

Book Review

Empathetic identification with disability. **By Mrs. Rukmini Krishnaswamy-Director, Spastics Society of Karnataka, Indiranagar, Bengaluru.**

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***Disability studies in India; Global discourses, local realities.* Renu Addlakha, editor. Routledge India; 2013, 441 pp. ISBN 978-0415812122 Rs 846.00.**

Disability is a subject arousing much professional interest, research effort and analysis and is the focus of expert Perspectives yielding documentation and literature from Scholars, policy makers, people with active engagement in the subject and “subjects” with a vast variety of disabilities. This Book is a remarkable effort to string together contemporary research in India, the conditions of disability on a vast canvas of gender, class, caste, and locational disability (eg rural/urban) and their effect on policies, health issues, culture and family. It is a unique document in terms of content, style, relevance and analytical quality.

The collection which features chapters from seventeen authors is superbly edited by Ms Addlakha, a scholar known for her interest and writings on the sociology of medicine, mental health as a facet of public health, ethics, gender, family, disability and society. The volume reflects her broad perspective and deep knowledge of the field, and will serve as a reference source for a wide spectrum of people engaged in disability issues.

Beginning with a chapter on history of disability in India, Shilpa Anand analyses the inhuman handling of the microcephalic by some, and the protection received from others as an example. Thus there is a marginalizing attitude on the one hand and empathy and acceptance on the part of a few, on the other. Contemporary attitudes have a distressing similarity to those in history, showing the marginal impact of technology and associated developments, if any.

Jagdish Chander’s essay on rights and the emergence of disability studies provides a guideline for both advanced scholars and community based workers on disabilities. His tracing of the evolution of attitudes from Manu’s exclusion philosophy to the more recent approach of looking at problems from the social action angle is fascinating and instructive.

Sunderesan tracks disability-related policies and actions through the past five or six decades, with a particular focus on the millennium development goals set in 2000 raising hopes for action, as strategies and goals are thoughtfully developed and plans laid out. This is a positive development indeed!

Prenatal diagnosis is a component of “Family care and wish (!)”. This poses grim issues to be dealt with, the most relevant and ethically important being sex selection versus medicalisation of disability, involving deep cultural overtones and ethical issues. An innovative suggestion which can be explored is for the genetic counsellor’s role to be played by persons with disabilities as a perspective-facilitating strategy.

Chakravarti's section on comprehensive and long term care has a thoughtful analysis, with sample narratives, of the complex problems, both physical and emotional, faced by care givers. Clues for deriving coping strategies are indicated here and elsewhere in the book.

Mahrotra and Shubhangi Vaidya's section on intellectual disability constraints in Delhi and Haryana is illustrative and informative. The influence of the rapid changes in the structural and cultural milieu in society on intellectual disability, whether in terms of definition, severity, or functional consequence cannot be underestimated.

The impediments people with disability experience in urban India today are enormous. One has to view them from the human rights angle and seek redress and remedy. Nandini Ghosh poignantly conveys the grim lot of the woman with disability. The young child growing to womanhood faces sexual exploitation, devaluation of her body in the public space, and further inhuman marginalisation, all of which need to be addressed.

The editor's own writing on "Body politics and disabled femininity" - dealing with the perspectives of adolescent girls from Delhi - traces diligently how the concept of medical disability has acquired wider dimensions— the need for self-advocacy, and political action to achieve a more supportive, and understanding environment to ensure dignity. In short, strong advocacy is necessary for women with disability to be heard and honored by the public.

Identity provides empowerment. Hearing impairment, a good example, has its own culture, space and location. "The inner world of adolescent girls with hearing impairment: Two case studies" - is an unforgettable part of the narratives in the book. That the blind can see the world with senses other than the visual, and the illustrations given thereof are a poetic illustration of the potential for human creativity beyond what we label as handicaps. There are sections devoted to mental illness, psychiatry in self and identity constructions, with inclusion of choices of women users.

Much of disability literature inevitably assumes a rhetoric complexion. The essay on participation, inclusion and law rightly titled "Beyond the rhetoric", by Jeela Ghosh, boldly and unequivocally argues for legalizing social inclusion, with appropriate illustrations. This essay, in the reviewer's perception, provides relief from the jargon and juggling of phrases and arguments, inevitable in a field such as disability.

The reviewer having spent over five decades of her active life in the field, as a student, teacher, counsellor, Institution builder, advocate and most importantly, connected to hundreds of families and thousands of young people of all description of disability, labels, medical, social and cultural, has not come across a collection of essays such as these. While generic in nature, they are specific to our culture; they are analytical, yet deeply sensitive and empathetic; theoretical, yet practical in giving leads and directions. It is commendable that the editor and the erudite authors have identified so deeply with a human condition from which profound lessons are yet to be learnt.

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