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Slow Progress for Women with Disabilities in India

RENU ADDLAKHA

It is not always the case that one witnesses social transformations directly connected with one’s identity in one’s own lifetime. This has been my good fortune as a female with congenital visual impairment, born at a time when having such a deficit was a curse that predicted lifelong trauma for the family even before the disabled body took on a life of its own as a social being. Stigma, self-blame, fatalism, financial hardship, an endless search for a cure within available biomedical systems and alternative medicines, and prayers and penance—this is how my parents would have described my infancy and childhood. My early memories are of wearing thick glasses as a toddler, being looked at with pity and aversion by adults, being constantly monitored by my parents, having no playmates, suffering isolation and bullying in school, and sitting by myself in empty classrooms.

Disability and Equality

Eighth in a series

Fast forward half a century. In a vast expanse of the Indian landscape, the above description would still be valid. But much has happened since the 1960s when it comes to the issue of disability, both discursively and institutionally. Considering these changes through a reflexive lens as both an observer and a participant in this process is both rewarding and painful. The realization that so much that I went through would have been unnecessary, had a different perspective on disability been at play, fills me with a strange emptiness. On the other hand, the fact that so much can be changed when disability need not be considered

the lifelong curse that it has been for eons is empowering. But between possibility and reality, there is still a yawning gap.

It may be said that disability as a human rights issue was propelled globally by the United Nations through its declarations of the International Year of Disabled Persons in 1981 and the International Decade of Disabled Persons from 1983 to 1992. Before that, disability was a peripheral issue, confined to the domains of social welfare in state policies, and programs and service delivery in the civil society sector.

The movement of disability from an impairment-centric medical issue to a rights-based social issue was mediated in India, as in most other countries, by the law. The passage of the Americans with Disabilities Act in 1990 and the United Kingdom’s Disability Discrimination Act in 1995 inspired collectives like the Disability Rights Group in New Delhi, which became the fulcrum of campaigns for disability-specific legislation in India. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, passed by the Indian Parliament in 1995, set the stage for highlighting disability not only as an individual medical problem, but also as a social phenomenon of stigmatizing disabled individuals and their families.

This understanding of the social construction of disability, which had taken shape during the 1970s and 1980s in the Western world, made its way to India through advocacy by disabled activists like Javed Abidi, J. L. Kaul, and Lal Advani, among others, who had been exposed to the social model while visiting Europe and North America. They became founders and members of leading disability organizations in India. Their groups began collectively lobbying the government in the 1990s for

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the passage of disability-specific legislation, constituting a powerful cross-disability forum. But the members of these groups were mainly elite men, and they conceptualized disability as a gender-neutral social issue.

Around the same time, the women's movement in India began widening its concerns to include a greater focus on sexual and reproductive health in response to the AIDS pandemic as well as the UN Beijing Platform for Action of 1995. A case of involuntary hysterectomies in a state-run home for intellectually disabled women in 1994 in Pune district, Maharashtra, eventually led to bridge building between the women's and disability rights movements after women's groups opposed these violations of the sexual rights of developmentally challenged women, but disability rights groups did not join them.

Feminist support for disability rights has not been unconditional. Extant provisions of the Termination of Pregnancy Act of 1971 and the Pre-Conception and Prenatal Diagnostic Techniques Act of 1994, allowing selective abortion of fetuses in cases of prenatal disability, have only recently been opened up for discussion by a few feminists in disability studies. By contrast, in the context of widespread preference for sons in India, it was felt legitimate to outlaw the use of available medical technologies for knowing the sex of the fetus so that female fetuses would not be terminated and further skew the national sex ratio. But the abortion of a disabled fetus did not merit any discussion at the time.

In fact, cases of antenatal disability selection have been increasing. This is clear from the number of pleas coming before the courts for termination beyond the gestational age limit for abortion, which was only recently increased from 20 to 24 weeks. In all such cases, a medical board constituted by the court sets the terms of adjudication. It often comes down in favor of termination of the disabled fetus for a variety of reasons, ranging from postnatal nonviability of the fetus to the projected costs of lifelong medical management exceeding the financial resources of the petitioner.

A handful of feminist activists and scholars who were either disabled themselves, like Bhargavi Davar and Anita Ghai, or carers for disabled relatives, such as Asha Hans, became the torchbearers

for disability within the women's movement from the mid-1990s. Through their writings and advocacy, they have played an important role in engendering the issue of disability through the lens of feminism. Even though the mainstream disability rights movement in India continues to be largely male-dominated, feminist disability scholars and activists have succeeded in carving out a niche to examine the lived realities of women with disabilities (WWDS) and to work for their empowerment through grassroots interventions and lobbying the state.

A prime example of such initiatives is the Women with Disabilities in India Network (WWDIN), of which I am a founding member. WWDIN, started in 2013, is an independent, cross-disability, virtual platform run by and for women with disabilities who have come together to exchange views and advocate for policy interventions. Its objective is to bring visibility to the lives of this multiply disadvantaged minority group by highlighting both disability and gender as intersecting variables. Indeed, WWDS constitute a heterogeneous group, since disability and gender also intersect with other socio-demographic factors, such as type of disability, class, caste, ethnicity, or rural or urban residence. Some of WWDIN's prominent members

include disabled feminist disability activists and scholars like Jeeja Ghosh, Nandini Ghosh, Nidhi Goyal, Sandhya Limaye, and Kuhu Das.

Another important development that has played a big role in bringing gender and disability to prominence is the increasing amount of research at the postgraduate level, particularly in departments of women's and gender studies, as well as Centres of Social Exclusion, which are distinct administrative units separate from other social science departments. I have had the opportunity to examine many such theses by young scholars working not only in the large institutions of higher learning located in metropolises, but also in smaller cities and towns. One of the factors contributing to this scholarship is the increasing number of WWDS, particularly women with visual and mobility impairments, entering higher education. Of course, outside such privileged institutions, which are few and far between, the situation is still very grim, given the size and diversity of India's disabled population.

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DATA GAPS

Moving beyond anecdote (in the form of fact-finding reports, media reportage, and small-scale cross-sectional research) to hard macro-level data, in order to obtain the evidentiary basis for legal and policy changes to improve the life conditions of WWDS, is a tall order in India. Most of the state's existing macro-level data-gathering efforts, apart from the Census, do not incorporate disability. When it is incorporated, it is not disaggregated by gender. This makes it impossible to develop a comprehensive understanding of the problem of disability and its gender implications.

The last Census, from 2011, puts the total number of WWDS in India at 11.8 million, out of a total disabled population of 26.8 million, comprising 2.1 percent of India's total population of more than 1.3 billion people. That this is a gross undercount can be gauged from the World Health Organization's estimate that 15 percent of any given population can be presumed to have disabilities. As in other low- and middle-income countries, the majority of persons with disabilities in India (69 percent) reside in rural areas, which means they lack access to even basic health, education, and employment facilities. The plight of WWDS in such a situation can be imagined.

The 2011 Census has other limitations, including its recognition of only seven types of disability—movement, seeing, hearing, speech, mental retardation (*sic*), mental illness, and multiple disabilities. Nonetheless, the Census is the only database to provide a national profile of the disabled population. Even with gross undercounts, it captures the difficulties of the lives of WWDS. Although the percentages may not seem to vary widely, when these are translated into absolute numbers, the disparities are stark.

As expected, disabled persons residing in urban areas in India have higher educational status than their rural counterparts; measured by an aggregate of educational attainment, from primary schooling to higher and professional education, the ratios are 69 percent and 31 percent, respectively. Around one-third of persons with disabilities are between the ages of 10 and 29, which corresponds to the fact that 65 percent of the Indian population is under 35. The second-largest disabled age cohort (21 percent) comprises those above 60 years of age.

The gender gap among disabled persons narrows as the population ages, until the number of disabled women outstrips men among those 90 and over.

This is in consonance with life expectancy trends by gender in the nondisabled population.

The rate of Indians with disabilities who are single (41.7 percent) is nearly as high as among their nondisabled counterparts (46.3 percent). But more disabled men than disabled women are married (the ratios are 62 percent and 54 percent, respectively), testifying to the patriarchal advantage of the former. This finding is important because marriage is typically considered the most important event in an Indian woman's life, conferring the status of full personhood.

In the same vein, more disabled women fall within the divorced/separated and widowed categories (13 percent) than both their disabled male (6 percent) and nondisabled female counterparts (2 percent). This finding indicates the level of destitution among WWDS. Some studies show that most WWDS marry men who are older, infirm, and not well off.

The Census points to higher prevalence of mobility-related and multiple disabilities in rural areas, whereas disability in hearing and speech was found more often in urban areas. Could these differences be attributed to non-biological factors? Sensory modalities like seeing and hearing may be more necessary to optimal functioning in the urban environment; any deviations from the norm may be more easily identified and labeled in such a context. Similarly, the rural economy, dominated by agricultural activities, requires more physical mobility; difficulty in movement may easily become an obstacle in day-to-day life outside cities and small towns.

Looking at types of disability through a gender lens, trends among disabled men and women are more or less similar, except that men outstrip their female counterparts in the category of disability in movement (the ratios were 23 percent and 18 percent, respectively). The number of women with disabilities exceeds the number of men in the categories of seeing and hearing. Because of social restrictions on the physical mobility of women outside the home, difficulty in movement may not be considered so disabling for a majority of women, whereas for men, who occupy the public sphere, any limitation in that area challenges their lives in a more fundamental way. Women's mobility disabilities may be statistically undercounted because of these assumptions.

Around two thirds (64 percent) of disabled people in India, across all seven categories of disability, are grouped in the nonworker category of

dependents and students. This underscores the absence in the state's discourse of any notion that a disabled person can productively function. The gender gap among disabled workers is also noteworthy: 47 percent of men and 23 percent of women were employed. Yet small-scale surveys and ethnographic studies have consistently shown persons with disabilities, including WWDS, engaging in housework and productive work in the informal economy, which does not seem to be registered in the Census.

This highlights a glaring contradiction between India's guarantees of human rights and citizenship and the denial of these rights to a sizable section of its population. If a majority of persons with disabilities do not have livelihoods, this reflects social and political neglect more than any incapacity or inability to engage in work.

INACCESSIBILITY AND EXCLUSION

Accessibility is a critical concept and a primary goal of the disability rights movement, since most if not all of the disadvantages suffered by persons with disabilities stem from barriers created by an insensitive society that does not recognize the existence of this large segment of the population in its midst. These barriers may be physical, infrastructural, environmental, institutional, attitudinal, or information-based. Either individually or in combination, they can lead to the denial of rights, entitlements, and services.

Persons with disabilities cannot access health, education, livelihoods, recreation, and more in the absence of accessible and safe infrastructure, which is often lacking due to negative stereotypes, neglect, prejudice, and discrimination imposed by the nondisabled world. Many studies and interventions have noted that enhancing physical accessibility is not an exorbitantly expensive process, as businesses and other organizations often claim it is, attempting to abdicate their responsibilities. The situation is so bleak that the vast majority of persons with disabilities in many parts of the developing world, including India, have no knowledge of accessibility as a concept and right.

WWDS in India are at a dual disadvantage in this regard, because no gender perspective is incorporated in infrastructure design. For instance, none of the available mobility aids, such as wheelchairs, tricycles, or crutches, are manufactured with specifications suited to the needs of WWDS. The Indian government's Aids and Appliances scheme does not have any specific standards or customized

options for WWDS. Consequently, men with disabilities have greater potential access to such assistive technology than their female counterparts. The gender gap in access can be gauged from the figures available from the Artificial Limbs Manufacturing Corporation of India: the ratio of male to female beneficiaries is at least 2 to 1.

Disability and gender are inextricably intertwined in the lives of WWDS, and nowhere is this more apparent than in restrictions on mobility outside the home. Even if infrastructure is accessible, WWDS first must be in a position to exit their homes to gain access to it. The physical inaccessibility they face is an outcome of the deep-rooted negative stereotypes that society has constructed about them—they are presumed to be weird, unattractive, asexual (or hypersexual), incapable, always in need of support. Since they are excluded from the traditional roles of wife, homemaker, and mother, their intrinsic worth is constantly challenged. In such circumstances, it is difficult to imagine that society would make any extra effort to accommodate them in a respectful and dignified manner. Indeed, both in infrastructure and in services, conception and implementation of gender-friendly accessible features are poor.

OVERSIGHT AND POLICY NEGLECT

India's legal regime has proved to be ineffective in ensuring that disabled citizens, particularly female citizens with disabilities, enjoy civil, political, economic, social, and cultural rights. This is a reality that needs to change.

Although disability is not included as a prohibited ground of discrimination under the Indian Constitution's Article 15 on fundamental rights, the Supreme Court has recognized persons with disabilities as a vulnerable group to whom the principles of equality and nondiscrimination should apply. In this muddled state of affairs, WWDS remain far from achieving either *de facto* or *de jure* equality. Extant legal provisions like those on "lunacy," covering both mental illness and intellectual disability as grounds for divorce, continue to be used and misused. Far more men than women use such claims in divorce cases. Similar instances of gender- and disability-based discrimination are also found in inheritance laws.

The policy landscape is equally dismal. Falling between the cracks, WWDS are neglected within both disability-specific and gender-specific policies and programs, aside from some perfunctory provisions that exist mostly on paper. Although

there are disability-specific provisions in the form of affirmative action (known as “reservation”) in education and employment, patriarchal logic ensures that the bulk of the benefits goes to men with disabilities, since WWDS are not singled out as a group requiring special attention. In women’s empowerment programs, such as reservation of seats in legislatures and local bodies, more benefits go to other groups of women, like the lower castes and tribes (referred to as scheduled castes and scheduled tribes), who are also marginalized but still have more clout than WWDS.

In the jockeying for benefits among different social groups, persons with disabilities, particularly WWDS, find no place. They are excluded from sexual and reproductive health programs, due to the power of stereotypes linking disability with asexuality and unsuitability for marriage and motherhood, even though the 2011 Census found over half of WWDS to be married. In flagship government schemes like Right to Education and the National Rural Employment Guarantee Scheme, WWDS are absent. Gender budgeting—mainstreaming a gender perspective in the allocation of resources and determination of expenditures in order to promote gender equality—has not been applied even in disability-specific policies and schemes. In light of this precarious positioning, it is necessary to highlight WWDS’ needs and concerns, making them a separate constituency for strategic intervention.

Yet the category of women with disabilities is an amorphous entity, precariously perched on the intersection of gender and disability, but not owned by either the disability or the women’s rights movement. As a discursive category, it is only in the past few years that it has made its presence very slowly felt in the domains of law, policy, and media. For instance, some measures, like providing reasonable accommodations to disabled women who come to register police complaints, have been incorporated in the Criminal Law Amendment Act of 2013, which also invokes statutory rape provisions when a case involves sexual assault on a woman with disability.

The Rights of Persons with Disabilities Act of 2016 lacks a separate article on women with disabilities, unlike the UN Convention on the Rights of Persons with Disabilities (CRPD), which India signed and ratified in 2007. But it does speak about

equality between men and women (presumably referring to those with disabilities) in its preamble.

Chapter II of the 2016 Indian law, on rights and entitlements, again makes reference to women (and children) in the context of equality. Chapter V, on social security, health, rehabilitation and recreation, mentions support for women with disabilities for child care, livelihood provision, and sexual and reproductive health care. Chapter VI, on benchmark disabilities (registering above 40 percent on a scale of impairment of normal function, as determined by a recognized medical practitioner in an elaborate certification process), provides for prioritization of women with disabilities in poverty-alleviation schemes and other government-run development programs. It also reserves 50 percent of seats on disability advisory boards at federal, state, and district levels for women.

Though the scattered mentions of WWDS in India’s laws may not appear to mean much, any registration of their presence in the legal space has the potential for instantiating change on the ground in the long run. One can think of ad hoc references

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(even if they are inserted merely for tokenism) as beacons of hope, considering the harsh realities of the lives of WWDS in the country. Just as the experience of being disabled exposes them to multiple discriminations in the

domains of culture, society, politics, and the economy, the specificity of each particular disability creates its own obstacles, needs, and requirements.

Even if we avoid comparisons both with non-disabled women and with disabled men, it cannot be denied that the operation of patriarchy is differential. Nondisabled women do not experience the sexual annulment and gender role deprivations experienced by their disabled counterparts; nor do men with disabilities experience the same erasure of personhood that is often the lot of their female counterparts. The complex issues affecting WWDS must be understood in relation to their differential locations within the overlapping and intersecting frameworks of patriarchy and ableism.

THE ROAD AHEAD

As someone who has witnessed and experienced developments unfurling in India over the past half-century around disability in general and WWDS in particular, it appears to me that a lot has

changed. My observations cannot be generalized for the whole country, given my specific position as a disability studies scholar residing and working in the capital city. But due to some recognition in national policies and programs, largely driven by India's being a signatory to the CRPD, and some visibility in popular media outlets, disability is registering its presence in a limited fashion in the public sphere as a human rights issue rather than just a matter for social welfare or charity (though those perspectives are also still very much alive). Meanwhile, thanks to the proliferation of social media through mobile phones, more people with disabilities are able to find virtual communities while sitting in their homes.

Thus, recognition of disability as a social issue has been propelled by a combination of international law and technology. These developments have worked in tandem with neoliberal capitalism and postcolonial, postmodern epistemology to create the space for putting marginalities of all

kinds at center stage, both for understanding and for action.

Generational changes are also exerting their influence in the arena of disability. Many Millennial and Generation Z disabled persons, at least those in higher education and vocational training, appear to have more self-confidence and higher aspirations than members of my generation. WWDS of this younger cohort are more assertive of their femininity and display a greater consciousness of personal agency. Men with disabilities are attempting to transit from a subordinate to a more empowering form of masculinity.

But the road ahead is not easy. So much more has to change before the goal of total inclusion can be achieved. But it is so encouraging to see the drive to overcome and the gleam of self-pride as a newer generation of persons with disabilities in India, particularly women, challenges entrenched structures that for so long have been the sources and sites of their oppression. ■