

Disabled Women: An Excluded Agenda of Indian Feminism

Anita Ghai

Abstract

I write this piece from the epistemic location of a woman with visible physical disability. My purpose in is to locate disabled women within the women's movement as well as the disability movement in India. I underscore the existential question for disabled women in the South Asian scenario. The lived realities of women with disabilities are impacted by the socio-cultural context of disability, including inescapable inequity and typecasting by patriarchy and normative hegemony. Based on my analysis of disability and gender, I submit that the concerns of disabled women strike at the core of both the disability rights and feminist movements. I hope that my musings will contribute to nuancing the understanding and awareness of both gender and disability.

Author Profile

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When I dare to be powerful – to use my strength in the service of my vision then it becomes less and less important whether I am afraid. – Audre Lorde

All human life begins in a complete state of dependence. Human minds and bodies are always in transition, moving from an incomplete, imperfect and vulnerable existence to a relatively autonomous existence. During this process of transition, individuals undergo experiences of shame and loss. But persons with disabilities are constituted as being overpoweringly the 'Other', their disability is symbolically considered a bundle of 'lack', 'tragedy', 'loss', 'dependency' and 'deviation'. They are considered inferior human beings, incapable of autonomous existence. This experience of disability transcends fault lines of nation, gender, class, caste, race and myriad other identities.

Approximately one billion people, or 15 per cent of the world's population experiences some form of disability. One-fifth of the estimated global total, or between 110 million and 190 million people, experience significant disabilities (comprehensive information can be found at <https://www.worldbank.org/en/topic/disability>). Prevalence of disability is estimated to be even higher in the developing countries. As per 2011 Census of India, 2.68 crore persons are 'disabled', which is 2.21 per cent of the total population.

Within the Indian subcontinent consciousness about the issues and concerns of disability is a fairly novel phenomenon. It was only in the 49th year (1995) of independence that the first legislation advocating for equal rights for disabled people became a reality. Historically, it is reported that the 1880s saw initiation of some educational and rehabilitative services (Chauhan, 1998, p. 46). When the United Nations declared 1981 as the International Year of Disabled Persons, efforts to rehabilitate disabled were renewed. The intervening period saw attempts at rehabilitation both by disabled people and by non-governmental organizations (NGOs). This got a significant boost as a consequence of advances in the 'scientific' understanding of the causes of impairment. The panacea for disability shifted from 'religion, charity and human rights' to medical science's ability to 'rehabilitate and cure' the disabled. It is important to note that within India the first statutory body established to deal with issues of disability was called the Rehabilitation Council of India (RCI), which started functioning in 1992. Disability at that time was largely framed within 'charity' and 'medicine', thereby severely limiting questions around its social and cultural constituents. There was an underpinning idea of 'personal tragedy' to the medicalized consideration of disability. Disability was attributed to terrible chance which occurs at random to unfortunate people (in India it is still commonplace to attribute it to past sins).

Research on disability in India in the last twenty years has laid emphasis on disability as a physical or a mental condition. It has not been recognized as a social condition, which carries heavy stigma. As Brian Watermeyer says

Some losses relate directly to disability, some do not; often disability and impairment are interwoven with identity and experience in a complex narrative which renders

separation or identification of ‘disability losses’ meaningless. The very real danger for disabled [women] is that this sphere of our human experience, of our sense of self, may be rendered less admissible or possibly banished entirely from view under the host of moral imperatives exercised by a medicalizing society — to overcome, normalize, disguise, defeat, disown, defy or otherwise avoid the perceived emotional trappings of disablement. (Watermeyer, 2009, p. 99)

The social model contrasted with the medical understanding, which treated disability and impairments synonymously so that disability was located within the body or mind of the individual, whilst the power to delineate, control and cure rested with the medical and paramedical profession (Oliver, 1996a). The social model emphasized disability as a category located within society. It did not attribute the problem to individual limitations, of whichever kind, but the society’s failure to include the needs of the disabled people in organizing itself. The object in this model, shifted from the disabled to the social structure, initiating also a shift in subjectivity from ‘them’ (read able-bodied society) to ‘us’ (read disabled). The social model proved to be particularly empowering for persons with disabilities as Tom Shakespeare (1992, p. 40) reflects, ‘To mention biology, to admit pain, to confront our impairments has been to risk the oppressive seizing of evidence that disability is really about physical limitations after all’. Social model opened the possibility of disabled men and women as embodied beings offering insights on the surrounding environment. In other words, it helped demonstrate that it is not disabled bodies per se which script the understanding, rather, the way in which society constructs ideal bodies that some bodies are labeled ‘disabled’.

Although men and women with disabilities experience similar forms of devaluation, isolation, and discrimination, the gender quotient has a profound effect on the material and non-material experience of disability for women. The prevalence of disability is higher among women than among men. The WHO World Report on Disability (2011) estimates that 19% of women and 12% of men have a disability. Women are more likely to develop a disability throughout their life cycle. During childhood due to neglect, while giving birth, or due to abuse, poor health and poverty.

Gender and disability combine to form some of the most severe forms of marginalization and discrimination. Women with disabilities face exclusion from education and employment and are at higher risk of violence, neglect and poverty than women without disabilities. Since the rights of people with disabilities were forgotten and neglected in society, it is not surprising that the women’s movement in India was equally exclusionary in acknowledging disability as a critical marginal category. Feminist scholarship too failed to pay attention to the experiences of women with disabilities.

Despite its empirical vicissitudes and even the violence that sometimes accompanies it, care for disabled people was either romanticized or demonized. The organization of care was regularly represented as a significant barrier to the emancipation and independence of disabled people. However, the multiple perspectives that could dispel romanticizing impulses within caregiving accounts (that privilege loving experiences and neglect traits like aggression or relational discord) were ignored (Simplican, 2015).

Disability Studies contends that the feminization of care in a phallogocentric culture makes participants in a caring relationship—regardless of gender identity—necessarily subordinate. I recall Julia Twigg’s work on older people’s experiences of being given a bath. What she says is illuminating,

One person, strong and able, stands above and over another who is frail and physically vulnerable, forced to rely on their strength and goodwill. Being naked in the face of someone who is not, contains a powerful dynamic of domination and vulnerability, and it is often used in situations of interrogation and torture as a means of subjugating the individual. (Twigg, 2000, p. 21).

Even if dependency is recognized as an essential part of the human condition this should not obscure the fact that some people’s experience of body (with its impairment/s) places them at much greater risk of losing their dignity and rights. Someone who, for example, does not use speech to communicate, has a high level of cognitive impairment, and/or relies on others for help with all their daily bodily functions. While it may help to recognize the way—as social beings—individuals dependent on one another, limitations are qualitatively different. However, in contrast to ‘cure’, ‘Care’ means providing support, making differences less problematic, acknowledging difference, even though functional capacity may change over time.

Legal capacity legislation that address issues of care, and the debates around it, have made a significant impact in bringing these issues to the forefront. Conversations with persons with mental health problems and persons with intellectual disabilities underscore the impact that legal capacity legislation can have on the everyday lives of persons with disabilities. Generally, participants lose their legal capacity in situations where they face hopelessness and powerlessness. The recipients of care and guardianship express frustration at the limitations on their capability to take decisions for themselves, although some acknowledge the support needs they have. Nonetheless, very few confront the decision to rob them of their legal capacity or to change their protectors, in some cases because the very absence of competence leaves them powerless to initiate such change.

The predicament of disabled women is made more complex by virtue of the fact that they are simply not regarded as women—they are encouraged to be childlike, dependent and apologetic towards able-bodied society, which usually fails to acknowledge their existence. Historically too, able-bodied society has failed to recognize the different experiences of disabled women. It is assumed that disabled women do not have to deal with the same oppressions that non-disabled women confront, primarily because disabled women are not seen as ‘women’ in a heteronormative able-bodied society. While non-disabled women fight for equal rights in a patriarchal order, disabled women are rarely recognized as “persons”. This holds not only for those whose disability is very severe, but also for anyone who is different from “the ideal form”. Right from childhood, disability imposes a subordinate status on women with disabilities (WWD), and increases the likelihood of denial of rights. In the Indian context, where being a girl is considered a curse, being a disabled girl is a fate considered worse than death; carrying the burdens of gender and disability.

While it is true that women with disabilities have not been ‘entangled’ in the web of patriarchal social expectations of marriage and motherhood that feminists have challenged. This freedom from patriarchal social expectations is indicative of the rendering of their lives, as dependent, childlike and asexual, incapable of performing the roles of life partner and mother. The specific issues for women with disabilities may vary from those of non-disabled women, the reality of womanhood, which includes ‘experience of fear of violence’ in a patriarchal society, are bound to be similar. However, with a body that does not ‘measure up’ to societal norms, the situation becomes precariously balanced. The denial of women’s ‘traditional roles’ to disabled women creates ‘hopelessness’ (Fine & Asch, 1988), a social invisibility and denial of femininity, that forces the disabled woman to pursue the female identity—valorized by culture but denied to her—more vigorously.

While both women with disabilities (WWD) and men with disabilities experience discrimination and marginalization, WWD face specific challenges. Feminists tried to address these challenges using the intersectional approach. However, this approach has failed to capture adequately the disabled woman’s experience. The idea that disabled women go through ‘double disadvantage’ or triple burden is not helpful, as a disabled woman has to face all the oppressions that are embedded in not only patriarchy and normativity, but those of caste, religion, class, region, ethnicity, and sexuality, differently. Women with disabilities escaped the scrutiny from the forward-thinking movements. My objection to the theory of ‘double disadvantage’ is that it does not empower disabled women. As Morris (1996, p. 2) notes, ‘I always feel uncomfortable reading about our lives and concerns when they are presented in these terms’. When Lonsdale (1990) writes, for women the status of ‘disabled’ compounds their status of being female to create a unique kind of oppression, I feel burdened by the disadvantage, I feel a victim . . . Such writings do not empower me. We have to find a way of making experiences of WWD visible, sharing them with each other, and with non-disabled people, in a way that — while drawing attention to the difficulties in our lives — does not undermine our wish to assert our self-worth (1996, p. 2). In the Indian context, often the condition of a woman with disability is pitied with the statement, “Eke to ladki oopar se aapahij,” i.e. “one a girl, and that too disabled” (Ghai, 2002). While this intermingling of disablement and gender reflects reality, it offers little hope for empowerment.

The double disadvantage hypothesis also fails to produce tangible action, as the society does not move beyond tokenism and rhetoric. The absence of disabled body is an oversight that reflects a historical practice that continues to render the disabled invisible in a manner very similar to the invisibility experienced by black people in a white racist society. It is ironic that feminists engaged with the issue of difference, united in their attempts to empower the powerless, resolute in transforming social inequalities, failed to focus on the meanings of ‘impairment’ for disabled women. As I state elsewhere, one reason for this has been that within the feminist movement, challenging the universal subject of ‘woman’ was problematic (Ghai, 2003). While feminist discourse in India has included disabled women’s voices into the narratives of marginalized women, the tokenism that is evident in both activism and research, is undeniable. Though couched in politically correct language, disabled women are still an afterthought.

As an illustration I recall that there was a nation-wide protest, from Indian women’s groups when 14 mentally-challenged girls were compelled to undergo hysterectomies in the

Sassoon General Hospital in Pune, (a city in the state of Maharashtra) on 5 February 1994. The incident was reported in the major newspapers on February 24. The case involved developmentally disabled girls who were under institutional care. The girls were not allowed to wear pajamas with drawstrings as well as sanitary napkins with belts, as it was claimed that they might use these strings to commit suicide. The records regarding the stay had not been kept very carefully, so it was difficult to prove that there were attempted suicides. To deal with the problem of menstrual hygiene, the hospital decided to go ahead with hysterectomies. Notwithstanding this paternalistic deprivation of women's necessities, boys in the same institution were issued pajamas complete with drawstrings without any fear of suicides. Sadly, this incident did not lead up to a broader dialogue about the enforced sterilization of developmentally disabled women (both within institutions and those living with families in their homes). This failure indicated that Indian feminists did not see women with disabilities as an important and enduring constituency. Though later there were efforts (*The Hindu*, August 4, 2013) which sought to ban forced hysterectomy of women with disability.

The issue of sexual and reproductive rights of women with disabilities who live with their families is even more complex. The mothers of women with disabilities who live with their families want their daughters to get hysterectomies because they are apprehensive that abuse/rape might result in pregnancy. This indicates how even within the family, abuse is accepted but pregnancy is avoided at all costs. However, feminists have failed to take cognizance of this issue. Such experiences of disability continue to be confounded with the identity of being a woman, such that its specific character does not receive its due and is lost in the concern for women's rights, more generally. Assertions are made about layers of oppression but disabled women continue to be invisibilized. This oversight cannot be condoned in the name of prioritization.¹ To the disabled woman, this feminist oversight is not very different from the patriarchy inherent in Disability Studies and activism where men determine the agenda and the priorities.

Another example of the unique experience of women with disability is the evaluative male gaze. If the male gaze makes able-bodied women feel like passive objects, the stare that the disabled are subjected to turns them into a grotesque sight. I am very concerned about the 'stare', which becomes extremely oppressive. Disabled women contend not only with how men look at women but also with how society stares at disabled people, stripping them of any semblance of resistance. Although there are commonalities between the experiences of disabled men and women, the form that this oppression takes for WWD is refracted through the prism of gendered location. Though feminist voices have questioned patriarchal oppression, many of their concerns have not resonated with disabled women.

In a society where there is widespread female abortion, aborting imperfect children will not cause any stir or agitation. While there is an on-going discussion of the ethical contradictions that prenatal sex testing poses for feminists, prenatal testing to identify and abort children at risk for disabilities does not get addressed (Ghai, 2003, p. 69). Disabled people have been highly critical of prenatal screening and selective abortion, seeing them as a new strategy of eugenics. New reproductive techniques reinforce the notion that humanity must aspire for an ideal body. Such a position reinforces disability as deficit. However, this approach is like a slippery slope to other forms of selection, and thus eventually to a world of new 'designer

baby' eugenics. However, the ideas of homogenization that designer baby eugenics propagates is to be resisted. In this context, Disability Studies offers resistance to homogenization. What is perhaps required is to reflect on the social values and structural inequalities that promote 'ideal body choices'. I believe Disability Studies can expand the contours of existing feminist debates on new reproductive technology and new technologies such as augmentative communication devices, robotics.

Another aspect that is critical to my mind is sexuality. There has been a conspiracy of silence about the sexuality of disabled women and it is not rated as a high priority issue even amongst those who are active advocates of the cause of disabled.

Nivedita Menon (2012) notes that issues of sexuality in connection with disability are marginal in feminist discourse. One reason, according to Aloka, is that non-disabled women 'do not grow up thinking of disabled as sexual beings'. Aloka's account reminds us that access to sexual relationships and sexual expression are often caught in barriers which bear a close resemblance to the ones faced by disabled in their attempts to be included in the 'mainstream society' (personal communication). Since disabled people are socialized into a form of desexualized subjectivity, disabled peoples' expression of sexuality and desire is a form of resistance. Steven Seidman (1996, p. 1) reminds us, that "there is one aspect of human life that has resisted disenchantment, [and that is] sexuality" However, while sexuality is vital, sexual abuse and sexual violence are part of disabled women's experience. Often members of extended family and acquaintances perpetrate this abuse and violence. Family is directly implicated. For many women it leads to 'fear psychosis' as their accounts are treated as overexcited imagination. Asmita, a fellow disabled shared this experience with me. Says Asmita. "I tried telling my mother about my uncle. She had such a look of disbelief as she said to me, '*Arre woh tumhe kyon tang karega? Usko ladki ki kami hai kya? Tumne kabhi apne aap ko shishe mein dekha hai?*' (Why would he be interested in you? Is there a paucity of girls for him? Have you ever seen yourself in the mirror?)

Women with disabilities are left defenseless; being less able to secure themselves as the risk of assault and rape from acquaintances is generally greater than the risk from strangers. Most families tend to infantilize and patronize women with disabilities, and do not consider them seriously; their choices are not respected. Women fear that they may not be seen as trustworthy — thus reporting abuse may not be an option; they also face damaging social values of being labelled 'inferior' or 'disposable', which leads offenders to believe that abuse is justified. Repeated instances of violation, like fondling of breasts, damage the disabled women's self-esteem. Similarly, verbal abuse such as "you are my life's burden" and "when will you die" have a negative impact on the sense of self. The tragic part is that since the systems do not support the disabled, they accept the abuse as inevitable.

The body and our knowledge of it are largely, though not wholly, socially constructed (Wendell, 2001). The patriarchal and normative cultural messages about how the body should look, what its size should be, how it should be maintained, and how it should be experienced contribute to understandings of the ideal body. But the ideal body is not an aspiration for the disabled. I believe the fissure between 'impairment' and 'disability' needs questioning as it creates false dualism. An embodied ontology offers the best entry point for women with

disability to reassert their rights. With a feminist leaning, such an understanding provides the possibility to interrogate the specific and unique challenges of women with disabilities.

The intersection of Disability and gender can also enrich the understanding of human predicament both for academics and activists in the two fields - disability and gender studies. We cannot continue to ignore the socio-political, economic and cultural context of disabled women. My trepidation is that the lived realities of disabled women are still not prioritized, as society prefers to accept only the ideal 'clean and proper' body.

Shakespeare's work from the mid-1990s assists in building a critical understanding. He argues that non-disabled people project their fear of death, their unease and their physicality and mortality onto disabled people, who represent all these difficult aspects of human existence (Shakespeare, 1994, p. 298). Thus, if disability is a natural/constructed category, then differences between disabled and non-disabled are merely the effect of degrees of false consciousness and liberation that arrives when both able/disabled have come to authoritative consciousness of their own identity. The fact remains that women with disability have to fight the battle of normality as unified subjects in their own right. As I have stated elsewhere, to be a political subject then, is to have a politically recognized identity, an identifiable self, and a consciousness to claim as one's own (Ghai, 2015, p. 263). Thus, the politics that proceeds from this emphasis on disabled as subjects, united in a common struggle, usually going by the name 'identity politics' becomes a viable methodology to gain Voice.

To conclude, identity cannot be essentialised, as it has to be understood as relentless movement. Disabled identity has to be understood as a compendium of subject positions that can never be completely secure in an obstructed scheme of differences. It has to be continuously fluid for which a diversity of conversations must happen, some of which may even appear unrelated.

End Notes

¹ The pretext for ignoring disabled women in women's movement was the subjection of the Women's movement, as it was dealing with multiple issues. Though they did want to hear the voices of all marginalised groups, but a real inclusion remained a token for political appearance, rather than a genuine commitment to the issue. For instance, disabled women would be called on at the last moment to sit in front for a group photo, only as a symbolic gesture.

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