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Guest Editorial - Perspectives on Disability Studies

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Guest Editorial - Perspectives on Disability Studies

Disability as an axis of social marginalization and discrimination has gained traction as a category of academic analysis over the past two decades in India. A robust body of work in the social sciences and humanities has emerged, examining its intersections with gender, caste and class; accessibility and exclusion/inclusion; care work and domestic spaces; developmental discourses; representation in arts, literature, life writing and cinema. The edited volumes by Addlakha (2013); Hans (2015); Ghosh (2017); Ghai (2018); Mehrotra (2020) ; Sati et al (2022) and Sati (2024) for instance, bear testimony to the growing body of scholarship in the field and its entry into mainstream academic discourse in India. The burgeoning of disability-themed seminars and conferences, the inclusion of courses on disability studies in University curricula and the presence and visibility of teachers and students with disabilities in the higher education system are encouraging developments. The past decade has seen the Rights of Persons with Disabilities Act (2016) come into force, expanding the categories of recognized disabilities, including conditions like Autism and Specific Learning Disabilities within its ambit. The rights-based provisions, emphasis on accessibility, inclusion and full participation of persons with disabilities that the RPDA clearly articulates have played an important role empowering persons with disabilities and sensitizing the community.

Persons with disability are considered the world’s largest minority; the World Health Organisation estimates that around 1.3 billion persons-one out every six human beings on the planet- lives with a significant disability. In India, now the most populous nation in the world, the 2011 Census counted 26.8 million persons with disability, across eight major disability types. It is acknowledged that this figure is likely to be far from representative, given the limited number of categories included and the stigma and invisibilisation that surrounds disability resulting in undercounting and exclusion. Disability is also unequivocally an issue of development, and its inter-relationship with poverty and disability is stark and bi-directional (UNDESA, 2018). Despite its ubiquity and universality through history and across cultures, the experience of disability continues to be mired in denial, rejection and stigma and persons with disabilities experience pervasive ‘othering’ and devaluation of their personhood. The quest for ‘cure’ and ‘fixing the problem’ persists in mainstream thinking, and is frequently the source of untold physical, psychological and financial distress to affected individuals and their families.

Once regarded as the domain of bio-medicine, psychiatry, rehabilitation science, special education and social work, disability is now recognized as a social, cultural and political category which requires a holistic perspective in order to understand its intersections with other social categories such as caste, class, race and gender. The interdisciplinary field of ‘Disability Studies’ and the global Disability Rights Movement are the products of the mobilisations and activism of persons with disabilities demanding recognition of their personhood and agency as citizens with rights and entitlements rather than needy dependents and recipients of charity and welfare. The ‘social model’ of disability that emerged in the UK and USA in the 1970s and 1980s reframed disability as the product of environmental, attitudinal and institutional barriers that stigmatise, exclude and marginalize individuals with physical, sensory and cognitive impairments. However, while it paved the way for activism and struggle for entitlements and rights, legislative reforms and social inclusion, the social model was critiqued for its erasure of the embodied experiences of impairment, pain and debility that is often an undeniable reality that marks the lives of persons with disability, particularly women. The unique subjectivities and ways of being in the world of persons with intellectual and developmental disabilities are also not adequately captured by the social model (Vaidya, 2024: 165). However, the fundamental shift in perspective that the social model engendered has informed our understanding of disability as an interdisciplinary area of inquiry. Disability is also seen as an expression of diversity and pride rather than disorder and deviance particularly with the emergence of ‘Deaf Pride’ and ‘Autistic Neurodiversity’ which celebrate rather than bemoan ‘difference’ and forge social networks and solidarities based upon shared biological conditions or ‘biosociality’ as Rabinow (1996) termed it. Mehrotra (2013: 35) aptly describes disability as “the quintessential post-modern concept, because it is so complex, so variable, so contingent and so situated. It sits at the intersection of biology and society and of agency and structure”.

The COVID 19 Pandemic has reconfigured our understandings and experiences of illness, debility, disability, isolation and stigma in profound ways. The worlds of domesticity, work, education, consumption and leisure were transformed and recalibrated to meet a new social reality which was predicated on ‘social distance’ rather than social engagement. The repercussions were disproportionately experienced by marginalized persons; the poor and homeless, migrants, women and persons with disabilities. The existential frailty of the human body, the precariousness of livelihoods, the overburdened public health systems and absence of social care were brought into sharp focus. The everyday realities of persons with disabilities-stigma, physical and social isolation and inaccessibility-were experienced by non-disabled persons as well due to nation-wide lockdowns and enforced confinement within the four walls of the home. In this context, the role of Disability Studies in critically examining unequal and discriminatory social structures and institutions has become even more relevant.

Disability Studies is a dynamic and interdisciplinary field, that interrogates deeply entrenched social norms and practices and challenges longstanding societal structures shaped by ‘ableism’. It provides a framework to recognize and dismantle systems of marginalization and discrimination. This issue of Perspectives explores the diverse dimensions of disability, chronic illness and debility, advocating for a more inclusive society where differences are embraced and the voices of marginalised persons drive social change. The issue is dedicated to the late Professor Anita Ghai whose life and work we honour and celebrate. Her pioneering contributions have been instrumental in theorising the lived realities of persons with disabilities and placing them front and centre in academic and public discourse. Transcending disciplinary boundaries and working at the intersections of gender and disability, Anita brought context and nuance to discourses around these categories with a feminist post-colonial lens, illuminating the realities of persons with disability in South Asia, particularly women (Ghai 2003; 2015). Her celebrated, much-cited paper in Hypatia "Disabled Women: An Excluded Agenda of Indian Feminism" (2002) foregrounded the existential realities of women with disability in India and raised the critical question of their absence and erasure from both, the women's movement and the disability movement in India. Ghai's reflections on cultural constructions of disability and gender in South Asia also paved the way for critical engagements with education, mythology, literature, life-writing and cinema; themes which are explored in detail in the articles in this issue. Nilika Mehrotra's note reflects upon Anita's contributions and her enduring legacy to Disability Studies and the Disability Rights Movement.

The ten papers in this issue (including one in Hindi) cover a diverse terrain and emerge from multiple disciplinary orientations including history, political science and legal studies, literature and cultural studies and feminist studies. They address critical themes in Disability Studies, particularly the deeply entrenched ableism and paternalism that mark everyday interactions, cultural representations, social structures and institutions and devalue and infantilise persons with disabilities. They problematise and interrogate the very definition of disability; the social construction of 'normalcy'; the fears and anxieties that 'different' or rule-defying subjectivities present to 'normal' society and the manner in which difference is sought to be delegitimised and snuffed out, often with violence. Narratives of autonomy and agency, resistance and resilience underscore the struggles to reclaim the self and carry on with the business of living in a world that is primarily designed for the able-bodied. The sheer heterogeneity of disability—locomotor, sensory, intellectual, developmental and psycho-social—and the varying experiences it engenders comes through clearly in the papers. The capitalist patriarchal social order that commodifies bodies and discredits and discards them when they become 'defective' is questioned and critiqued. Accounts of activism and advocacy, legal and policy interventions in both the national and international contexts provide insights into the way in which disability rights movements have informed and brought change in legal frameworks even though it is acknowledged that much needs to be done on the ground.

Wars and conflicts are major causes of death, injury and disablement of both soldiers as well as civilian populations. Minyoung Kim's detailed exploration of the psychological and physical consequences of war for Indian soldiers during World War I brings to sharp focus the harsh realities of the colonial medical system and systemic racism that destroyed not just the bodies of the soldiers at the frontlines, but also their self-esteem and self-worth. These "broken bodies and challenged identities" that failed to find closure and peace even after their removal from the battle front were also racialized bodies used as cannon-fodder by the colonial state that had little use for them thereafter. The paper deftly captures the 'disabling' of the masculine identity and self-concept of the soldier that is framed in terms of "strength, resilience and duty" and highlights the cultural construction of disability as a fate worse than death and the inadequacy of the bio-medical model to address these psychic wounds.

While the figure of the amputated soldier exemplifies disabled masculinity, the woman with a surgically removed breast symbolises disfigured femininity. The dehumanising of women by the medical system; the discomfort of society with 'anomalous' or 'non-standard' bodies; the rigid standards of health and beauty and the culture of ‘victim blaming’ are some of the themes unpacked by V Rachel Touthang in her close reading of Audre Lorde’s Cancer Journals. The author explores Lorde’s ‘radical defiance’ that questions ‘carcinogenic capitalism’ environmental pollution and dietary practices that can adversely impact women’s health. As a black queer subject rejecting a prosthetic breast to ‘normalise’ her body, Lorde’s memoir is seen by the author as an act of resistance and protest. Exploring the intersections of disability and illness with race, gender, sexuality and other markers of ‘difference’, the paper posits life-writing as a ‘political act’ wherein the personal becomes the political.

Emile’s discussion on the representation of disability and disfigurement in contemporary German literature examines the themes of embodiment, disrupted identity and dependence. The story of Gillian who suffers a disfiguring accident to her face and has to work through her sense of loss and de-personalisation to reclaim a competent identity is compared with that of Hans’ bitterness, anger and resentment at his dependent state. Reflecting upon relationships of dependence and care which are frequently fraught and mired in power struggles, the author quotes the philosopher Eva Feder Kittay:

> Is it not better to acknowledge our dependency as a feature of all human life, and to develop relationships that are genuinely caring and respectful? Is it not better for relationships of dependency to be replete with affective bonds that can transform otherwise unpleasant intimate tasks into times of trust and demonstrations of trustworthiness, gratifying, and dignifying to both the caregiver and the recipient of care? (Kittay 2011: 54).

Surasree Deb Burman’s paper compares the representations of disability with a gendered lens in two short stories: ‘Jyoti Binaki Ujyalo’ by Sanu Lama and ‘The Cleft’ by Prajwal Parajuly. In the case of Kaali whose cleft lip is “not merely a physical trait but a social marker, serving as a locus for the community's anxieties and biases", disability is a "spectacle and stigma," positing Kaali as an object of derision and ridicule. Whereas Manda's family is supportive and attempts to provide her with support through her impending blindness. Disability is narrated as "a shared family experience, emphasizing adaptation and support rather than alienation" collectively negotiated and managed by the family.

Psycho-social disabilities or mental /psychiatric illnesses have been relatively marginalised within the domain of disability studies. The framing of psycho-social disabilities as 'disorders' that can be treated or managed with pharmacological drugs and other therapies is deeply entrenched and scant attention is paid to the social contexts of mental illness and the structural inequalities and resultant psychological distress that underlies many manifestations of mental health conditions. Unnati's reading of the memoirs of three women who identify as having psycho-social disabilities questions the hegemony of the biomedical model in addressing the mental health of women. Through a close reading of these life writings, the paper draws attention to the relationship between gender and mental illness on account of rigid socio-cultural norms and expectations and the insecurities and vulnerabilities of being a woman in a patriarchal social order. The themes of order, control and labelling of difference as inherently subversive inform Arthya's close reading of Ken Kesey's iconic text "One Flew Over the Cuckoo's nest" published in 1961. It locates mental illness within the context of a society undergoing social change and churn and the tensions between individuality and agency, regulation and social control played out in the setting of a psychiatric ward. Who is 'mad'? Who is 'sane'? How is the 'other' controlled and neutralised? The fundamental question of 'normalcy' and who determines it is examined and critiqued. The contemporary relevance of the text in a 'post truth' era where the lines between reality and fantasy are blurred and difference is 'othered' cannot be overstated.

Vandana Rastogi’s article (in Hindi) draws attention to the social and cultural dimensions of disability in India and explicates the various myths and stereotypes associated with it. Arguing for social inclusion and recognition of persons with disabilities, she makes the point that new terminology like ‘Divyang’ or ‘differently abled’ alone cannot bring about attitudinal change; rather, there is a need for the state and civil society to work alongside persons with disabilities to create a just and inclusive society. Neenu’s short piece on the film ‘Rautu ka raaz’ echoes the theme of inclusion and acceptance and ‘normalising’ the existence of persons with disability as members of society just like non-disabled persons.

Laws, policies and implementation are critical in paving the road towards inclusion and full participation of persons with disabilities. Using a comparative legal framework, Medha discusses the impact and efficacy of disability rights legislation in a global and local context through an examination of the legal provisions in various legal systems across the world; their compliance to international frameworks such as the United Nations Convention on the Rights of Persons with Disabilities and their impact on practical outcomes for stakeholders. Shivpal Chawda’s paper examines the crucial issue of accessibility, as mandated in the Rights of Persons with Disabilities Act (2016) drawing upon recent judgements of the Supreme Court. His analysis of the judgments affirms that the right to accessibility is interpreted within the fundamental right to life and access is a human rights issue. Disability has been understood as within the framework of the social model with ‘reasonable accommodation’ an underpinning principle.

Ableism, the myth of ‘normalcy’, intersectionality, agency, autonomy and accessibility are the major themes reflected this diverse yet interconnected set of papers. They encourage a deep dive into questions of culture, social institutions and relations, questioning the entrenched and ableist premises upon which the world is organised. The emancipatory potential of

Disability Studies has been effectively tapped by these contributions and readers will hopefully find it an enriching and thought-provoking read.

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