



Anita Ghai (ed): *Disability in South Asia: knowledge and experience*

SAGE, 2018, 443 pp, ISBN: 978-9352807079 (HB)

Deblina Dey¹

Published online: 19 November 2019
© O.P. Jindal Global University (JGU) 2019

‘Disability in South Asia: Knowledge and Experience’ is a treatise that focuses on the production of knowledge around disability in South Asia. The book, written by Anita Ghai, consists of twenty five chapters divided into seven thematic areas. The chapters cover a wide range of themes. The book begins by presenting the historical and theoretical perspectives of disability studies. In Part 2, it discusses issues around disability and sexuality. In Part 3, the chapters highlight the centrality of the ‘self’ through autobiographies of persons with disabilities followed by discussions related to the representations of disability in literature and comparative cultural discourses about disabilities in Part 4. Part 5 focuses on a discussion around disability and family, educational and employment opportunities in India. The chapters in Part 6 are a critical intervention in disability jurisprudence in India. Part 7 takes us through the idea of ‘disability as a diversity’, thereby finally tying up with the book’s primary objective of understanding disability across multiple registers in localized spaces and forms. Far from being a closure, the chapters provide ample food for thought with regard to further potential research on disability studies. It speaks to a wide audience as the book consists of various theoretical and experiential insights which will be useful not only for academicians in various fields, policy and law makers, but also to the layperson.

In this review, I have selectively analysed two sections (Part 2 and Part 6) in the book that highlight newer ways of understanding the intersection between disability and gender. Anita Ghai argues that disability studies is an under-researched area of work in India, and the intersectionality of gender/sexuality and disability is even less researched. The specific experiences of a person with a disability (hereafter PwDs) or as a caregiver of a disabled person changes as we carefully make sense of these experiences vis-à-vis one’s gender. While experiences of disability related to exclusion and marginalization in the society may be further complicated by aspects of

✉ Deblina Dey
ddey@jgu.edu.in

¹ Jindal Global Law School, O.P. Jindal Global University, Sonipat, India

one's identity, such as one's caste, religion and class, the three chapters in Part 2 of the book, entitled 'Disability, Body, Care and Sexuality,' discuss various ways of understanding the intersection between disability and gender

In the first chapter 'Experiencing the Body: Femininity, Sexuality and Disabled Women in India', the author Nandini Ghosh presents a riveting set of narratives about disabled women in India and their internalization of certain conceptions about ideal femininity. The narratives highlight the battles faced by disabled girls and women in their everyday lives and the constant pressure to fit into an idealized gender role carved out by society. Disabilities mark out women as 'incomplete' (p. 105) and make the pre-existing social constraints on women's lives doubly binding upon them. For example, a girl mentioned how her mother instructed her not to mingle with boys as it would malign her. Having close friends from the opposite gender especially prior to marriage is not considered a 'womanly' trait, and in addition she was disabled. The author has also discussed the tactics used by disabled women to hide their impairments from the rest of the world to prevent statements of sympathy or disgust from others. In a very nuanced and thought-provoking manner, the author has presented in this chapter the routine difficulties in the lives of women with various kinds of impairments, and also reflected on the different strategies used by women to combat the double stigma of being a woman with a disability. Wearing a sari to hide the calliper, engaging in productive work, staying away from men and marriage on the advice of the family members - all of these instances portray the entrenched nature of patriarchy in our society which becomes the dominant determining factor of the lifeworld of these women.

Janet Price and Niluka Gunawardena, the authors of the second chapter entitled 'Emergence of Epistemological Questions of Crip Queer across Shifting Geo/Bio-political Terrain,' provide an overview of studies and epistemological inquiries along the intersection of disability and queerness, with a special focus on India and Sri Lanka. This chapter critiques the contradictory normative frameworks of heterosexuality and desexualisation that govern the lives of PwDs at the same time. Homosexuality is commonly viewed as abhorrent by society, and the stakes are higher for PwDs, who must not only not be homosexual but also must be desexualized. The authors argue that this questions their capacity as individuals with desires and the ability to reproduce, erasing their agency.

The authors aim to break away from sexuality-disability epistemologies propounded by the Global North. They stress on the fragmented and plural forms of non-normative embodied identities of persons and mark out the various interpretations and responses to such identities in South Asia instead. Expressions of companionship, love and myriad forms of sexual relations in South Asia are found in temple architecture, folk literature and mythology. These often depict 'liminal anomalous bodies and fluid sexualities' (p. 125) through regional, local cultural narratives which attribute awe or devotion towards these transgressive depictions. However, colonialism lent newer interpretations of such non-normative depictions of disability and sexuality, subjecting both to a strict moral regime of discipline. The nationalist discourse reinforced the notion of an able-bodied heterosexual, with *Bharat mata* representing the ideal feminine that must be protected by able-bodied, heterosexual men. Post-partition, the symbolism of disability-sexuality gets constituted as the

partitioned *Bharat mata*, with Kashmir being an ‘unhealed wound within the conjoined body’ (p. 131) of Pakistan and India.

The medico-legal framework of addressing ‘deviant’ sexualities and disabilities continues to govern lives of people in South Asia. In the 1980s and 1990s the cripqueer identity began to get further consolidated in South Asia through civil society movements critiquing the absence of reproductive and sexual rights in law. The authors opine that the discourse of rights of the cripqueer in South Asia, over time, has been heavily influenced by and reframed within a universalized discourse propagated by the Global North, thus barely taking into cognisance the region-specific, local experiences of cripqueer. One of the most poignant and insightful observations about the local experiences of cripqueer as illustrated by the authors is how the cripqueer subjectivities in South Asia get constituted differently from that of people living in Western, imperialist societies. The authors claim that neoliberalism, globalization and neo-colonization impacts the lifeworlds of people in South Asia differently. The neoliberal state influences the hermeneutics of the cripqueer body, allowing us to understand them from newer, emergent perspectives. Surrogacy, offering body parts for drug testing, selling body parts, debility and exhaustion of bodies under capitalist regimes are some of the things discussed in this context. As claimed by the authors, this chapter opens up fresh vistas for research and provides food for thought about existing cripqueer paradigms in South Asia.

Upali Chakravarti in her chapter ‘Ethics and Practice of Care’ reviews significant literature on the ethics of care and critiques theories of justice that fail to speak about caregiving work that is usually undertaken by women in the private and public sphere. The tendency to essentialize the caregiving role of women is predominant in society. Care for a dependent person in the house is undertaken by women and is unpaid, and if a family hires help from the market, they too are women who remain poorly paid. Even if there are more job opportunities today for women, the fact remains that they bear multiple burdens, as they are expected to perform the care work at home, do the housework as well as earn money as wage labourers. The most important contribution of this chapter is that it highlights the needs of a caregiver, whether also employed elsewhere or not. The author points out there is a need for ‘enlarging the imagination’ (p. 152) to understand the concept of dignity attached to caregiving and the disabled in a more holistic manner than it currently is. She highlights that a change in perspective about disabled persons will also positively change the way society values care work for such persons. She argues that to see a disabled person only as worthy of compensatory care for the erstwhile contribution as a ‘productive’ member of the economy is a skewed way of understanding disability and the care work related to it.

It has often been seen that promoting the interests of caregivers in the context of dependent persons (for example, the disabled), is possible only by highlighting the disadvantages suffered by the caregivers when caring for them, Chakravarti observes. It may be asked why the rights of a PwD and that of her/his caregiver need to be pitted against each other? Why does this have to be a zero-sum game? To answer this, she prods us to consider feminist literature that emphasizes the fragility of independence and autonomy of every person. However, despite providing important conceptual anchorage to understand care for PwDs, the chapter only

tangentially discusses South Asian discourses on that same and highlights the Indian state's recoil from its welfarist agendas. Most of the literature consulted is written by scholars not specializing in South Asian cultures and it does have the potential to become more relevant to this audience.

In Part 6, entitled 'Legal Discourses of Disability in India', the discussion shifts to the lawmaking processes and the impact of key laws on familial relationships. In the chapter 'A Disability Studies Reading of the Law for Persons with Disabilities in India', Amita Dhanda explains the shortcomings of the present system of law-making in India in which, she argues, the emic perspective is gravely missing. She opines that the law-making for PwDs happens on the basis of 'charade consultations', if at all there is consultation, with PwDs (p. 398). She highlights the need to democratize and decentralize the process of consultation and the urgency for PwDs to reclaim the legal space and voice on their own terms, which according to her only a disability studies approach could provide. The 2007 Convention on the Rights of Persons with Disabilities (hereafter CRPD) has been hailed as a watershed moment in the history of disability jurisprudence because of its inclusion of PwDs' experiences in the drafting and enforcement of the same. The author traces the legislations before and after the CRPD came into existence and concludes that, despite the CRPD having a more grounded approach (unlike a lot of other United Nations instruments), it was not able to drastically influence law-making in India.

Prior to the ratification of the CRPD, the laws used the disability-as-deficit model and the perspectives of PwDs were at best 'smuggled in' (p. 388). Referring to the Persons with Disabilities Act of 1995, she highlights the infantilization of PwDs in which they were viewed as beneficiaries of socio-economic rights (and not civic and political rights). This, she argues, hurts the dignity and autonomy of such persons and reinforces the idea of PwDs being a burden on the state exchequer. The statist approach created an objective benchmark for determining disability, side-lining other factors that may determine a person's experiences. For example, Dhanda suggests that, often, a person with a lower percentage of impairment may face greater exclusion and may need greater assistance, social support and technological aid than a person with higher impairment who already had the necessary support and hence faced less exclusion. Thus, one needs to be sensitive to various kinds of constraints that the former may be experiencing. An objective criteria to determine needs may not do justice to people in actual need of assistance. Dhanda concludes the chapter by suggesting 'strategies of recovery' for the disability discourse by encouraging a bottom-up approach (p. 399). She says that consultation and dialogue are important but there must be a mechanism by way of laws to hold the lawmakers accountable for 'sham' consultations (p. 399). She opines that a disability studies approach is useful not only for law-making for PwDs but for all those marginalized sections of the society whose voices are overshadowed by professional knowledge.

On a slightly different note from Amita Dhanda's critical take on the lacunae in law-making for PwDs post-CRPD, in the chapter 'Reimagining Kinship in Disability-specific Domesticity: Legal Understanding of Care and Companionship' Rukmini Sen deconstructs the idea of care and the role of the caregiver as envisaged by recent legislations post-enactment of the CRPD. On the basis of the definition of 'caregiver' in the two laws, viz., the Rights of Persons with Disabilities Act, 2016

and the Mental Healthcare Bill, 2016, she opines that while there has been a growing legal recognition of caregiving by professional caregivers, there has also been a subsequent stress on the role of the family and community in the lives of PwDs in law, such that the disabled children can claim to be with the family and adult disabled persons can choose to form a family legally. This is an important step towards granting more dignity to the disabled.

In the contemporary legal discourse on disability rights, a caregiver can be paid or unpaid, which implies that care is understood by the law as a service, primarily delivered by a person in the family or availed from elsewhere. As rightly pointed out by Sen, this framework may further sideline the work of care put in by family members, who are mostly women. She seems to suggest that the law uses a rational-technical approach to identify needs and overlooks many aspects of the familial care which are considered as natural. She opines that ‘Care in the affection/affective sense cannot be spoken about or imagined in a legislative discourse’ (p. 406). This, according to Sen, does great harm to women within families, as it is they who perform most of the care work. Sen argues that in the Rights of Persons with Disabilities Act, 2016, the state’s discomfiture about recognizing the PwD as someone who may choose to marry and form a family is clear, since despite the (UN)CRPD ensuring the rights of marriage to PwDs, the Indian law remains silent on the question of marriage. There are sections in the law that refer to the right to information about reproductive rights and the role of the state in fostering respect for the choices regarding ‘family life, relationships, bearing and raising children’, but their being no mention of marriage per se in the law is striking, according to Sen. She argues that the state’s retreat in matters of providing assistance to families with disabled persons further naturalizes care and altruism within the family. To combat that, she proposes the feminist ethics of care framework whereby care and justice are not viewed as binaries and, echoing feminists like Virginia Held, she suggests foregrounding care in the political discourse of the country.

In most of these chapter discussed above, there is an acknowledgement of the need to use the feminist ethics of care approach to building a caring democracy in which both the care-receivers and the caregivers are considered as political subjects (Chakravarti, Sen). The subjectivities of women with disabilities are shaped by different responses to their disabilities by their families and societies in different contexts. For example, in some contexts, the women face the pressure to conform to standards of beauty and femininity by undergoing therapy to ‘treat’ themselves or hide their impairments in strategic ways. Sometimes, they are taught to restrain their sexuality, and in some cases their expressions of even same-sex love may be ‘tolerated’ within disability residences. Thus, sexual governance of women with disabilities operates within the larger patriarchal setup that disciplines women to make them accept heteronormative scripts. In all the case studies provided across the chapters, the agency of women with disabilities is barely evident. The chapters, in a few places, provide poignant insights that make us think about the notion of care itself. For instance, sometimes, the families may perpetrate a certain kind of violence through the way they care for the disabled girl child by not allowing her to work at home, thereby casting aspersions on and de-valuing their abilities to work or provide their labour in adulthood. The chapters discussed here speak to a diverse

audience, from academicians in various social science disciplines and law to social workers and policy-makers. They provide a meaningful insight touching upon issues of disability-sexuality from the perspectives of persons with disabilities living in different parts of South Asia.

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.