

# REVIEWS

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## The Inauguration of a burgeoning discourse

The fine print readily supplied to us in published pages often has a resonating story outside its pages and precedent to its print. Nilika Mehrotra's edited volume *Disability Studies in India: Interdisciplinary Perspectives* typifies such a resonating origin. As we are told right in the preface, the edited volume is the culmination of proceedings of a conference 'Disability study in India: Reflections on Future', held at the Centre for the Study of Social Systems (CSSS), Jawaharlal Nehru University (JNU), back in 2015. However, the foundations for the thoughts found in the volume can actually be traced back to a similar conference held sometime in 2011 at CSSS, JNU, organised by Mehrotra. As one looks back now, one notices without fail the forethought of the deliberations then, in that the conference saw exactly what was to come a decade down the line. The theme of the deliberations at that time was 'Disability studies in India: challenges and possibilities for social science research', extended further in the 2015 conference. *Disability studies in India*, henceforth, is the work of a decade that reflects many changes and continuities of disability discourse in the Indian subcontinent.

The book is divided into three parts, each representing a distinct theme relevant not only for disability studies in the Indian context, but also for an interdisciplinary discourse across the board. The first part, 'Epistemologies and Representations', has chapters that touch upon the topics ranging from 'decolonising disability discourse' to 'strategies of teaching disability'. In between this vast expanse lie the chapters that uncover conceptions of "disability and difference", "public spaces and universal design" and "ignorance and epistemologies".

The second part dealing with 'policy and institutionalisation' carries chapters that bring to fore the issues of "Service and knowledge", "Disability education", "disability and social work education", "Disability and legal Accademia", and the "Institutionalisation of the idea of disability". Part 3 of the volume sets out to examine the interface between 'academia – activism and Enabling Practices' has chapters on the emancipatory potential of disability studies, the genesis of disability studies in the University of Delhi, the right to work for persons with disabilities, field notes on encounters with persons with disabilities, deaf education, and accessibility of field sites for visually disabled.

As one can gauge from the broad outline mentioned above, the volume covers a wide range of conceptual issues, policy matters and experiential concerns. Each chapter in the book is a theme in itself, potentially informing the readers of a distinct field of research

within the disability studies discourse. This review is in no way intended to summarise each chapter individually, but to present the flavour of the book as a whole. In the same vein, the discussion herein may not follow the exact chronological order of the book but would try to emphasise the semantic proximity visible across the pages.

To begin with, Nilika Mehrotra's chapter 'Situating Disability Studies: A Prolegomenon' serves as a perfect prelude to the volume. The chapter gives us the exact idea of the book, explains the logic of its layout, tells us about the essence behind its arrangement, and makes a convincing case for its relevance for today. As anyone familiar with the Indian higher education scenario would agree, the academic discourse on disability is closely tied up with the day-to-day concerns, special services and struggles of disabled persons in the university and outside. It is such concerns as accessibility and reasonable accommodation that are pushed harder to the front than academic issues on disability. In fact, it is often exceedingly difficult to make a strict separation between disability services and disability academics. It is, for example, perfectly possible for a disabled student/teacher body to demand for the establishment of a Disability service unit and teaching-cum-research Centre under the same umbrella.

Mehrotra's chapter, like the book itself, is deeply sensitive to the mutual relationship between disability activism and disability academics. The chapter, therefore, begins with the descriptive details of the University Grants Commission (UGC) sponsored enabling units in the institutes of higher education in the country. It then gives us a glimpse into the genealogy of disability discourse, particularly in the last three decades. *The physically handicapped in India: A growing national problem* (1963) by Usha Bhatt is considered to be one of the early texts on disability in India, and Mehrotra's edited volume begins exactly there.

*Disability Studies In India* has a promise for collating the emerging scholarship on disability across the spectrum through an interdisciplinary approach, documenting "resources and relationships ... in pursuit of knowledge construction and activism for realizing social justice", all this with an explicit agenda to "take the dialogues further and help consolidate the basis for strong disability platforms and disability activism" (p. 20).

One of the strong contentions of the book is its insistence on 'decolonising disability discourse in the global south', and James Staples' chapter, 'Decolonising Disability Studies? Developing South Asia-Specific Approaches to Understanding Disability', calls for an introspection in this regard. Staples is fully aware of the risky terrain his argument walks on, and therefore, asks as to how appropriate the culturally specific approaches are, and as to what extent they might be fruitfully applied without ghettoizing regional disability studies (p. 25). Since the conceptions of disability evolved in a particular western context – the post-World War-II socio-economic political regime – it is important that scholarship in the global South try to shape a model capable of representing culturally embedded experiences. Such an attempt is not just desirable but is highly warranted. The caution, however, is that "one be beware of straightforward links being drawn" between the past practices and present realities, for example the linkages often hastily drawn between the "texts written thousands of years ago and contemporary understandings of disability, which have clearly been shaped by many other things along the way" (p. 36).

So, what we have in Staples' schematic outline is an emphasis on the need for a culturally informed approach to disability studies and a caution against the possible parochialisation in adopting such a locally embedded experiential model. To put it succinctly, Staples has a two-fold argument: first, scholars interested in disability studies scholarship in the Indian subcontinent "need to look inwards", without losing sight of, perhaps with due attention to, "the particular socio-historical, cultural and material conditions that shape the experience of bodily difference for the majority population in the subcontinent"; second, these scholars should also be accommodative enough to allow cross-cultural comparisons without necessarily falling prey to Western assumptions on such wider issues as personhood and human rights (p. 38). Staples considers ethnographic method suitable for such an exercise.

Anita Ghai's chapter on ignorance of disability in Academia is the perfect continuation to the propositions made by Staples, though it is arranged at a little distance from his chapter in sequence. Ghai, a long-time contact point for academia-activism interface not just for disability discourse but even otherwise, takes the debate to newer heights by bringing to light the subtle practices of "epistemic oppression" (p. 75).

Ignorance about the disabled people and their being in the general social sphere may not be all too surprising, but the ignorance of disability in the system of knowledge production is a concern worth attending to. Clearly identifying herself as a woman with disability in a highly patriarchal, traditional society, Ghai offers self-reflexive glimpses into the ontological struggles of people with disabilities to find a place for themselves in the episteme. But the epistemological structures (academia in this case) have their own struggles within and outside. It is these struggles, along with other prejudices and stereotypes, that act as hindrance for the disability discourse to make a niche for itself in the order of knowledge production and circulation. In a specific elaboration, Ghai explains as to how our long-time obsession with the medical model as a primary lens to view disability becomes a barrier for other disciplines to engage with disability discourse as a discipline in its own right.

As promised right in the title, Ghai's chapter deals substantially with the idea of ignorance, emphasising its active deployment in the epistemological engagements (see p. 83). Drawing inferences from subaltern and indigenous studies, the chapter explicates the subtle ways in which notions of disability are pushed to the margins, thereby simultaneously resorting to disability-ignorance on one hand and facilitating ignorance of disability on the other. This is quite an interesting argument that the scholars of disability studies and interdisciplinary pursuit may not wish to give a miss.

In between these two theoretically important chapters one comes across the nuanced interventions of Shubhangi Vaidya and Shilpa Das. Das re-locates disability in public spaces using universal design as a heuristic tool. Scholars in disability studies and practitioners of disability services all know universal design as a concept encompassing accessibility, reasonable accommodation, and inclusion. It may also not be an overemphasis to state that the seven principles of universal design are now a buzzword for the industry provisioning services and products alike. Thanks to the adoption of the

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by a large number of countries, universal design is now entering the policy lexicon; the process may be slower than expected but has promising prospects going forward.

Having a general understanding of universal design – which I tried to hint at above – is one thing but taking it up as an interdisciplinary pursuit is another, and this is exactly what Shilpa Das does. Her chapter highlights universal design as a cross disciplinary approach intrinsic to both disability studies and design studies, with equal importance for other sciences, engineering, arts, and humanities. This is certainly an exciting invitation for disability studies to look outward and for other disciplines to see inward, as they all begin interacting with the design studies and research from a universal design approach

Making a case for “(Re)presenting Autism in India”, Shubhangi Vaidya examines the notions of ‘disorder, disability and difference’. Vaidya’s essay is a perfect prelude to academia-advocacy-activism as a strategy for re-learning disability. The chapter deconstructs margins, reorganises formal learning and family experience, day-to-day sociability, and brings community and clinic together in the context of experiences and articulations of autism in India. Vaidya’s chapter presents a three-decade history, commentary on current trends, an ethnographic preview, personal reflections and futuristic analysis, all in the context of disability discourse with a focus on autism in India. For anyone interested in Indian disability studies in general and autism essentials in particular, this chapter has instructive lessons and remains a must-read.

The first part of the book that sets out to delineate ‘epistemologies’ and representations has a concluding chapter by Shilpaa Anand, highlighting teaching disability in humanities and/or history classrooms. Unlike all other authors in this part, and most authors in the volume, who proceed from the vantage point of research, Shilpaa looks at the discourse from the lens of teaching. Given the trans-disciplinary nature of the subject matter at hand, teaching disability is not always as straightforward as teaching, say, poetry, physics, sociology or computer science. The issues of disability have to be framed in, and rooted through, the methodological scheme of the discipline/academic branch in which the concerned teachers and students are procedurally located. For example, the modules on disability prepared for the audience in humanities are considerably different from those designed and taught in social sciences. Within these broad academic categories there can still be differences based on the disciplinary parameters. Anand’s chapter brings to the table some of these nuances, with a primary focus on literary and historical studies situated in the branch of humanities. The chapter gives us a historical account of disability teaching in the literature classes, and this history begins in the United States. It then moves on to identify the factors that inform and shape the classroom interactions of disability discourse in the Indian context. The chapter contains a rich description, a well-researched account and critical analysis of teaching disability in literature and history – details the aspiring scholars would greatly benefit from.

One of the exciting features of the book is that it places a high premium on the institutionalisation of disability academics and action, which generally translate into ‘Disability studies’ and ‘disability services’. Part II of the book has chapters dedicated to

discussing the subject in detail. Though both the disability studies and disability services often seem to go hand-in-hand, their relationship is intricate, if not complicated. There are two broad strands: one making a case for complementary relationship, and the other arguing for a dichotomous functioning. The reader gets a chance to witness both of these strands in their vigour and vitality. While Tanmoy Bhattacharya's chapter, broadly on disability studies as an extension of service-knowledge cordiality, represents the complementary relationship, Amita Dhanda's account of establishing Centre for Disability Studies in a prominent Law University and contributing to the evolution of disability policy in the country does not take exactly such a position. Reading these two chapters together, however, has an advantage, in that one can clearly see the difference of perspectives in approaching disability discourse, where one considers it as an extension to service delivery, and the other looks at it as a product of academic advocacy. This is exactly the kind of debate the scholars committed to the growth of disability studies as an interdisciplinary enterprise should eagerly be looking for and, now that it finds the right inaugural tone at last, one should engage with it rather than draw ready-made conclusions from it.

Coincidentally or otherwise, an overall survey by Nilika Mehrotra and Ritika Gulyani of disability programmes – services and academics included – in Hyderabad brings to fruition the debate Bhattacharya and Dhanda overtly engage in – not necessarily with each other but through the subjects they present to the readers. The chapter by Mehrotra and Gulyani maps out the services and academic activities run through the disability units in major institutes of higher education located in and around Hyderabad, Telangana state. University of Hyderabad (UOH), National Academy of Legal Studies and Research (NALSAR), English and Foreign Languages University of Hyderabad (EFLUH), Maulana Azad National Urdu University (MANUU) find prominent place in the survey, for reasons best explained by the authors of the chapter. Each of these institutes of higher education has a unique arrangement to cater to the special needs of students, faculty and other staff with disabilities. The readers would do well to get into the text to know the details. This particular chapter would be useful not just for the ethnographic details it records but also for the methodological model it offers for the researchers interested in surveying the growth and dynamics of a field of study in a particular urban conglomeration.

Neerja Sharma has a narrative account of the evolution of disability studies in one of the oldest colleges established to teach home sciences in the national capital, Delhi. Her chapter is instructive in so far as it informs us the potential disability studies can have even outside the social science-humanities studies and research set-ups. But the conclusions drawn at the end of the chapter, particularly the casual approach shown by the author with regard to the rigour and expertise required for disability teaching and research, seems a bit problematic. These are the issues the future researchers would have to carefully tread through, though.

The chronicles of disability studies in India, if ever to be written as a separate account, two prominent centres of higher learning would compete for an equal space in it: Centre for disability-studies at NALSAR (whose account by Amita Dhanda has already been

referred to in the preceding paragraphs), and Centre for Disability Studies and Action at the Tata Institute of social sciences (TISS), Mumbai campus, whose first-hand account is presented by one of its chief architects, Srilatha Juvva. Juvva's chapter is a combination of personal reflection about, and professional participation in, a project that literally took off from scratch but quickly gained ground, carving out a niche for itself and for the cause it initiated in the first place. Srilatha Juvva has been part of this long journey, and her chapter is full of anecdotes, evidentiary facts and experiences. Chapters by Dhanda and Juvva can, indeed, come handy for academicians and administrators looking for advice to run disability studies centres for teaching and research in Indian higher education ecosystem.

The volume has an equal space for academia-activism linkages that contribute to knowledge production. Several authors have contributed chapters that examine issues ranging from deaf education to accessible tourism. Jagdish Chander outlines the history of visually impaired youth in Delhi almost from 1970s which eventually contributed to the rise of disability debate and discourse; Ritika Gulyani examines the question of deaf education; Deepa Sonpal and Vanmala Hiranandani make a convincing case for the potential the emancipatory research holds for the growth of disability knowledge and its empowering effect for disabled persons as stakeholders; Nimushakavi Vasanthi evaluates "right to work" as an entitlement through the lens of critical disability theory; Mahima Nayar brings to light the concerns emanating from, and the lessons imbibed within, the engagement between non-disabled field researchers and disabled field subjects; Kavita Murugkar, Anurag Kashyap and Abir Mullick demonstrate, through their field research, the hidden prospect of converting the heritage sites as spaces of knowledge creation, provided one is ready to take that extra step of making them architecturally accessible and socially inclusive.

The academia-activism interface, like service-knowledge engagement, is a contested field, and it would do no good to debate as to which one of these processes precedes the one on the other side of the hyphen. As more and more research bring newer facts, each of these alternative arguments becomes stronger than before, making the episteme a contested terrain. The disability studies discourse in India, like anywhere else, will have to grapple with some of these challenges in the days to come and, should find ways to respond effectively, if it is to remain relevant as an interdisciplinary pursuit. The present volume inaugurates this re-invigorating field as it opens up the discussion for a full public view.

*Disability Studies in India* edited by Nilika Mehrotra with contributions from the archetypal theorists and active practitioners alike, is long awaited. The most distinguishing feature of the book, in my view, is that it contains in its fold the research findings and experiential notes written by the chief architects of disability scholarship in the Indian subcontinent, along with reports of the ongoing research put forth by the scholars on whose shoulders the future of the discourse squarely rests. The watchful readers like me wish the volume in its next avatar to initiate a one-to-one dialogue between disability studies and other disciplines like law, literature, sociology, economics, and perhaps biology and artificial intelligence. In the meantime, *Disability Studies in India* would remain

a must-read text for scholars in disability studies and all others engaged in a serious interdisciplinary research.

*N. Annaram*

