key tool for social empowerment but existing legislation on disability is silent when it comes to the concerns of women. Ironically or expectedly, the disabled rights movement all over the world including India is male dominated. It may even be blatantly sexist. Even within the women's movement, women with disabilities rarely figured as a distinct group in international covenants until the Beijing declaration in 1995. The Beijing document, *Platform for Action*, specifies women with disabilities as a particularly vulnerable group with little access to information on their fundamental rights. This is a serious lacuna, which needs to be rectified at various levels. One of the most important features of *The United Nations Convention on the Rights of Persons with Disabilities*, which was passed by

the General Assembly in 2006, is the incorporation of a separate article on women with disabilities. Being a signatory to this Convention, the India state is henceforth duty bound to incorporate a gender perspective in all its policies and programme in the disability sector.

Check Your Progress: What are some of the reasons which make women with disabilities especially vulnerable? Try to explain with the help of your own examples - either from real-life situations, or from books that you may have read, or films/movies that you might have seen.

5.6 DISABILITY AND FEMINISM

Even though the principle of the personal is political shows up very starkly in the way in which disabled women are portrayed in society, they have been missing from the mainstream agenda of feminism. Women's studies all over the world including India has tended to reflect a non-disabled or able bodied perspective, and it is this perception that has generated a critique within feminism itself by women with disabilities. The critique of feminism from the disability perspective has been done through key feminist concepts of gender roles, body image, sexuality and care.

Feminists with disabilities like Jenny Morris (1992) pointed out that disabled persons were rarely considered physically attractive. In fact, asexuality is intrinsically associated with persons with disabilities, particularly women with disabilities. According to Harlan Hahn (1988), desexualisation results in asexual objectification (as against the sexual objectification of women critiqued by feminists). Since physical appearance is so critical for a woman's identity, a negative body image will necessarily result in developing a negative self image undermining self confidence and increasing the sense of worthlessness. Furthermore, the denial of disabled women's sexuality and expulsion from traditional gender roles has not protected them from the threat of male violence, which is actually exacerbated due to their relative powerless position in society. According to Fine and Asch:

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

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

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

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

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

Many disabled persons including disabled feminists are of the view that disability can also be a source of strength, celebration and empowerment like race and class when it is viewed through the subjective lens of those directly experiencing it rather than the story of a perpetual passive victim. Only when this experience is politicised, can it become the springboard for genuine participation, integration, and empowerment of disabled persons.

There is no doubt that feminist categories of analysis and perspectives of analysis of the body help to illuminate the personal and social dimensions of disability. For instance, feminist ethics questions the notion of independence as a desirable, even viable category (Kittay, 1999). In her detailed analysis of disability constituted as a form of abnormality in cultural representations), Rosemarie Garland-Thomson (2002) locates feminist disability studies within the broader arena of identity politics and the body. Feminist disability studies foreground the ability/disability binary as a category of analysis, questioning the notion of biological normality and highlighting the socially constructed nature of the body.

5.7 FEMINIST DISABILITY STUDIES

The previous sections have broadly mapped the intersections between gender and disability and given you an insight into the manner in which feminist thought and disability perspectives can mutually enrich and expand each other.

This section will introduce you to some seminal contributions in the field of feminist disability studies. What exactly is feminist disability studies? According to Rosemary Garland-Thomson, it is much more than studies about women with disabilities.

“Like feminist studies itself, feminist disability studies is academic cultural work with a sharp political edge and a vigorous critical punch... it seeks to challenge our dominant assumptions about living with a disability. It situates the disability experience in the context of rights and exclusions. It aspires to retrieve dismissed voices and misrepresented experience in the context of rights and exclusions. It helps the social processes of identity formation. It aims to denaturalize disability. In short, a feminist disability studies re-imagines disability” (Garland-Thomson, 2008, p.197). Feminist disability studies counters or challenges oppressive narratives that dominate the collective understanding of disability. According to Garland-Thomson, these include the bio-medical narrative, which sees ‘impairments’ as flaws or defects that can be ‘put right’ through technology/bio-medicine; the ‘sentimental’ narrative that views disabled subjects as “lessons in suffering”; the narrative of ‘overcoming’, that views disability as a defect that must be compensated for; the narrative of ‘catastrophe’ that sees disability as a dramatic, disastrous event that elicits great coverage or utterly defeats a person and the narrative of ‘abjection’, that views it as a sorry state that must be avoided at all costs (Garland-Thomson, 2008, p. 206). Feminist disability studies, on the other hand, look at the disability experience as part of the great variation of humankind, rather than as a great disaster or calamity. Let us now briefly review some of the

seminal works that have contributed to our understanding and appreciation of disability as an integral part of life, embodiment and relating to the world.

Michelle Fine and Adrienne Asch's collection of essays, *Women with Disabilities: Essays in Psychology, Culture and Politics* (1986), set the stage for much future work in the area. Fine's introduction 'Beyond Pedestals' analyses the convergence of gender and disability as axes of exclusion and oppression. The other essays pertain to a wide range of issues including embodiment, sexuality, relationships, dependence, subjectivity, and the medicalization of the body.

Pride Against Prejudice: A Personal Politics of Disability (1991) by Jenny Morris is an influential text which draws on the author's personal experience of disability and critiques the exclusion of disabled women from the feminist agenda. Particularly significant is the conflict within feminism between disability and the right to abortion. Morris holds that selective abortion of disabled fetuses is a form of genocide. Morris looks at the concepts of masculinity and femininity and how they are applied to disabled men and women. Masculinity as a social construct can be very oppressive for disabled men, as it celebrates strength, performance, the ability to support a family. To be masculine is, therefore, the opposite of being dependent. Cultural representations of disability also highlight the awfulness of dependence for men, thereby making it even more demoralizing for them.

Elsewhere, Morris also addresses the need for disabled feminists to tackle the experience of impairment. The 'social model' of disability, which focuses on external and societal barriers, constraints and attitudes has, in a sense, pushed aside the experience of the disabled body. This marginalizes the experiences of people with learning difficulties, mental health difficulties, and chronic or progressive illnesses. By denying the experience of the body, disabled people run the risk of having their behaviour and appearance 'policed' by a sexist world.

The issues of bodily suffering and limitation and their relegation as stigmatized states, find powerful expression in Susan Wendell's highly influential work *The Rejected Body: Feminist Philosophical Reflections on Disability* (1996). Wendell argues that disability studies have strong masculinist influences which valorize strength and independence and do not take into account the experiences of women or the chronically ill. Diagnosed with 'myalgic encephalomyelitis' or 'chronic fatigue syndrome' in 1985, Wendell engages in her book with definitions of disability, and who produces them, for what purposes and to what effect. She analyses the ideological underpinnings of the concept of 'normalcy' and its critical importance in the construction of a 'disabled identity'.

Another important work is the Marian Corker's *Deaf and Disabled, or Deafness Disabled: Towards a Human Rights Perspective* (1998) which calls for a greater inclusion of Deaf persons into the disability community and Deafness into disability theory.

Carol Thomas's sociological study, *Female Forms: Experiencing and Understanding Disability* (1999) studies in detail the gendering of disabled subjects. By including the voices of disabled women and using their narratives as the starting point of theory building, she practices the teachings of 'feminist standpoint theory' wherein the participants in the research are not just data for the researcher, but active participants in knowledge construction.

One of the neglected areas in disability studies is that of intellectual or cognitive impairments. The issue of care, dependency/independence, and embodiment are deeply interwoven in the discourses on intellectual disabilities. An important narrative in the feminist disability studies literature is Eva Kittay's *Love's Labor: Essays on Women, Equality and Dependency* (1998). Kittay writes movingly about her personal experiences of mothering a mentally disabled daughter and then moves on to a philosophical and politically informed critique of the highly individualistic liberal western notion of 'independence' and 'equality'. She asserts that liberal ideology negates and devalues the need for human interdependence and mutual care. Disability forces us to acknowledge the universal need for mutual assistance and interdependence and its incorporation into a human rights agenda. Feminist theories of justice, such as those articulated by Martha Nussbaum in her *Frontiers of Justice: Disabilities, Nationality, Species Membership* (2006) claims that the disabled do not participate in the social contract of justice and speaks of interdependence and inclusiveness as the basis for justice rather than rivalry and competition.

The books and authors discussed above have paved the way for a virtual explosion in feminist disability studies, in the past two decades. They have complicated feminism by forcing it to contend with the complexity of human variation and the reality of the 'lived body'. At the same time, disability studies have been informed by feminist thought, forcing it to deal with the way gender intersects with disability and the implications of this intersection on identity and discrimination.

5.8 LET US SUM UP

You have seen in this unit how disability has been historically viewed as a physical or mental limitation affecting an individual. Disabilities such as spinal cord injury, cerebral palsy, blindness, deafness and speech disorders,

amputation, mental retardation, autism cause disabling conditions. Thus, through this unit we have learnt about the concept of disability. The unit also discussed major scholarly works that dwell on the gender impact of disability on women. A lot of the work in this connection has been done in the Western countries reflected in the citations of Western feminist scholars in this unit. Most of their insights have been validated by Indian scholars like Anita Ghai, Renu Addlakha, Meenu Bhambhani, Asha Hans and Annie Patri. Since 'women with disabilities' is still more or less invisible as an academic category and public policy issue, a lot of their work has been focussed on making a space for this issue in different fora, including the academy. Consequently, important critical concerns germane to the Indian reality, for example, such as the interface between disability and caste, reservation policy and gender among a range of other issues, await detailed investigation.

5.9 GLOSSARY

- Discrimination** : It refers to the act of differentiating between stimuli or of recognizing or understanding between the things.
- Identity** : It refers to the sense of self and the nature of personhood. Identities are perceived through categories such as similarities and differences. Identity is not static. On the other hand, it is fluid in nature. It also refers to a sense of belonging. Identities are also human managed entities in day to day life.
- Rights** : This is a broad term that addresses the issues related to citizenship, equality, justice and legitimacy. Rights are theorized as active or passive. It is contested as claims, power, liberty, and immunity. It is contended as the mirror image of duties.
- Mental Health** : Mental illness is classified in to neuroses and psychosis. Neurosis refers to over reaction to reality. Psychosis refers to the loss of contact with reality.
- Stereotypes** : It refers to a partial, prejudiced, biased, exaggerated view about a group, class of people, tribe, etc.
- Stigma** : The social attribute that discredits particular groups or individuals. It is applied in the context of body, character and social collectivities.

5.10 UNIT END QUESTIONS

1) Group Discussion

Discuss the following:

- a) How does disability affect the experience of gender?
 - b) How does gender affect the experience of disability?
 - c) In what ways are the experiences of men and women with disabilities different and similar?
- 2) There is an idea that persons with disabilities are freer than their non-disabled counterparts because they are less subject to gender role expectations. Is this true? If so, is the price of disability worth the potential freedom it may offer?
- 3) Popular Indian cinema has started engaging with disability related issues too. Write a critical review of any recent film dealing with disability and discuss it with your peers at your Study Centre (examples, 'Guzaarish', 'My name is Khan', 'Iqbal' in Hindi).
- 4) Try and identify a person with disabilities or the carer of a person with disabilities in your community. Using the ideas/concepts in the unit, discuss their experiences of disability. Write a note of about 500 words and compare it with your colleagues at the study centre.

5.11 END NOTES

¹ Please note that these figures are dated, since the 2011 Census has just been concluded in February 2011, and the most recent macro-level data on disability is yet to be made public. In addition a new disability law to replace the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 is currently in the drafting stage.

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