Nilika Mehrotra *Editor*

Disability Studies in India

Interdisciplinary Perspectives

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Editor
Nilika Mehrotra
Centre for the Study of Social Systems
Jawaharlal Nehru University
New Delhi, Delhi, India

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Preface

This book volume has been in the making for the past five years. The conference titled "Disability study in India: Reflections on Future" was organised at Centre for the Study of Social Systems, JNU, in February 2015 to take stock of how Disability Studies (DS) perspectives inform the assumptions, theory and practice in different disciplinary contexts. The idea was that the conference would initiate interdisciplinary dialogues on the meanings and dynamics of disability studies in India, its origins and what shape it is taking in diverse higher educational institutions (HEIs) in India. A handful of scholars have been working in different disciplines of social sciences and humanities using disability studies perspectives. Meetings and conferences have been organised on a regular basis especially since Indian state became signatory to United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 galvanising bureaucrats, activists and academics. This volume is a product of compilation of the papers presented in the conference and few newly invited ones.

My research work "Disability Studies in United States and India: Issues in institutionalisation" funded by Fulbright-Nehru senior research fellowship (2013–2014) informed the planning of the conference. One of the major findings from the fieldwork in US universities was that there DS programs are varied and heterogeneous in character owing to their locations in different disciplinary contexts; DS in India, however, is still in its beginnings (Mehrotra 2017). This conference tried to deliberate and understand the origin, history and nature of disability studies in the Indian context. Prior to this, virtually no research was published in terms of coherent view of practice of DS in higher education institutes in their specificity in the Indian Context.

This book volume has emerged out of the conference papers that many scholars had presented there. I had envisaged the conference to include papers from cognate disciplines like sociology and social anthropology, social work, law, political science and education and also interdisciplinary perspectives from literature and linguistics, community sciences, development and policy studies and also architecture and design. Out of a total of 20 papers presented, 14 papers are being published here. At the time of conference, presentations by medical and rehabilitation on public health scholars from DS perspectives could not be received, which also shows that the small DS community was largely drawn from social science and humanities' disciplines.

Long gestation period in making of the volume meant that the scholars had to take cognizance of the recent changes especially the passing of Rights of People with Disability bill (2016) by the Indian Parliament in their final drafts. Unfortunately in the long process, we lost a promising DS scholar, Navneet Sethi from JNU who had presented the paper on DS and literature. She was one of the first scholars to launch a course on disability and cinema at the school of Language and Literature studies at Jawaharlal Nehru University. Some other very interesting papers by DS scholars were not included, who for their busy schedules could not contribute chapters to the volume. My research study on Disability Studies in India (2015–2017) funded by UPOE-II, JNU contributed significantly to the crafting of this work.

This volume makes an effort to capture and map out the relationship between disability rights movements and disability studies globally and also locally. Further how disability can be understood from different disciplinary locales and how exchange of ideas about the definitions, theories and methods could enrich what is claimed as an interdisciplinary study area titled as Disability Studies. This volume thus presents the history, growth and challenges of institutionalising Disability Studies in the Indian context by specifying not only the locational challenges but also conversations and learnings from each other in order to enrich the subject.

Introduction of the volume maps the history of the origin of Disability Studies through its linkages with disability theories from the global north, their relevance and patterns of adoption in the Indian as well as Global South context. A brief review of the recent publications in Disability studies by largely Indian scholars follows. The making of disability studies' culture in largely the metropolitan higher education settings is deliberated upon and the role of key Disability Studies' scholars, and both persons with disabilities and their allies are also elaborated here. The volume presents three important themes along which the papers have been classified. The first theme "Epistemology and Representations" reflects on how disability is being defined, conceptualised and represented in Philosophical debates, Mythology, History, Fiction, Media, Literature and Design studies. The second theme is the "Policy and Institutionalisation" which locates DS in relation to the State policy, i.e., The Persons with Disabilities (Equal Oppurtunities, Protection of Rights and Full particiaption) (PWD) Act 1995 with Rights of Persons with Disability (RPWD) Act 2016. This section also looks at the history of the how the study and pedagogy of disability emerged, evolved through the past and how their foci have changed in recent times. This section includes chapters from Community Science, Law, Humanities and Social Sciences in trying to understand policy formulations and how DS grew and evolved in university setups, its relationships with service delivery and disability activism on the ground. This section presents diversity of disciplinary contexts that inform the shaping of DS.

The following third theme titled "Activism Interface: Enabling Practices" underscores how Disability Studies have grown in relation to disability rights activism and how they mutually enrich each other. The chapters highlight how DS and activism go together. They highlight the importance and challenges of practical dimension of doing DS and its emancipatory potential. How DS perspectives inform the rights of persons with disabilities in relation to labour market and legal provisions. This theme includes chapters from Law, Social work, Development studies, Architecture and Political Science.

Many chapters have overlapping themes, and they cover a large array of topics from representations, activism, policy, and local practices, but for the sake of analysis they are classified into three themes. Interestingly, most chapters talk to each other since they are dealing with similar issues of theory and practice. Methodologically, they appear very different and use different strategies of understanding the phenomena and writing about them. They are, however, also united by similar concerns and draw from very similar sources. This volume hopes to take the deliberations further and tries to help build global Disability Studies for future.

New Delhi, India Nilika Mehrotra

Reference

Mehrotra, N. (2017) *Disability Studies in India: Issues in Institutionalization*. Unpublished project report submitted to Jawaharlal Nehru University.

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Disability Studies community in India is very small but a fairly cohesive one. It would not be exaggeration to say that many of us have grown together in building the bases of this new discipline. Though not naming them individually, I affirm their presence in this work. I deeply acknowledge my sincere regards and gratitude to all the scholars who have contributed chapters to this volume and have been very patient since the publication process has been delayed for many unavoidable circumstances.

My faculty colleagues have always been encouraging and helpful in sustaining a positive work environment in the centre. My Fulbright research work (2013–2014) and US colleagues informed shaping of my ideas about documenting the emergence and expansion of Disability Studies in India.

Thanks are due to my research scholars who have worked on Disability Studies and otherwise on other subjects contributed in multiple ways to the making of the volume. Students with disabilities in JNU have been an inspiration to my work. My special thanks are due to Ritika Gulyani who at every stage of writing and editing of the volume acted as a solid support and an efficient associate. My friends and family have been strong pillars of support. Nita Mathur's polite reminders for completing the volume in time pushed me to work as always. Soumendra Patnaik has always been concerned and deeply engaged with my work. Vandana Chaudhary has always been inquisitive about this work, and discussions with her were useful. My mother and sisters are anchors in often messy routines of life. My understanding of disability has also grown out of experiences that I have shared with their lives and work.

Finally, a big thanks to colleagues from Springer for providing a very easy and supportive publication process.

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Nilika Mehrotra is a Professor at the Centre for the Study of Social Systems, Jawaharlal Nehru University, New Delhi. She has taught sociology earlier at Delhi School of Economics, University of Delhi. She has been a Fulbright-Nehru senior researcher at University of California, Berkeley, USA (2013–14). Her specializations are in the fields of Gender, Disability, Social policy and Development processes.

Chapter 1
Situating Disability Studies: A Prolegomenon

Nilika Mehrotra

Disability Studies (DS) in India is of very recent origin in terms of critical examination of the meanings and dynamics of disability in the Global South. In the past two decades, one finds the emergence of various disability study programmes as well as disability service centres, known was enabling units, being set up in many Higher Education Institutions (HEIs), ushering in discussion around the disability. Study of disability was and to some extent still remains the preserve of Medical and Rehabilitation sciences. It is gradually moving out to acquire an identity in terms of critical social science and humanities perspectives on the subjects. Mehrotra (2011) argues that DS understanding largely remains within that of medical model in the Indian context and State policy remains welfare-oriented. This volume tries to historically examine and document the processes of crystallization of disability studies in India post ratification of the Persons with Disabilities (PWD) Act 1995 and Rights of Persons with Disabilities (RPwD) Act 2016 in relation to role of disability activism, growing number of disability study scholars in the Indian Universities and the burgeoning disability scholarship. There are several questions that emerge when we try to examine the phenomena, i.e. how much has changed on the ground in past two to three decades? How is DS being defined in Indian context? What are the terms of discourses? In what ways does DS represent the issues and agendas of persons with disabilities? What are the kinds of linkages DS have with Disability Rights Movements (DRMs) and how they feed into each other? Do the traditional disciplines accommodate disability perspectives and in what ways? Whether the university structures allow for translation of disability laws in terms of attendance of persons with disabilities (PWDs) in HEIs, providing physical and social accessibility and technological support, etc., and changes in Curriculum and research support systems? Is the emergent DS scholarship growing organically? In what ways it negotiates

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N. Mehrotra (✉)
Centre for the Study of Social Systems, Jawaharlal Nehru University, New Delhi, Delhi, India
e-mail: nilikam@gmail.com

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with the global discourses and remains true to the local realities in representations and understandings? In what ways voices of disabled persons are grounded in these dynamics?

Scholars have argued for developing South Asian perspectives in disability studies in India, as the Global North theories appear largely incompatible with ground realities of people with disability living on this continent (Mehrotra 2013). Though large number of PWDs inhabit this part of the world, many of them live in abject poverty, having little access to education, healthcare and employment, and other social resources. Nevertheless, little decolonized theorization has been attempted in this part of the world. There is a tendency among scholars here to rely and reference Anglo-American theories and literature which hardly pays attention to ground realities in the Global South. Till a decade back, Disability Studies in the Global North was marked by the debates on medical versus social models mainly exemplified in British context. These debates created a binary between the body as perceived through the medical models and the social structure by the social model. Disability activists in Britain argued that disability is largely constructed by the socially oppressive discriminatory practices and exclusion. People with disabilities were seen to be largely discriminated and oppressed by inaccessible physical and social structure. Post-structuralists, on the other hand, came to emphasize on the body in pain in relation to unfriendly social structures. DRM in Britain has been voicing and emphasizing on social model which has also facilitated DS elsewhere.

DS in United States was far more eclectic in nature having its roots in also in social science understanding. They coined the ‘minority model’ for people with disabilities, gearing towards policy reform issues. Society of Disability Studies (SDS) was established in 1982 which became the nodal point to bring DS scholars together, belonging to different disciplines and who were united in critiquing the rehabilitation perspectives and building legal capacity of PWD. In 1980s, Americans for Disability Act was passed after a long and active disability activism. It was hailed as the most progressive legislation on this matter, overtime SDS came to be dominated by Philosophical and cultural perspectives on disability and efforts to engage with the medical issues were frowned upon.

> Disability studies recognizes the fact that disability is a key aspect of human experience, and that disability has important political, social, and economic implications for society as a whole, including both disabled and nondisabled people. Through research, artistic production, teaching and activism, disability studies seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change. (SDS Mission.)

However, despite all attempts, a single coherent definition of Disability Studies is still to emerge, which is tandem with the interdisciplinary field that it exists in (Ferguson and Nusbaum 2012). Within disability studies, it is believed that an active part should be played by disabled people in the course of the research projects as they are to be considered as an expert with the experiences of their life, feelings needs, etc. (Barnes 1992 and Stone and Priestley, 1996 cited in Davis 2000).

In the American DS over decades, the agenda has been expanded to be more inclusive of blacks, Hispanic and Asian disabled people in their fold. In both UK and US, DS scholarship, however, totally omitted and neglected to figuring PWD's perspectives from the non-Western context. Of late some scholars like Campbell and Oliver (1996), Goodlay (2010), Shakeshpeare (2013), Grech (2015) (Britain), Meekosha (2011), Soldatic (2018), (Australia), Opini (2015) (Canada), Kolářová (2016) (Eastern Europe), Mehrotra (2013) and Ghai (2018), (India) and Chataika et al. (2019) (Africa), have called for decolonizing DS. They argue for not only including concerns of PWD from the Global South but highlight the colonialism of psychic, cultural and geographical life of South by the North and ignorance of the resistant subaltern positions of Global Southerners (Meekosha 2011). The question of poverty and underdevelopment unemployment, malnutrition and indifference of the State government to the question of disability have been highlighted in these works. Intersectionality paradigm developed in Western discourses has been extended to include question of caste, religions, rural, urban and Indigeneity in order to understand how disability operates in the Global South. Disability nomenclature contentions reflect the growing chasm between Government, activists and lay people over contentious terms like 'Differently abled', Disabled and 'Divyang'. There is the growing realization that medical versus social model, rights/rehabilitation binaries fails to capture the ground reality of life worlds of PWD in this part of the world. In the absence of adequate laws and social protection policies, family and community support continues to be important here (Mehrotra 2013).

The hegemony of the northern discourses and often blind import of these discourses in explanation of the disability continue to be problems in building DS theory in the Global South and specifically India. Uncritical reliance on Western models often led to partial misleading understanding of the phenomena (see Mehrotra 2013: Staples this volume and Friedner 2014). Unlike in the West where charity and rehabilitation have been dismissed, there is need to engage with these perspectives, along with cultural once (Mehrotra 2013; Staples and Mehrotra 2016, Staples et al. this volume).

How disability has been understood and studied, and the purpose of such studies have typically been intended to serve, are deeply bound up with specific national, political and welfare traditions. Like in some European countries, Disability Studies in India also get funding and legitimacy from the state. More research is required to examine how DS perspectives within diverse disciplines raise pertinent issues regarding ground realities of the ways in which disability is represented and how PWDs engage with life in their specific local and globalized contexts. This volume has made attempts to arrive at a state-of-the-art review of disability studies in India through critical engagement in interdisciplinary perspectives.

There have been many contributions to the field of disability studies by social scientists earlier. One of the first works done on disabled in India was by Usha Bhatt, where it was discussed how the society perceives those with a physical disability as being punished for earlier sins and how change has occurred over the years within these societies (Bhatt 1963) Jagdish Chander argues that prior to the 1990s, the main approach to seeing literature was from a welfare point of view (Chander 2008). In the recent years, Anita Ghai has tried to look at the concept of disability from an academic point of view in which she looks at not just at the disability rights movement but also how women took part in it (Ghai 2002). The work of Asha Hans and Annie Patri also examined various disability rights and feminist movements from the point of disabled women, which provides a theoretical analysis of women with disabilities in the society as well as provides understandings of disability from various viewpoints (Hans and Patri 2003). Further, Mehrotra argues that the way disability is understood in Indian society is still cloaked in a basic will to survive as well as to understand it culturally, and due to this, models of prevention and rehabilitation are more relevant. Thus, it becomes very important to see disability as an important marker for social inequality (Mehrotra 2011).

Last one decade has been very critical for DS in India as a number of important publications have come up that focus on realities, experiences and voices of persons with disabilities. More disabled and 'non-disabled' scholars have been contributing to the field but a systematic review is still wanting. DS has to grow with emergent literature on disabled people in their lived environments. Ethnographies, therefore, contribute in significant ways to reflect differential life worlds inhabited by PWDs (Mehrotra 2012).

The edited volume by Addlakha (2013) is important in its approach as all the essays are India-centric, and it also simultaneously deals with impairments that deal with the physical, sensory, communication, psychosocial as well as intellectual. It goes beyond the medical and social models of disability and instead looks at the experience of disability and that of impairment as being universal experiences of a human condition. The work lays a foundation for beginning of a serious engagement with disability studies in the academy and provides insights for formulating culturally sensitive and socially and economically viable public policies on disability in this country (Addlakha 2013: 10).

Another pertinent work in disability studies in the context of South Asian communities was that of Nilika Mehrotra, titled *Disability, Gender and State Policy: Exploring Margins* (2013). The work, while touching upon all relevant issues of disability, also looks into how the new debates seem to have surfaced in the arena such as the emergence of Critical Disability Studies, the moving away of the perspective of the Global North to that of Global south and cross-cultural perspectives as well, which includes the understanding of the interrelatedness of the discourses on disability and post-colonialism. An important issue that the work brings up is that of the shaping of feminist disability theory through foregrounding the care roles played by family and communities in the understanding of disability as well as its negotiations in varied social contexts. Not just these but an intersections of kinship, gender and caste along with the state policies of India have been highlighted here. This work strongly urges for theorization of disability in a South Asian perspective rooted in existential and experiential realities of persons living with disabilities in diverse contexts. Vaidya's (2016) ethnographic work on middle families with autistic children and Nayar's (2018) exploration of women with psychosocial distress in resettlement colonies provide valuable empirical insights to how disability is constituted in political and economic contexts and reflect diverse cultural patterns.[1] Staples's important work on conceptualizations of disability and intersectionalities of masculinity and

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[1] Pooja Singh's Ph.D. work on disability in the rural Uttar Pradesh, Ritika Gulyani's Ph.D. work with deaf in Delhi, Vaijyanti Bezbaruah's Ph.D. work on ageing are important ethnographic additions to growing field of DS.

disability challenges rhetoric and prevalent discourses (2007). Staples and Mehrotra map out the anthropological contributions to growing DS in the Global South and highlight the questions of personhood, power, representation, personhood, embodiment, culture and ontology, as well as more recent foci on citizenship and human rights (2016: 36).

Underlining disability as a social, cultural and political phenomenon in contrast to it being treated from medical, clinical or therapeutic perspectives, Ghai (2015) questions perceptions about disability, who is constituted as a disabled as well their exclusionary experiences in Indian society. The work also explores the lack of dialogue between people with disabilities and those without. In addition, it also looks the development of the disability theory and critical disability issues as well as looking at issues of identity within the context of disability (Ghai 2015: xxiv–xxv).

Examining the question of disability, Kannabiran (2012) examines the constitution and tries to locate discrimination within it as it can be seen in three spheres of Indian society, namely, within the confines of disability, as relating to various diversities that exist in the county, in intersectional terms. The section that is dedicated solely to disability looks at how disability rights have been treated within the Indian jurisprudence and suggests that even though disability law is relatively new in India, it can take a stepping stone from the previous discussion on non-discrimination in India. Further, it critically talks about the policy and legislation surrounding the discrimination based on disability while also talking about philosophical basis behind these laws such as the concepts of personal liberty and the ideas of non-discrimination (Kannabiran 2012, 49–50).

Disability and Development as one of the core issues appears in the edited report by Kannabiran (2016). The report by Council for Social Development was indeed a very important one and highlighted important aspects of disability studies, which highlighted various issues such as labour perspectives, gender issues, educational barriers as well as governmental policies. More such data around economics and disabled people's access to the market needs to find their way into the disability discourse. Chaudhry (2016) also provides a useful examination of disability in neoliberal governance in rural Andhra Pradesh while Friedner and Weingarten (2016) while looking at disability as diversity opens the field for further discussion on the topic of disability as something that is in need of conservation and is in direct opposition to the eugenics movement. Friedner's work (2015) talks about the deaf in India and how they are emerging as a separate community, by tracing the importance of sign language, vocational institutions as well as religious institutions such as the church in the lives of deaf.

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, (PWD Act) was enacted in 1995 and enforced in 1996, with a central aim of trying to bring persons with disabilities into the mainstream as well as to provide them with equal opportunities to education, employment as well as the access to essential services (Kothari 2012, xvii).

With the emergence of UNCRPD (United Nations Convention on the Rights of Persons with Disabilities), the issues of disability rights are now becoming more recognized, especially at the global level. At present, the disability rights in India are at a very emergent stage and according to Kothari, it is required that we deepen our understanding of the concept if we are to understand the distinctive needs to people with disabilities. The work, *The Future of Disability Law in India: A Critical Analysis of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act* provides a detailed summary of the Persons with Disabilities Act 1995, which has been largely absent in the disability narrative so far. Additionally, since there was a strong demand that the PWD 1995 be replaced by a new bill that is compliant with the suggestions of the UNCRPD. The current work looks into this as it suggests what the possibilities for the future laws are while simultaneously trying to understand the present one (Kothari 2012, xviii).

It was with the spread and popularity of the disability rights movement that disability studies also owes its existence. In the past few years, the realm of disability studies has grown beyond the applied fields of medicine, social work and rehabilitation in order to become a vibrant new field of inquiry within the critical genre of identity studies. Recently, interesting works on architecture and universal design in relation to disability are emerging. Architecture as a design discipline has a strong underlying social commitment and the potential to facilitate social inclusion by addressing needs of all sections of the society. Such a thought usually remains vague and a generalized idea, and is rarely taught in the schools of architecture and minimally practiced by professional architects. Barriers in architecture continue to hinder People with Disabilities (PWDs) basic access and activities. The cold response to disability issues is evident from the poorly designed standards, and approach to functional and clinical solutions prescribed and undertaken by architects for mere compliance.

Nandini Ghosh in her edited volume ‘Interrogating Disability in India Theory and Practice’ (2016) examines the theory and practice of interrogating disability and tries to look at the academic as well as the practical and lived approached to disability issues in India. The work draws from different disciplines and recognizes the need to bridge the gap between theory and practice, especially within the context of South Asia and development studies.

It is also interesting to note that now more publications within the field of Disability Studies now include work from persons with disabilities and their narratives, which includes works by Chib (2010), Valliappan (2015), Ghai (2018), and special volumes on disability narratives, such as that of *Café Dissensus*, which has been regularly publishing issues on disability since 2013.

In the last decade or so disability studies has grown in the Global South and many scholars who linked the question of disability to welfare state are more recently talking about disability rights and social justice. Disability rights movements which speak often in contested voices direct their agenda to the State and call for implementation of legislation and policy in realizing the rights of persons of disability. In this context how disability has been understood and studied, and the purpose of such studies have typically been intended to serve, or are deeply bound up the specific national political and welfare tradition. As I have argued elsewhere (2011) that disability studies in India draws funding and legitimacy from the state. This book volume tries to arrive at a state of review of disability study in India to critical engagements through interdisciplinary perspectives. Taking a historical perspective, the volume examines the social and institutional setups within which DS are promoted as well as their relationship with DRM and Civil society organizations in the policy context.

Next section discusses how scholarship in different disciplines have been informed by DS perspectives and how they have negotiated, evolved and shaped the structures and discourses around disability issues through higher education settings in India.

Epistemologies and Representations

In the Indian context, critical DS perspectives are being employed in different disciplines where terms of discourses can be understood in terms of disability and representations and different imageries of PWD are being examined through deconstructing popular culture, folk constructions, etc., to understand why discrimination against disabled persons exists and continues to exclude them. Further, ableist portrayals need to be understood and challenged in theory and practice.

In the United States, the humanities-based approaches in disability studies have been critiqued in terms of (1) lacking a pragmatic value to the real-life situations of disability peoples, (2) texts based on objects that are inherently graded in its representations of disabilities, (3) a focus on history that proves irrelevant to the problems of today and (4) an overemphasis on metaphor.

Materialist approaches still over-value bodies as primary locales on relevant information—particularly in the case of disability (Mitchell 2000). One of the primary tasks is to cultivate media and literature critics who can intervene in the cultural images of disability that influence our responses and ways of imagining differences.

While there is a tendency in disability studies across the non-Western counties to often import the information, definition and models from the Western discourses, there is a growing realization that South Asia specific approaches are required to understand disability in the Indian context (Mehrotra 2013). **James Staples** calls for the possibilities of decolonization of disability studies using the South Asia specific framework. He critiques the usages of Anglo-American models in examining disability questions in South Asia. Further discussing the limitations of the cross-cultural understanding of disability, he brings forth his ethnographic insights that people often blame culture either as superstitions or as impediments in universalizing health programmes. Highlighting the disparity of ideas and practices between disability scholars in and of India and the experience of the majority of the disability people of the subcontinent, he alerts us to heterogeneity in the disability community. He further examines the complex character of cultural cosmologies of different religious communities as well as new level tendencies to craft disability in particular ways based on specific impairments. Notions of personhood and alterity in South Asian ways are being invoked in this paper as well as neoliberal rationalities which constitute the disabled subjectivities in diverse ways. Similarly, what is also desirous is that the existence of charity and religious models that still hail as important starting points for understanding disability among many communities be unpacked.

While presenting a panorama of rich representations of autism spectrum in the Indian context, **Shubhangi Vaidya** specifies the urban middle-class context and allows to understand disability as a relative concept.[2] This chapter looks as cultural images as historically constituted and discursive in nature. Interestingly in examining the imaginations of the autism spectrum, she works through medical, social, cultural (mythology and medial) and legal perspectives to foster and political understanding of the manner in which individuals and community understand and leave the experience of the disability. She ends the chapter at a positive tone 'Disability has come out of the closet and has become more visible in public spaces. 'Disability stories' are being told in the media, often in tokenistic ways. An ecosystem around rehabilitation and special education has also grown, and the 'helping professions' are now being seen as viable livelihoods, rather than 'social service' exclusively rendered by family members. 'Inclusion' has become a buzzword in theory, if not in practice, and mainstream schools are slowly but surely opening their doors to children with autism'.

Physical and social accessibility is often seen in DS discourses as one of the key themes in understanding discrimination and exclusion of persons with disabilities. The intersections of disability, society and design in the Indian context are the theme of the chapter by **Shilpa Das**. She explores 'systems model of disability' and how this model, like other models such as the medical model and the social model of disability, is underwritten by different kinds of cultural and historical determinants, and is a powerful ideology that constructs categories of identity. She further discusses universal design approach and the models in terms of design decisions, processes and actions that are taken to often frame social policies. She finds design approaches ableist and falling short of using disability perspectives. This chapter discusses the need to incorporate the concerns and voices of disabled people in design thinking and practice. By taking examples of public spaces as inaccessible to most disabled people in India, e.g. public toilets she makes a case for disability sensitive universal design practice. Question arises here that the public toilets have been a concern for the state policy for one decade or so under *Bharat Nirman Mission* (Building India Mission) and *Nirmal Gram Yojana* (Clean Village Planning), and *Swachh Bharat Mission* (Clean India Mission). Building and provision of toilets is being promoted but they are still not acceptable to many people in rural areas. The other issue is also questioning if universal design thinking is only limited to relationship between disabled people as users and state as the provider? Shilpa Das's chapter examines how universal design approach enriches the field of design practice, design education and disability study in India, and raises more important questions about users' perspectives and voices being grounded in the design practice.

Why has DS been ignored for long time in academia and what does such an absence imply? **Anita Ghai** in her chapter examines the epistemologies of ignorance, regarding disability and how study of the same is not given the recognition that it deserved in academic discourse.[3] She employs her experiences as disabled woman, to sensitize the readers towards the lack of emphasis on the study of knowledge of disability in India. She writes that "disability provokes fears and anxieties

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[2] The paper presented by Shubhangi Vaidya at the conference was related one but the chapter is freshly written for the volume.

[3] Anita Ghai's chapter was specially invited one as she was not able to present it at the conference.

about ‘able’ body mortality, and very easily renders itself as the other’s” (p. 4 this volume). Using Memmi (1967), she underscores the processes of alterity or othering in life processes. Explaining the marginality of disabled people and disabled perspectives in universities where not only knowledge but also patriarchal neoliberal and normative values produce and reproduce values, she points to the radical potential of disability/ability discourses whose deconstruction can help dismantle the privilege academic knowledge systems. She treats ignorance of disability perspectives as denial of inequalities and particular kind of violence. Further interconnections between disability, women’ studies, caste studies are also seen as moving towards the idea of social justice for marginalized communities. She also suggests ways to prevent epistemological exclusion of disability from the academy.

How does DS perspective inform understandings of characters in literature and other types of text? **Shilpaa Anand** through ‘Rethinking Monsters’ takes the readers through her journey of teaching disability studies in history and humanities. Her chapter presents an interesting interdisciplinary approach to examining cultural images and metaphors that figure in historical and literally sources. Using Lennard Davis’s ‘Enforcing Normalcy’ (1995) and Rosemary Garland Thomson’s ‘Extra ordinary bodies’ (1997) and others, she presents a view of what the field has brought to the Indian context. Conceptualizing corporeal differences through historiography, she taught the courses focusing on ‘monster flicks and mad Women’ through English literary sources. In another course, she explores the contemporary practices in boxing and racing and how professionals in these fields conceptualize their body. For this iconography from USA and India are utilized. The combination of literary text and iconography was utilized to understand amputation of limbs as well as ageing in different contexts. She argues that significant aspect of the task of teaching and researching disability studies critically in the Humanities is to make explicit the idea that one is not looking for a new object called disability in the primary sources and cultural material, one is working with but learning and trying to find new ways of knowing embodiments that are already part of our world. It is also critical that works on disability be also carried out in languages other than English so as to offer a wider scope of engagement with the current population of the Global South.

Navneet Sethi had been making similar efforts in the context of Literature and Culture Studies Centre, Jawaharlal Nehru University, and was the first to introduce a course on Disability Studies within the curriculum. Her area of specialization was in African-American literature, and within this field, she managed to introduce disability-centric themes for her course. She also used cinema to understand disability representations.

Policy and Institutionalization

The linkage between state policy and setting up of DS centres as well as disability resource centres are of recent emergence in Indian Context. **Tanmoy Bhattacharya** in his chapter on ‘Service and Knowledge: The emergence of Disability Studies

Extension' examines the fundamental issues of inequality among various social grips in accessing higher education in India. He tries to examine how disability figured in the policy documents from University Grants Commission to NITI Aayog on the question of students with disabilities in higher education institutions. He underlines the ignorance and absences within the centres within for the marginalized like the (1) Centre for the Study of Exclusion and Inclusion Policy, (2) Human Rights and (3) Centre for Potential for Excellence in a Particular Area (CPEP). These centres were supposed to address issues of inequities, discrimination and marginalization but disability hardly figured in these. DS centres which came only in the last one decade were supposed to specifically locate it at an interdisciplinary juncture. These centres were designed to promote research in disability, document lived experience of PWD and to act as a knowledge base for the disability-centric view of the academia in general. On the other hand, UGC also recommended setting up of Equal Opportunity Offices/Cells to provide facilities, enhancing employability, and creating opportunities for them in the mainstream. This chapter looks at the interface between policy and practice especially with regard to examples from Delhi University, and tries to underline the relationship between service and knowledge. Bhattacharya also focuses on issues of awareness building, implication of technologies for people with disabilities. He also highlights the challenges of the interface between knowledge and service system, i.e. the relation between disability studies as knowledge base and disability service delivery systems. The work on the accountability of these Higher Educational Institutions is still very scarce, and the question on whether they are following the prescribed policies has only found mention in a few works (Mehrotra 2017).

Prior to policy recommendations by MHRD and UGC to set up DS programmes, disability was studied and examined in variety of context, especially in science education. DS in India has had origins in disciplines like rehabilitation sciences, medical sciences, psychology and such, where one sees a direct connection between early efforts in nation-making around 1950s post-independent India. Evidence of this is visible through welfare policies of the Indian state, with the establishment of the ministry of social welfare where disabled along with other categories of groups were assigned as beneficiaries (Mehrotra 2011).

Some of the early higher education institutions focused on home science disciplines especially to advance the idea of women's education. This could be seen as a continuing legacy of Indian reformers emphasis on looking at home science education as very important for women since their role as child-bearers and nurtures became the central pivot of empowering them. Focus on women, children and families continue to be one of the prime concerns in women's education in India, which could be seen as extension of women's 'natural gendered roles'. The idea of special education focusing on special children in relation to their mothers has also been part of this overall picture. Identification of disability and their rehabilitation was seen as one of the core tasks of knowledge building and practice in home science education. **Neerja Sharma's** paper is an interesting documentation of how disability was defined, interpreted and taught as part of home science education at Lady Irwin College, one of the premier institutions at University of Delhi. As against the newly formed DS programmes, Sharma traces how approaches to disability have always been interdisciplinary in their institution. Through variety of courses, from child development to community development, to family studies, apparel and textile studies as well as food and nutrition, disability appears as a category where biological, environmental, cognitive and social aspects are brought in together to understand its multidimensional character.

Both at the level of theory and practice, insights drawn from psychology, biology, sociology, anthropology, development studies and educational studies, an interesting amalgamation of perspectives are brought in to underline issues of especially children with disabilities. From more medicalized approaches, there is a consistent move towards construing disability as a social construction.

The dissertations written by Masters' and doctoral students cover a variety of array and aspects related to disability and impairments and their social responses. As a true combination of theory and practice, Lady Irwin College also ran a school and day care for special children which also became a site for further research and understanding. Their major publication 'social ecology of disability' draws form variety of interdisciplinary perspectives based on students and faculties research around the issue. It took many decades for Lady Irwin College to develop a special interest in DS and the chapter is a testimony to how institutionalization of DS was closely determined by changing political, economic and ideological shifts in its meanings.

Moving away from medical model inspired disability education to rights-based approaches, recently DS centres where critical perspectives are being utilized have been institutionalized. **Amita Dhanda** recounts her experience of a setting up of a disability study centre in a law University claiming the urgent need for establishing a disability studies in all aspects of knowledge to help remove barriers in the social labelling of the disabled she argues against ableism, as a demeaning pressure that not only underestimate the disabled but also creates a hindrance in them to reach their potential as a human being. She suggests multidisciplinary classes as suitable sites to explore the manner in which different disciplines could feed into the development of disability studies. After persistent efforts by Dhanda and her colleagues at NALSAR became the pioneer institute to have established a Centre for Disability Studies. She discusses the importance of the research and documentation and reaffirms how a law university could throw light on how to provide legal education about rights of people with disabilities and also to generate knowledge from their perspective. By bringing in different types of disabilities under the purview of legal education a symbiotic relationship between teaching and research was established. She especially points to the difficulties faced by persons with psychosocial and intellectual disabilities.

DS in India is gradually emerging in different parts of the country. A study undertaken in 2015 by Mehrotra (2017), across different higher education institutions found that it is still in the making and fully fledged DS programmes exist in very few institutions. This ethnographic study in three primary sites, i.e. Delhi, Hyderabad and Mumbai, revealed a heterogeneous character of how DS has emerged and institutionalized in different university setups. The study was largely focused on how disability perspectives are evolving in Humanities and Social Science disciplines and it tried to document the history, practices, role of DS scholars and their links with civil society organizations. In the context of US especially, DS or as it termed, critical DS largely emerged from Social Science disciplines and has moved towards more humanity-based cultural studies. But in the Indian scenario, disability perspectives are emerging in these disciplines almost in parallel fashion. **Nilika Mehrotra** and **Ritika Gulyani** elucidate the diversity of practices of disability studies in the city of Hyderabad in southern India in four major Higher Education Institutions (HEIs).[4] In NALSAR, there is a fully fledged DS programme headed by Amita Dhanda (Chap. 7) who works on the interface of disability and legal education. NALSAR Disability Studies contributed to the drafting of the bill which was finally passed in as RPWD 2016. There are a number of scholars who have conducted research in DS. Policy and practice go hand in hand at this place. Whereas at MANUU, Shilpaa Annad teaches literature courses using interdisciplinary approaches from disability studies as well as history, literature and anthropology to postgraduate students at the School of Languages, Linguistics and Indology (Chap. 5).[5] The chapter also examines the aesthetic approaches used by EFFLU in representation in English literature texts. Disability Cell at EFFLU has been trying to use technology to help students get access to resources. One of the findings of the study was feeble interaction between the community organizations and DS units in HEIs. The binary between academic and service delivery seem to be one of the issues in keeping the two somewhat disconnected.

On the other hand, sociology faculty at Hyderabad Central University is also encouraging research in DS, though there are no courses run by the scholars there. In these institutions, disability service units have also been established to support students with disabilities. In Hyderabad city as a whole, there is greater disability awareness. Disability activism was visible and scholars had set up networks to carry out deliberations on the subject. Many sociology departments especially at JNU are encouraging research on disability issues in recent years.

There is a strong link between DS and DRM in the Indian context and the research generated in the higher education institutions is feeding into movements, strategies and action. At one level, it appears that scholars and activists are working in their own niches but at another, one finds them coming together on common platforms. Another institution, Council for Social Development also promotes research on disability. They brought out a special report on Disability and Development in 2016 providing a comprehensive picture on research on the grassroots level examining the issues of discrimination, as well access and inaccessibly to resources like education, healthcare, work opportunities and such (Kannabiran 2016).

One of the key ways in which disability perspective has been recognized in the academic discourses in Indian context was through rehabilitation studies, and it is not surprising that Government of India set up Rehabilitation Council of India (RCI)

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[4] This chapter is a new one since study on the subject was undertaken after the conference.

[5] At the time of the fieldwork in 2015 at MANUU, Shilpaa Anand was teaching DS. At present, she has moved to BITS Hyderabad and one is not aware if the courses are still being taught there.

under Ministry of Social Justice and Empowerment which oversaw the role of governmental and non-governmental organization working on disability issues. Clearly informed by the medical model, the comprehensive rehab programme included rehabilitation experts, physiotherapists, occupational therapist, audiologist, speech therapist, psychologists and disability social workers and in this context social work became one of the key sites where professionals were trained to engage with persons with disabilities especially from the marginalized sections. Access to healthcare within the biomedical terms and the context of traditional medicine systems is also a theme that is not very well researched (see Singh 2018). An intersectional perspective on how caste, gender and disability interact within healthcare would also help understand disability as a public health issue.

Srilatha Juvva elucidates how within the discipline of social work, disability perspectives emerged and became specialized, culminating in the beginning of Masters' programme in Social Work in Disability Studies and Action, TISS. This was largely done to fill up the gap between social work practice to engage especially with persons with Disabilities through social work approaches. Her paper traces the development of teaching programmes in disability social work, the antecedents and the trajectory since its inception in 2008. This is one of the very few specialized programme in the country focusing on the needs and requirements of the persons with disabilities. This chapter focuses on the background research which informed the building of the pedagogy including classroom teaching, field visits and documentation to setting up of curriculum. Since social workers, especially working in the field of disability need to undergo certification by RCI, the practices in the centre have to broadly follow its mandate. So to begin with, rehabilitation seemed to be the focus with which social work practices at TISS began. Gradually, the curriculum negotiated between the ideals of social work practice and rights-based approach towards disability, which included:

1. Respect for the dignity of persons with disabilities, including integrity, empowerment, confidentiality, autonomy, individuality and self-esteem.
2. Individualization, meaning that persons with disabilities are individuals first, and must be considered, assessed and accommodated individually.
3. Rights of persons with disabilities to inclusion and full participation.

This chapter also highlights the issues in institutionalization of DS within School of Social Work which was being restricted a decade back. As TISS expanded, new school opened and disability studies courses had to fit into the larger structure. Besides teaching, the centre also engages on research on disability issues through UGC support, on the one hand, and interacts with NGOs and corporate sector, on the other hand, as one of the requirements of training disability social workers s to find jobs in these sectors. In short, this centre is trying to combine theory, largely informed by social model, with practice, i.e. working among the marginalized, within the larger social work ambit.

Besides humanities especially English literature and Linguistics and some social science disciplines like Law, Political science, Sociology and Social Anthropology, Social Work, institutionalization has just begun in other disciplines like Architecture and Design (Das and Murugkar et al. this volume). Satender Singh, a medical doctor at Delhi has been documenting the activism regarding eligibility and DS perspectives in medical institutions through his special interest group 'Infinite Ability.' In addition, Educational Studies, Geography, Economics, History, Women' studies, Environment studies and Development Studies, Science and Technology Studies, Policy studies, Media studies, etc., are also sites where critical DS perspectives could contribute in important ways. And some work has already begun.

One of the important lessons in the processes of institutionalization is how few DS scholars played a very important role in raising the issues and have resilience in struggling within the otherwise extremely conservative higher education settings to introduce disability perspectives. In order to open up spaces and make higher education settings more inclusive, disability activism has made important contributions.

Since there is a very small community of disability studies scholars in the Indian context, they have been meeting regularly in conferences, seminars and closed-door meetings for more than a decade. Importantly the discussions around medical/social models, rehabilitation/rights, academia/activism, theory/practice are often the themes of their discussion. In these deliberations, interdisciplinary dialogues have importantly carried the debates further (see Mehrotra 2017). In order to develop a critique of Anglo-American theorizations and shape locally specific DS discourses which do not necessarily reject them but negotiate an understanding, interdisciplinary dialogues go a long way. James Staples's chapter reminds us of the constraints and possibilities in this process. Almost all the chapters in the volume have drawn from Global Northern discourses but described and interpreted local specificities and the kind of challenges they have to meet with realities. Passing a law is not sufficient condition for a suitable implementation in the Indian context.

In most of the institutions, Disability Studies has not grown organically except in a few places like NALSAR and Centre for Disability Studies and Action, TISS. In the other places, it has been consistent efforts of a few individuals. Thus, it is safe to say that Disability Studies has failed to percolate down, as most of the institutions are not growing from below but rather are emerging as a result of the pressure from above, such as the directives of the UGC and Ministry of Social Justice and Empowerment. Establishment of such centres and enabling units might be seen as more of a lip service than anything else (Mehrotra 2017).

Also, even though India has passed a disability law in accordance with the UNCRPD in 2016, but little to no additional funding has been provided. There is no data available as to whether universities have any budget that has been especially earmarked for a DS cell or a DS centre. It is also seen that the personnel in most of these centres are those with disabilities themselves, and if these individuals were not present, then these subjects relating to disability would also not be considered important.

Academia–Activism Interface: Enabling Practices

Globally, DS and DRMs have been closely connected and in fact, much of the thrust on how and what would be the goals and agendas of DS comes from the ground where activists have been waging battles to win a life of dignity and opportunities for PwDs. Since there is very little documentation of the role of few significant individuals and collectives in steering ahead the movements and raising concerns about absence of voices of PwDs, this section tries to map out the role of PwDs in civil society organizations in dismantling stereotypes, laying out felt needs, experiential narratives and questioning laws and policies which create barriers in actualizing the potential of PwDs. One also finds that the gap between academics and activists often cease to exist when one examines this relationship.

Jagdish Chander historically traces the protest movements led by blind scholars and students in the context of University of Delhi for self-advocacy around issues of education, both at school and university level as well as employment. Since 1970s, he also highlights the role of National Federation of Blind (NAB) in building leadership among the blind persons. According to him, it was the persistent efforts of the blind activists that state and society could understand the aspirations of blind persons for higher education, jobs and dignified life. Self-advocacy movements by the blind people challenged the dominant construction of blindness and also helped build the notion that they were suitable for faculty positions, as well as civil service jobs. The chapter also brings out the dissensions within the blind movements about their goals and strategies. He further examines the role of blind collectives in building a national level movement beginning from Delhi. University of Delhi became the site where blind collectives like *Mubahisa* (study circle in Urdu) which consisted of faculty members and students. *Mubahisa* carried out discussions and organized lectures related to disability issues from time to time, and later the NGO *Sambhavna*, which deals with the concerns of disabled faculty members, has been laying a very important role in building awareness about Disability issues. Chander argues that these groups were pivotal in building disability centred ambience in University of Delhi, which gradually led to University of Delhi setting up various services for blind as well as persons of other disabilities. He further examines the role of EOC (Equal Opportunity Cell) and more recently enabling units in several colleges. He hopes for articulating more disability centred curriculum and disability activism in University of Delhi. Blind students have also played an important role in steering ahead movement at Jawaharlal Nehru University for a long time (Mehrotra 2017). JNUDPA (Jawaharlal Nehru University Disabled Persons' Association) has large membership of teachers, students and karamcharis but they are mainly blind or persons with locomotor disabilities (Mehrotra 2017). It is interesting to note here that Ritika Gulyani in her chapter points to a near absence of deaf persons in higher education settings and how their concerns are not being registered. Students with psychosocial and intellectual disabilities are also very few in number in HEIs (Palan 2016). Thus, a hierarchy exists among persons with disabilities in relation to their access to higher education.

Documentation of disabled activism and their participation in popular protests and among different political groups at different levels is negligible. None of the political parties in India see disabled as a potential vote bank. Efforts are being made by a lot of activists, such as Satendra Singh who has campaigned for accessible voting booths among other things. But this is just a begining, and the efforts need to be continuous on this front. Unlike the disability movement efforts outlined by Grech and Soldatic (2016) regarding the Global South, the disability movement in India is still very invisible.

A majority of persons with disabilities in the Global South are disenfranchised and experience profound exclusion in Indian context. Their access to resources and basic services are severely restricted. **Deepa Sonpal** and **Vanmala Hiranandani** argue that the policy measures suffer, as very little evidence-based research is available, both in statistical and qualitative terms, further leading to their marginalization. Disabled peoples' voices are missing in policy deliberations and execution of programmes and they push for the idea of emancipatory research on the premise that the agenda must be set by persons with disabilities with them being at the helm of such studies. Their chapter is a good example of how collaborative approach between persons with disabilities, civil society organizations and academia could generate meaningful outcomes, leading to setting of future directions and course of action to be taken. PWD Act 1995 recognized the need for disability research and Ministry of Social Justice and Empowerment clearly identified the gaps and had set the agenda for promoting research since late 1990s. They have been supporting research studies undertaken by civil society organizations to generate data on the subject. The concept of emancipatory research argued by the authors is in line with Rights of Persons with Disabilities 2016, and therefore the coming times are filled with opportunities, especially to examine the implementation of new law and its impact. Emancipatory research practices according to them could contribute to enriching disability studies. This may include capacity building of Disabled Persons Organisations (DPOs) which strive for self-advocacy, engaging various stakeholders' participation to change the attitudes and offer reasonable accommodation in all spheres of life; and striving for governance reforms for better service delivery. They cite the example of Action Research undertaken by Unnati Organization for Development of Education in 2012–2014, for enabling DPOs. They critically examine some of the challenges faced by DPOs from primary as well as secondary literature. They critique the role of elite urban educated young individuals in taking leadership of DPOs unlike most persons with disabilities residing in rural areas who are not well educated or employed. The chapter draws heavily from the participation of persons with disabilities in designing accessible tools. The second study cited by them was about awareness-raising among the civil society organization for learning and documentation. And the third initiative cited was to carry out the debates and discussion, whereas in the last initiative, persons with disabilities as citizen leaders took the initiative to avail the benefits of the public schemes. In disability research, disabled people call for being treated as contributing participants and not as study objects. They also call for documenting oral histories, participation in decision-making at all levels and ethical ways for carrying out research in disability studies. Lack of data has been cited as one of the main hurdles in implications for disability policy building. Additionally, data is also in want of further research in works that are relating to disability and caste (Mehrotra 2013) and in works that look at disability among the indigenous population, i.e. among more marginalized social groups.

For persons with disabilities in India, right to work is one of the fundamental issues as disability rights activists have been pointing out that much discrimination occurs when they try to access jobs in different kinds of work sectors. A few works (Chaudhry 2016; Friedner 2015) have discussed the ways in which government agencies and corporate sector might provide reasonable accommodation keeping in line with the new RPWD law. **N. Vasanthi's** chapter elucidates the question of right to work for persons with disabilities form a critical disability theory perspective. Article 27 of UNCRPD sets out right to work and employment and also includes right against discrimination and the right to just and favourable conditions of work. Her chapter draws from decisions from the High Courts and the Supreme Court on the Indian Constitution and Labour Legislations to elaborate on legal responses to issues of discrimination and right to just and favourable conditions of work for person with disabilities. Following disability studies attempt to move away from understanding disability from a medical model to a social model, she makes a case for disability as a category for research in academic domains. This chapter makes a comparison of Persons with Disabilities Act 1995 with that of Rights of Persons with Disability Act 2016 in understanding the failure of legislations, schemes and decisions of the court in fully accommodating the rights of persons with disabilities. She criticizes the existing paradigms as being based on liberal model of rights, and argues for more grounded understanding of disability in order to fully realize their right to work in terms of their capabilities and capacities. In the Indian context, she writes about Supreme Court cases on labour where right to work has been invoked in a variety of cases such as unfair dismissal. In Meenakshi Mills vs Union of India, Supreme Court relied on right to work as fundamental right to life. Discrimination on the ground of disability is covered under the right to equality under the Indian constitution before the PWD Act came into force. Articles 14, 15 and 16 are often invoked against discrimination in employment. Article 14 was first involved in the case of Javed Abidi, who pointed out the callousness of various organizations in meeting with the needs of persons with disabilities, and called for jurisdiction of Supreme Court to give effect to right to equality to them. Another case of National Federation of Blind was also cited for a direct to Union Public Service Commission to permit blind candidates to appear for civil service exams. PWD Act 1995 clearly mandated that the services of the employee who acquires a disability during his service shall not be dispensed with, nor shall be reduced in rank. In the same vein, she has cited a number of cases where court invoked the idea of a welfare state to enable them to lead a life of dignity, equality, freedom and justice. Vasanthi examines how PWD Act 1995 and RPWD 2016 have facilitated constitutional provisions in realizing rights of person with disabilities with regard to employment and work. She critically examines how Indian law has to move from medical to social model in order to effectively change the access to right to work for persons with disabilities and courts have to recognize the right to work in relation to several other rights in line with UNCRPD.

Within fieldwork centred disciplines where encounters between the so-called non-disabled and disabled are common and part of the training process, what challenges are there? **Mahima Nayar** discusses how the novices within the social work discipline try to encounter people with disabilities in their mandatory fieldwork settings as part of masters' programmes at TISS. Since the centre specifically trains them to deal and support people with disability on the ground, students are allowed to take first-hand experience of working with them. This paper interestingly highlights ableism within the so-called non-disabled students comes to the fore in their interactions with the disabled. She talks about a continuum of reactions in students' journey from initial reaction of discrediting, stigmatizing to gradual comprehension of the social model of disability. Students, like others, have stereotypes and often charity perspectives which often leads to conflict within them, but how gradually in fieldwork settings, they learn to unlearn their prejudices, accept and intervene meaningfully in different social situations. She also underlines the role of compassion with special regard to provision of services. Tracing the nitty-gritty of training students through fieldwork, in terms of face to face interactions, and also developing skills to deal with existential realities, how they are exposed, they unlearn and develop new ideologies and discourses. Nayar also highlights the role of negative perception and stigma, which is harder to shed and changing attitudes, becomes difficult. Through narratives, she underscores how students become reflexive, understanding and accepting change makers through the disability social work fieldwork practice.

The role of technology also is seen as being very critical in this regard, as activism in contemporary times is aided by it, and students, both at the national and the global levels, are being connected to each other. Not only are the students now pushing for assistive devices and questioning the physical and social accessibility of the infrastructure around them, but also push the university administrations to take appropriate steps in this regard.

Understanding the importance of education in the lives of persons with disabilities, the chapter by **Ritika Gulyani** traces the question of deaf education in India.[6] The question of inclusive education as opposed to segregated education is one that has long been debated. The beginning of segregation, because of their origins in racism, is often seen as a negative connotation and is not considered to be the way ahead for education of persons with disabilities. However, in the case of deaf, segregated education or special schools are a good platform where they are able to start their academic journeys. The importance of Sign Language (SL) in the life of a deaf child is beyond compare, and it is essential that the exposure to this language should start at the level of the household. Unfortunately, as most deaf children are born to hearing parents, they do not learn SL until much later, probably when they enter formal schooling. So, it is critical that when the deaf students enter schooling they are exposed to an environment where SL is the sole means of communication and

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[6] Ritika Gulyani's paper has emerged out of her Ph.D. work in the last few years.

teaching. The chapter further traces the policies that are in place for the education of deaf students in the country. The new RPWD Act 2016 holds some promise for their education, as it is to ensure that appropriate language and means of communication be employed. Further, the chapter drawing from field experiences in Delhi outlines the challenges that the students face. These include lack of sign language exposure at a young age leading to communication barriers with parents and family, constant shifting between hearing and deaf schools, lack of empathy at the schools and the inexperience of the teachers to handle a deaf classroom due to their inadequate training. The courses designed to train teachers for teaching do not take into account the lived realities of a deaf child but rather emphasizes on rehabilitative perspectives. However, the situation takes a worse turn at the level of higher education. Here at the level of higher education, there are not any institutions which cater exclusively to the needs of the deaf students, nor do the current institutions have the facilities (sign language interpreters, presence of visual modes of teaching, deaf teachers) to be able to teach a deaf student. Due to this, deaf students after their schooling either enrol in a distance learning programme or else opt for vocational training. The chapter also throws light on the ways in which disability studies might be able to intervene in the issue of education of deaf. The works on persons with mental and intellectual disabilities is still scanty. Though Vaidya (2016) does talk about autism in urban locales, the research still needs to be done pertaining to intellectual and developmental disability in rural areas and small towns.

Accessibility is an important issue, and thus DS perspectives have entered disciplines like architecture which for long ignored the perspectives of disabled users' of spaces around them. The question of accessibility for PWDs is often understood in terms of access to physical spaces or functional uses. But **Murugkar**, **Kashyap** and **Malik** argue that architecture has a great role in constructing social identities of people in communities.[7] They lament the absence and exclusion of people with disabilities in the discipline of architecture. Since very little research has been conducted on DS on the field of architecture, their chapter builds on an in-depth research on understanding disability issues in heritage environments in India. Centring on people with visual impairments and their experience of visits to heritage sites, the chapter draws on their perception and cognition through a phenomenological approach. Leisure is one of the very important aspects of human existence, and PWDs are often excluded from leisure visits to heritage sites, due to their inaccessible structures. In this context, the study uses the findings to develop a more socially inclusive visitor and heritage management strategies and related policy-related framework for PWD in heritage sites. The chapter offers an exhaustive account of people with visual impairments, visits, spatial perceptions, cognition, interpretation and special representation of heritage sites. They highlight the accessibility-related issues not only critical for policy formulation but also for architectural design for virtual interpretation centres as well as an alternative to experience the inaccessible parts of a

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[7] This chapter is also freshly written though it is an extension of the theme on which Kavita Murugkar presented at the conference.

heritage site. The chapter provides a critical reflection on the conventional ways of thinking about design and architecture of spaces. The study uses an emancipatory research model where people with visual impairments are important stakeholders in research, and their experience becomes the ground for providing findings and making policy recommendations. However, while scholarship relating to physical accessibility is emerging, there is a need for there to be discussion on the accessibility of public transportation as well. Government's Accessible India programme does talk of physical and social accessibility for PWDs across disabilities but there is very little evidence of its implementation in an effective manner.

Important questions may be raised about large number of disabled persons who embody ableist perspectives and yet to be politicized. On the question of nomenclature often one finds people in general accepting the popular discourses. While the term disabled is not accepted, 'differently abled' often finds currency. The case of 'Divyang' is potent here as one finds state imposition of a terminology which activists abhor, but lay people complying with it. Conscientization and awareness-raising has been one of the most important goals of disability studies much like women's studies and Dalit studies where the slogan drawn from the North American context, i.e. 'Nothing about us, without us' is being emphasized often. Many chapters examine how pedagogy is utilized as a tool of awareness building in all students (Ghai, Anand, EFLU example by Mehrotra and Gulyani, Srilatha) whereas how fieldwork practice and social science research training are utilized in this emancipatory, participatory agential process (Nayar, Chander, Sonpal and Murugkar et al.). Sonpal and Hirnandani argue for radical potential of DS understanding emanating from the ground to feed into policy implications. Similarly, Das and Murugkar et al. speak of disabled users' perspectives to be utilized in building disability policy. Amita Dhanda recalls of NALSAR's significant contributions to building disability law for the country but as an academic how they felt challenged in the negotiation with DPOs and activists, on the one hand, and Government on the other hand. She writes: 'These political battles our experience tells us are best waged by the constituency affected by the political choices. Expert bodies like CDS can provide grist's to the activist mill but cannot with any credibility or legitimacy press for its ideological positions'. This case clearly exemplifies how disability studies' potential for radical changes could be blunted in negotiating with to civil society organizations' and the state as they work with logic and rhetoric and governance, respectively.

To sum up, this volume collates emergent scholarship from different disciplines, initiates and takes forward an interdisciplinary dialogue, and documents the resources and relationships, DS community seeks to work with, in pursuits of knowledge construction and activism for realizing social justice. The volume promises to take the dialogues further and help consolidate the basis for strong DS platforms and DS activism.

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Part I
Epistomologies and Representations

Chapter 2
Decolonising Disability Studies? Developing South Asia-Specific Approaches to Understanding Disability

James Staples

Abstract The dominant theoretical frameworks of Disability Studies (DS) have emerged historically in relation both to theoretical trends in the Western academy and to the material circumstances—from industrialization to civil rights movements—of the Global North. At a moment when the continuing hegemony of Western scholarship has led to increasing calls for a decolonization of the curriculum, this article explores the applicability of existing frameworks for studying disability in the South Asian context. It also asks whether culturally specific approaches might be more appropriate and, if so, considers how those might be fruitfully applied without ghettoizing regional DS.

Keywords Disability · India · Decolonization · Cultural relativism · Liberalization

Introduction

Disability Studies (DS) in Britain and the United States (US) developed, from the 1970s onwards, both as a counter to the hegemonic biomedical models that continue to frame international discussions of disability and in relation to particular histories of industrialization and civil rights movements. While Western DS has charted a course that those keen to embrace the study of how bodily difference affects social experience elsewhere in the world might follow and develop, there is also a need to recognize and counter the Eurocentric bias of existing social models of disability. In the context of the Global South, that requires scholars to look beyond the civil rights battles of the West that underpinned, for example, the independent living movement in the US, and to refocus on the contemporary and historical conditions—socio-economic, cosmological and environmental—that shape the particular experiences of living with different kinds of bodies in particular locations. If DS is to be emancipatory as well as intellectually exploratory, it also needs to draw on regionally specific experiences.

J. Staples (✉)
Brunel University London, London, UK
e-mail: james.staples@brunel.ac.uk

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In South Asia[1]—the region on which I focus in this chapter—these include, but are not limited to, struggles and experiences related to colonialism, caste and gender, as well as those shaped by the neoliberal rationalities that have become prominent since the early 1990s. Unless we attend to such specificities, as some Indian scholars have already pointed out, DS in South Asia runs the risk not only of being in thrall to Western-inspired structuralist and post-structuralist models—and therefore part of a particular intellectual tradition that developed externally to South Asian discourses—but also of focusing too narrowly on the needs of affluent disabled men (Ghai 2002; Mehrotra 2011).

Drawing on ethnographic examples from South India and beyond, including from my own anthropological fieldwork,[2] this chapter aims to set out the grounds from which a critical study of disability—that can both engage with DS elsewhere and recognize the contingency of disability to different places and times—might become more firmly established. I begin with an overview of the conditions within which DS developed in Britain and the US, before exploring how it has constituted and dealt with disability in India and the Global South more generally. I then go on to examine how the particular contexts of South Asia—socio-historical, political and material—might be reflected upon in order to develop more appropriate frameworks for studying categorizations of bodily difference in India.

Origins of Disability Studies in Western Europe and the US

Disability Studies as they have emerged in the West have been strongly influenced by the so-called British social model, a structuralist framework that differentiated between an ‘impairment’, as a biological anomaly (Barnes et al. 1999: 28), from a ‘disability’, as the social consequences of particular impairments (cf. Oliver 1990; Barnes, Mercer and Shakespeare 1999). It was a model that reflected the theoretical trends of its time in the Anglophone social sciences: the argument set out in Oliver’s *Politics of Disablement* (1990) is a Marxist, historical materialist one, classifying disability as a consequence of post-industrial revolution shifts in modes of production from the family unit to the factory. It also took as read the Cartesian splits between the physical and non-physical aspects of the body and was firmly located in the

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[1] For the purposes of this chapter, ‘South Asia’ is used to refer to the Indian subcontinent, encompassing India, Pakistan, Bangladesh, Nepal and Sri Lanka. As an Indianist—whose ethnographic work has focused on South India—I acknowledge my bias towards India.

[2] My long-term and ongoing fieldwork has been conducted both in a self-run leprosy colony in coastal Andhra Pradesh, on India’s south-east coastline, and in what was the same state’s capital, Hyderabad, with a range of people who identified, or were identified by others, as disabled. Research methods included the classical anthropological toolbox of participant observation and interviews.

structuralist paradigms that dominated the social sciences from the late 1960s through to the early 1980s.[3]

Disability, for Oliver, was not only socially constructed but in its contemporary manifestation, it was also a specific product of capitalism. Disability Studies in the US were likewise rooted in social constructionism, although, unlike in Britain, the American civil rights movements of the 1960s (Tyson 1998) collectively provided a more tangible template for the directions taken by disability scholars and activists, drawing on conceptions of universal human rights. Disability Studies has also developed subsequently in tandem with the related interdisciplinary areas of Gender Studies, Race/Ethnicity Studies and Queer Studies, each influencing the other (Ferguson and Nusbaum 2012: 70; Clare 2001). Additionally, the independent living movement has had particular prominence in the US—compared, for example, to the UK—arguably offering an activist base from which scholarly interests have developed or been influenced.

On both sides of the Atlantic, however, the radical opposition of impairment and disability (in common with other dyads, such as sex and gender, that found particular favour among structuralist thinkers) has subsequently been critiqued—and nuanced—for its initial failure to recognize that impairments are as socially constituted as disability, *and* that the social consequences of bodily differences can never be divorced from the body in the ways that Oliver's analysis suggested (Thomas and Corker 2002; Tremain 2002; Shuttleworth and Kasnitz 2004; Shakespeare 2006; Staples 2011). Constructionist accounts of disability have remained popular among disability activists, however, because they challenge what still remains the more hegemonic 'medical model' of disability. The 'medical model', as Oliver (1990) pointed out, is a framework that pathologizes and naturalizes disability in negative terms as a personal tragedy, locating it exclusively within individual bodies. As such, it failed to recognize the role played by institutional power in structuring bodily experience.

Consequently, contemporary disability scholars in the West have been loath to reject social model-based theories in their entirety, building on existing theory while also engaging with newer trends against grand narratives. Scholars such as Tom Shakespeare and Mairian Corker, for example, explicitly engaged with post-structuralism in their appropriately entitled edited collection *Disability/Postmodernity* (2002). Here, academics from various disciplines tried out Foucauldian, feminist and queer theories on disability, while others revived phenomenological approaches in a bid to bring the visceral, experiencing body—sidelined by structuralism and, specifically, the 'social model'—back into the frame. Such accounts recognized cross-cultural variation in how disability was constituted: a chapter by Anita Ghai on postcolonial perspectives on disability in India, for example, was included (Ghai 2002: 88–100). Nevertheless, for all their resistance to grand

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[3] French anthropologist Claude Lèvi-Strauss—inspired by structural linguistics—was the most influential proponent of structuralist theory in European social sciences, a model developed in *Les Structures Élémentaires de la Parenté* (*The Elementary Structures of Kinship*), initially in 1949. For a brief summary see also Eriksen (2001: 19).

narratives in favour of local knowledge, in as much as postmodernist approaches themselves developed in the West and in response to Western intellectual traditions, taking a stance that was exterior to those traditions remained problematic.

Contexts of Engagement with Disability in South Asia

Valuable though the theorizing of Western disability scholars sketched out above has been, both in terms of opening up debates and in challenging pervasive narratives about what disability is, it has been slow to engage with the majority world. To the extent that DS has engaged with the Global South at all, it has done so for one of two main purposes. First, examples from places where disability is done rather differently than in cosmopolitan, urban settings, have been used to provide a counter to the universalist assumptions of Euro-American scholarship, demonstrating that disability is understood and experienced in culturally contingent ways. Second—and conversely—such examples are used to highlight what is wrong with attitudes in non-Western settings and to find ways of countering what are often seen, particularly from biomedical perspectives, as the negative effects of ‘culture’ (here used as a synonym for terms like ‘superstition’, and often placed in opposition to science). Let me deal with each of these approaches in turn.

Cultural Relativism and Its Shortcomings

First, as a challenge to universalist assumptions, comparative ethnographic studies clearly have an important role to play. Ruth Benedict’s essay ‘Anthropology and the Abnormal’ (1934) offers a good early example of the value of ‘cultural relativism’ from anthropology. For the Shasta tribe of California that she describes, epileptic seizures were understood not as symptoms of a ‘dreaded disease’, but rather as a pathway to Shamanic authority. What may appear abnormal, and therefore undesirable, in one context, might well be highly valued in another. As Benedict put it: ‘Most peoples have regarded even extreme psychic manifestations not only as normal and desirable but even as characteristic of highly valued and gifted individuals’ (1934: 60). David Arnold’s later depiction of smallpox in India as ‘a form of divine possession’ (1993: 122–123) resonated well with this. With the disease—and its related impairments—interpreted as a manifestation of the personality of the Goddess Sitala, those touched by it were likely to experience it differently than those who conceived of it, as we might through the lens of biomedicine, as just an infectious viral condition.

The lure of cultural relativism continues to offer a key justification for the involvement of anthropology in disability. The questions posed by Ingstad and Whyte in the 1990s, for example, bore a striking resemblance to those that Benedict was asking over half a century earlier. In the introduction to *Disability and Culture*—the first non-Western-centred edited collection that focused on disability in cultural context—the editors ask such questions as: ‘How are the deficits of body and mind understood and dealt with in different societies? How is an individual’s culturally defined identity as a person affected by disability? What processes of cultural change shape local perceptions of disability?’ (1995: 3).

Such questions remain important, but we also need to be aware of their limitations. Asked by Western disability scholars, they tend to place those identified, from a Western perspective, as disabled people in the Global South in unwitting dialogue with the Western frameworks of disability I described above. And they do so, predominantly, for the benefit of Western scholarship and activism. In short, we—by which I mean anthropologists working in the field of disability, but that category might be extended to disability scholars working in the Global South more generally, and particularly those who have grown up and been educated in those locales—need *also* to ask questions that bear directly on the experiences of non-Western disabled people. Their experiences need to be analyzed in relation to the local and wider contexts in which they live, rather than predominantly in relation to theories about disability that have been developed elsewhere. To this, I shall return in the next section.

Countering Culture

With respect to my second category of engagement—in which I characterize the Global South as being deployed as a kind of repository of examples of what happens when superstition and ‘culture’ triumph over reason—we similarly need to challenge the presuppositions in which such an engagement is grounded. This is not, I should note, simply about how Western-trained scholars come to see the values in which they are inculcated as universal values: it is also about how certain Western scientific models—which are not anchored to particular places or exclusive to scholars from particular cultural backgrounds—become hegemonic while others do not. As Oliver (1990) demonstrated, for instance, insights from the social sciences and the humanities are often subordinated to those of biomedicine and the natural sciences.

Dr. Sharma, an Indian surgeon I worked with in urban South India who treated cerebral palsy-related impairments, and whose case I have described in detail elsewhere (see Staples 2012), offers a good example of this. As I got to know him and his medical work over a period of 16-months’ ethnographic field research in Hyderabad in 2005–2006, it became clear that he did not see the purpose of ethnography as being simply to explore and document how people created and experienced their environments in often radically different ways. He was supportive of my work, but, from his perspective, its key purpose was to unmask and combat what he called ‘superstition’. The ethnographic data I was collecting from patients, he explained, would enable us to distinguish between value judgments based on cultural knowledge—which might or might not be objectively useful—and judgments based on scientific evidence and, therefore, considered value-free.

The doctor thought that my data might show how people's superstitions, as he characterized them, might prevent them from getting treatment. 'People in this country tend to follow a blind belief in the Goddess or whatever it might be,' he once told me in a lull between patients. 'We could have developed the smallpox vaccine before the Europeans got there had we approached the problem in a scientific way. We mustn't be hampered any longer by superstition!' This was a common view, and one that persisted despite the facts that for most of my informants the key barriers to them accessing treatment, as I discovered through interviewing them, were cost, local unavailability of treatment and services, and, in the case of the poorest patients, the resistance of hospital receptionists even to allow them access to the clinic. Dr. Sharma's faith that folklore was the greatest impediment to the disabled poor from getting the treatment they needed was, nevertheless, a widespread conception, shared by medical practitioners across resource-poor settings. Keshavjee, in his recent book on neoliberalism and global health in Tajikistan, for example, notes how the Soviet state had blamed the poor health of their most marginal citizens on their 'national culture' (2014: 52), without any reference to the material poverty they endured. Such understandings had persisted in the post-Soviet era. Data on people's cultural beliefs about disability, within this epistemological framework, are seen as important for enforcing universalizing health programmes.

Constraining Disability Studies

Both the encounters with disabled people I have described above, then, are limited because they privilege certain forms of knowledge production over others. The first commandeers the experiences of disabled people from the Global South in the service of a wider—but predominantly Western-focused—project of understanding. Just as the young women of Margaret Mead's Western Samoa (1943, 1928) shone a light for Mead on the youth of America, non-Western understandings of bodily difference might be utilized in the service of disabled people elsewhere. The second category of engagement attempts to incorporate the values of evidence-based medical science—again, predominantly Western-focused—into policy relating to the treatment and rehabilitation of disabled people. Neither is as unambiguously negative as the above paragraphs imply—the first nuances our understanding of what bodily differences mean, the second, in some cases, help people get the treatments they want—but they do constrain the field within which local studies of disability might emerge. South Asian disability studies, emerging in this way, runs the risk of becoming a local subsidiary of a broader, more powerful disability studies tied to the needs and interests of Western intellectual debate and health policy.

Institutional Restraints

What is also worth noting here—before I go on to explore what a specifically *Indian* or *South Asian* Disability Studies might look like—is that it is not just theoretical intellectual frameworks that require interrogation for ethnocentric tendencies; we also need to be aware of the institutional power differentials that might allow some ways of framing disability to flourish and others to remain marginal. For example, in researching how anthropology has engaged with Disability Studies (for another paper: see Staples and Mehrotra 2016), it appeared that American scholars had been aided in this via the space made for the formation of a disability research interest group within the Society for Medical Anthropology (SMA) which, in turn, is part of the American Anthropological Association (AAA). This group was established by Louise Duval in the 1980s (Goldin 1988), and a few years later, developed by Devva Kasnitz, herself a disabled anthropologist (Kasnitz and Shuttleworth 2001a, b). As one scholar who attended the disability research interest group meetings confided in me, many of their discussions were actually about the *lack* of disability access within the AAA and how marginalized as scholars they felt within the wider association. Nevertheless, as my informant conceded, the fact that they were brought together at all did allow for a critical mass of scholars to congregate and for a disciplinary niche to develop in ways that did not happen elsewhere. Pioneering work on adult deafness (Becker 1983), limb reduction defects (Frank 2000) and dwarfism (Ablon 1984, 1988), for example, were among the early anthropological contributions to DS from scholars within this group (Inhorn and Wentzell 2012: 15). In Western Europe, by contrast, where comparable institutional support for the anthropology of disability has been less firmly established, anthropological work has been minimal compared to that conducted by sociologists who, in Britain at least, have been aided by a particularly active Centre for Disability Studies (CDS) at the University of Leeds.

In much of the Global South, however, obtaining institutional backing for a subject area already marginalized is a more significant struggle. DS in postcolonial settings consequently have what Mehrotra dubs a more ‘chequered history’ (Mehrotra 2011: 65); not, of course, because of their comparative lack of academic rigour or paucity of insight, but because the structures that permit some voices to be heard have not yet been sufficiently developed in the South Asian context. When disability-related scholarship does gain the academy’s attention, it often does so as an example of what Friedner dubs ‘feel good diversity’ (2017). Shilpaa Anand writes, for example, about an academic conference in an Indian University that included a disability strand not because it recognized the intrinsic importance of such scholarship, but ‘because it enabled them to get the required funding from the Indian Council of Social Science’ (2019: 3). And while such pragmatism may have afforded DS a niche it would otherwise have struggled to find, Anand’s own experience as a DS scholar suggests that the provision of such niches often serves as a way of bracketing disability. In her own work, she says, she became labelled by colleagues as a charity worker or a social worker; someone, thus, doing morally good rather than intellectually important work. This made disability less attractive as an area of study to fellow scholars precisely *because* of its representation as ‘non-threatening diversity’ (Friedner 2017). Unlike debates around caste, gender or sexuality, disability was viewed within the academy as a relatively uncontroversial kind of identity.

This is not, I should stress, to disparage the work of American or European disability scholars in carving out their own spaces for DS to flourish—many of which, it might be added, encounter the same kinds of problems that Anand outlines so candidly (2019). For example, likewise noted the lack of attention by anthropologists and scholars from other disciplines to disability in Western contexts. Indeed, the work that has been produced by Western scholars often responds effectively to the marginalization of disability within their own academic contexts, and as such, their work may be crucial in enabling scholars elsewhere to find institutional niches. Nevertheless, it remains important to recognize the unevenness of the playing field and to encourage us to reflect on the conditions and contexts within which scholarly work comes to be produced or not produced. This is not simply a matter of equity but, perhaps more importantly, about enabling the best intellectual ideas to be heard and debated on the basis of their merit rather than where they have originated from.

What I move on to now, then, is the question of what a specifically South Asian Disability Studies—one not beholden to the strictures of DS as it has emerged and developed elsewhere—might look like.

Developing Disability Studies in South Asia

Even scholars from the Global South, as Ghai (2002, 2003) points out in respect of Indian disability activists, have often—because of their own social positions within educated, liberal urban elites—been in thrall to Western-inspired structuralist and post-structuralist models. Disability legislation in these contexts consequently reflects this discourse, while disability rights organizations are criticized for being overly dominated by the interests of middle-class men (Mehrotra 2011: 68; Ghai 2003), such as concessions in air travel or special parking facilities, which remain irrelevant to the disabled poor. The Rights of Persons With Disabilities Act, 2016, in India, for example—which replaced the Persons With Disabilities Act, 1995—makes explicit reference to the United Nations Convention on the Rights of Persons with Disabilities 2006, which itself developed out of the 1948 Universal Declaration of Human Rights after the Second World War. While the work of the UN might not be overtly ‘Western’, one might well argue that, in as much as its declarations are agreed by those in power, that they are liable to ethnocentrism. Indeed, the very notion that persons have inalienable rights as *individuals* might—as I shall explore in more detail below—in itself be seen as an artefact of Western philosophy (see, e.g. Marriott 1976, 1989; Grech 2011: 92).

Positive though the effects of the thinking that underpins current legislation have in some ways been in India, clearly one of the limitations of such an approach is that it elides the sociocultural particularities that render disability different in different places (Ghai 2002, 2003; cf. Das and Addlakha 2007: 128). I was particularly struck, for example, by a news story that ran when I was conducting fieldwork on disability in India in 2005–2006, and which some of my informants—mostly from poor, low-status backgrounds—made reference to.[4] A complaint had been made by a disabled Indian aircraft passenger that an airline he was travelling with had disrespected his dignity by not deploying the appropriate hoists and other equipment to lift him comfortably aboard the aircraft while in his wheelchair, but had instead used two porters to manhandle him up the steps and dump him, unceremoniously, into his seat. His complaint about the cavalier and insensitive way in which he had been treated was, of course, entirely reasonable, and the newspapers were, in my view, correct to run the story and to express outrage in solidarity. But for the vast majority of my own similarly disabled interlocutors, often without jobs or access to medical care that might make their lives easier, the experiences of the man described in the news stories as a victim were simply unintelligible. Air travel was outside of their field of experience, and they were not, as they saw it, in a position to make comparable complaints in response to the everyday accessibility problems they faced. Many of them, as they told me, in any case, suffered far worse indignities in the course of their everyday lives, not because they were physically impaired, but because of their caste positions and low socio-economic status. Inadequate access to aeroplanes hit the headlines; obstructed pavements and inaccessible public buses, in the main, did not.

In addition to highlighting a potential disparity between many disability scholars in and of India—for whom Western models of disability might indeed have some resonance—and the experience of the majority of disabled people in the subcontinent, the case outlined above also alerts us to the fact that disabled people across the region are far from a homogenous group. Keeping that caveat always to the fore, however, it might nevertheless be possible to identify some particularities about the Indian context that highlight the limitations of models designed with the industrialized West in mind.

South Asian Cosmologies

First, in the Indian context, the ways in which bodily differences are understood and experienced might be seen as rooted in, or at least to some extent shaped by, Hindu philosophies and mythologies rather than either biomedicine or European philosophy. I should add here that this perceived ontological split between majority and minority world ways of constituting personhood has, in my view, been over-stated, and that the assumption of radical alterity, particularly when it is based on historical archives, is as dangerous as the assumption that we are all the same (see, e.g. Staples 2003). Nevertheless, the possibility that there might be specifically *Indian* or even *South*

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[4] I was unable to locate, many years later, the particular news story I refer to here, but there have been several subsequent aircraft-related stories, several of which are documented by the advocacy organization Reduced Mobility Rights on its website reducdmobility.eu (accessed 26 May 2015).

Asian ways of 'doing' disability that can be differentiated from constructions of disability elsewhere is worth exploring. Not all Indians are Hindus, of course—indeed, most of those I have spent time doing fieldwork with over the years have identified as Christians and Muslims—but the impact of Hinduism, as the religion of nearly 80% of the population according to the last Census, is clearly widespread.

The work of Miles has been especially prominent here, in identifying what he sees as the historical precedents of South Asian thinking in relation to disability, drawing on ancient textual sources in his search for clues to understanding what might be distinctive about South Asian understandings of disability in the present. He notes, for example, that according to the Laws of Manu (Burnell and Hopkins 1971), those guilty of particular crimes in one life will be reborn as 'idiots, dumb, blind, deaf and deformed men, who are [all] despised by the virtuous' (Miles 2001: 52). A significant character in the epic the Mahabharata, King Dhritarashtra, is deprived of his kingdom and his sons because he is blind—underlining that his condition is seen as rendering him unfit to govern—and it is later revealed that he was made blind in retribution for the sins of a previous incarnation (Vaswani 2005: 14; Miles 2001: 16; Ghai 2002: 26). *Karma* was not only interpreted in terms of punishment, however, as Miles (2001) also noted: historically it has also been understood as rehabilitative as well as retributional. Rather than an impairment always stigmatizing its bearer, then, in this sense, it might also be seen as teaching him or her a necessary lesson about life. And rather than always being about passive resignation, belief in *karma* might also prefigure certain action that contemporary disability activists working with globalized notions of disability might consider positive, such as resistance to amniocentesis and the abortion of disabled foetuses, on the basis that such bodies are meant to be (Johri 1998). Likewise, given the Hindu (and Islamic) imperatives to give alms in order to gain religious merit, those forced to collect alms on account of their conditions might be seen as serving a particular and valuable social function.

Cultural differences, some of them rooted in particular histories, are clearly worthy of consideration. Grech offers as an example the well-publicized and relatively recent case of a child born with eight limbs in north India, who was apparently revered by villagers as a Goddess (2011: 95). It reminded me of the story, during my 2005–2006 fieldwork with disabled people in Hyderabad, of a facially disfigured man whose apparent resemblance to the elephant-headed Hindu God Ganesh led to him being seen as a blessing, particularly during Ganesh Chaturthi (a festival to celebrate the God's birthday). He was rewarded accordingly with alms rather than, as might otherwise have been the case, reviled as an abomination. Such cases draw on a shared sense of religious history, even as they are also understood and experienced—as will become clear shortly—in the varied contexts of the present.

In a more general sense, McKim Marriott (1976) and his Chicago-based Indianist colleagues (later followed by Strathern (1988), Geertz (1983) and others) have long argued that people from India, and the Global South more widely, are inclined to think differently to their northern counterparts. On the one hand, those from the industrialized West are understood to view the person as a 'bounded, unique, more or less integrated motivational and cognitive universe, a dynamic centre of awareness, emotion, judgment and action organized into a distinctive whole and set contrastively against other such wholes and against its social and natural background' (Geertz 1983:59). South Asian 'dividuals', on the other hand, have been characterized as more substantially connected to other people and things, literally transformed through their transactions in ways that bounded Western 'individuals' are not (see, for example, Busby 1997; Daniel 1987; Das 1979; Marriott 1976, 1989; Staples 2003: 296–297, 2011). Such acts as birth, marriage and food-sharing are all seen as involving an exchange of bodies, substances or body parts (e.g. Inden and Nicholas 1977: 17–18), a perspective reinforced by classical Ayurveda, which describes the body not as a relatively self-contained unit but as an open field (Trawick 1992: 148).

As a consequence, it has been argued that people come to see and experience themselves as continuous with others rather than as self-contained units—an ontological difference that has implications for how bodily differences might be understood. In a practical sense, such interdependence suggests that disability might be constituted as a family or household concern (Grech 2011: 92). As already suggested above, the notion of individual *rights* that Western disability scholars tend to take as self-evident—and which is assumed in The Rights of Persons With Disabilities Act 2016—'may not be present, subsumed under relationships of mutual obligations' (Grech 2011: 92; see also Lang 1998; Miles 2000; Ghai 2002).

Values that might be taken as read in, say, an American or British setting, such as those espoused by the independent living movement, might well be anathema to those for whom a notion of the individual self is secondary to what the psychiatrist Roland described, in relation to India, as the 'familial self' (1988), a self that is inseparable from those with whom it is intimately connected. Such models, if they are to be of any use at all, need to be reinterpreted in culturally specific terms, with 'independence'—in this particular example—being recast as applying not to individuals but to the family or wider social group (Mehrotra 2011: 71; Singh 2008; Lang 2001).

Countering Assumptions of Alterity

Compelling though accounts of historically rooted cultural differences are, as also noted above, theories of radical alterity in respect of understanding notions of disability are at the same time problematic. Public reverence of an eight-limbed child or worship of a Ganesh lookalike might point to cultural niches within which physically impaired people might find an otherwise elusive sense of belonging or allow others to attribute meaning, but they tell us little about the more private, quotidian experience of having or caring for a body that differs significantly from the mainstream. As Parry (1991) usefully pointed out in response to Marriott's theories of Hindu selfhood, Indians do not walk around like lexicographers, consistent and readymade models for interpreting the world always close at hand. Different philosophical and historical conditions might indeed shape thinking in different ways cross-culturally, but there is no particular reason to think that Hindus have been any more constrained in how they encounter and experience the world by the Upanishads or the Laws of

Manu than they are by, say, their more recent experiences of colonialism or globalization. In short, we should beware of straightforward links being drawn from between texts written thousands of years ago and contemporary understandings of disability, which have clearly been shaped by many other things along the way.

Friedner and Osborne's recent work, for example, demonstrates how, as corporate rationality starts to play a growing role in the governance of a rapidly changing India, disability discourse comes increasingly to be shaped by what they call an assemblage of corporate capital, state initiatives and NGO-led interventions (2015: 11–12). By documenting how disability is represented and utilized by business, the third sector and the state, they argue that dominant discourse about disability in India has become less about demanding rights, social movements or challenging the state, and more about framing disability in ways that benefit corporations, NGOs and the state over the mass of disabled people they purport to represent. By ensuring disability accessibility is included in newly built shopping malls, museums, airports, city metro systems and other places of elite consumption, for example, the state or private organizations are able to showcase modernity on a global stage. When they fall short—as in the case of the news story about the wheelchair-using airline passenger who was manhandled to his seat—older narratives of India as insufficiently developed return to the fore. As Friedner and Osborne show, however, at the same time as accessibility improves for a disabled elite, for the majority population, cheap public transport still remains inaccessible, and state-provided equipment—such as the tricycles that are far more common in Indian cities, particularly among the disabled poor, than the universalized wheelchairs that architects tend to have in mind when they design shopping malls and the like—is perceived as poorly constructed and inadequate. In approaching questions of how disability is understood and experienced in contemporary South Asia—as well as questions about *why* it is constituted in the way that it is—disability scholars need to look not only at the historical background but at the impact of rapid liberalization and other more recent societal change.

A second and related problem is that the disability history on which Miles and others draw tends to assume a shared conception of disability as a category that might be applied cross-culturally. The bodily anomalies, and the meanings attributed to them, might be recognized as different, but it is assumed that all societies have a category to which the term 'disability' might be applied (Anand 2015: 169). Scholars like Miles, Anand argues, treat South Asian historical or religious texts and the processes by which they shape relations in the present as though such relations are structurally the same as those mediated through comparable historical texts in, say, Britain. The Mahabharata or the Laws of Manu, for instance, might be read as if they carry the same kind of force for Hindus as the stories of the Bible do for Christians, or as the Koran does for Muslims. As Anand argues convincingly, however, such texts are not comparable in this way. The stories of the Mahabharata or Manu's Laws, for example, are considered more contextual, and so are much less subject to wider application than, say, Biblical parables are. Trying to learn about disability history and its relation to the present simply by studying the archives, then, misses the point that it is the epistemic training that scholars bring to interpret these archives that determines how they are read (Anand 2013). Put simply, a story in the Mahabharata about living with a disability is likely to have a different impact on a Hindu than a Biblical story about disability will have on a British Christian.

Local Biologies and Political Movements

Aside from these epistemic concerns, what are also important are the immediate, material conditions of people's everyday lives in the present. Miles (2002), for instance, makes the useful observation that people in India tend to respond with less revulsion to non-normative bodies than people in, say, Britain or the US, because they are more used to seeing different bodies and have become acclimatized to them—even if this absence of revulsion is, in part, an effect of wealthier sections of society constituting themselves in opposition to those mostly poor, impaired bodies, which they constitute as scarcely human. Particular material conditions, such as poverty, *literally* create more impaired bodies (Harriss-White 1999: 140–142), especially in contexts where there are not the social security safety nets often relied upon in the Global North (Grech 2011: 90). The prevalence of impairment is at least four times higher for those living below the poverty line as for those above it, with as many as 80 percent of disabled people living in rural areas or urban slums (Ghai 2002: 29; Dalal 1998), so whatever meanings are attributed to different biological anomalies, they are attributed disproportionately to the poor and the excluded. Disability, in this sense, is often inseparable from other negatively construed and experienced identities, including those related to caste and gender. Once again, this challenges the liberal agenda that has so shaped Western disability studies: in the same way that access ramps and lifts in air-conditioned shopping malls do little to bring luxury consumer products to most disabled people, activist calls within India for integrated schools, for example, sidestep the fact that the majority of children from the lowest castes and economically poorest families are anyway unlikely to go to school, especially if they are girls, whether they are considered impaired or otherwise (Ghai 2002: 3; Friedner and Osborne 2015).

In addition to 'local biologies' (Lock and Kaufert) and the socio-economic and political contexts that give rise to them, we also need to attend to local political movements. If Disability Studies developed in the US in relation to the independent living movement, for example, or in the UK in response to the impact of industrialization, in the South Asian context we need to explore the movements that might provide the impetus for a scholarly interest in disability to develop. Mehrotra's work (2011, 2004a, b, 2006; see also Addlakha 2013) is particularly pertinent here in that it explores how local women's movements, environmental movements, and, more recently, Dalit and anti-caste movements have also shaped (and must continue to shape) studies of disability in India, as well as setting out the frames of references through which disability might be understood and experienced. There are, at the same time, both conjunctions and disjunctions between these influences and those—such as the movements for civil rights, anti-racism and feminism—that have moulded disability discourse elsewhere. In a globalizing world, these backdrops are also profoundly interrelated and dialogic, even as they speak across one another.

Conclusion

As a white, middle-class, currently able-bodied, male scholar from the West with an enduring interest in Disability Studies, the irony of writing a paper about what a South Asian Disability Studies—distinct from a DS that has grown out of firm roots in the Global North—is not lost on me. As an anthropologist, however—and as an anthropologist who began documenting the lives of disabled people in India before I was aware of a wider DS on whose theories I could have been drawing—I hope I can also stand back and reflect on how DS has emerged in very different locales. In addition, the danger of restricting regional Disability Studies to those who come from those regions, and/or to scholars who are also disabled themselves, is that the academic study of disability would become even further marginalized: an echo chamber that those dominating scholarly debate can safely leave to its devices. My argument here, as a consequence, has been that, if it is to avoid becoming a subsidiary of a wider Disability Studies whose agenda has already been forged in the Global North, those studying disability in India—wherever they might come from—need first to look inwards. They need to attend to the particular socio-historical, cultural and material conditions (including those that have been imported) that shape the experience of bodily difference for the majority population in the subcontinent. This is a task best done ethnographically, by exploring the minutiae of people's everyday lives rather than relying on essentialized accounts of 'Indian culture' that emphasize difference rather than similarity vis-à-vis the rest of the world. At the same time, in order also to be a part of that wider Disability Studies—but cast in the role of an equal player—those scholars also need to tread a careful path that allows fruitful cross-cultural comparisons to be made and wider theories drawn upon without them falling prey to Western assumptions about, for example, personhood and human rights. In short, DS in India requires what Meekosha calls 'intellectual decolonization' (2008: 16).

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Chapter 3
Disorder, Disability, Difference: (Re)presenting Autism in India

Shubhangi Vaidya

Abstract The paper traces the emergence of autism as a salient category in India, drawing attention to the diverse strands, including biomedical and psychiatric research and practice, activism and advocacy in civil society, and personal narratives and creative expressions that have contributed to the discourse around autism in India. It locates these discourses within the 'glocal' moment of circulation of information and experiences, and the construction of the category as disorder, disability and difference. It makes a case for interdisciplinary understandings of disorders and disabilities in order to obtain a holistic picture of lived experiences and their sociocultural underpinnings.

Keywords Difference · Autism · Literature · Representation

Introduction: Contextualizing Autism in India

The emergence of autism as a salient category in the disability landscape in India is of relatively recent provenance. The category of autism has evolved over the past two and a half decades from a 'rare' disorder addressed within hospital settings to a developmental disability that has found inclusion within India's new rights-based legislation, the Rights of Persons with Disabilities Act (2016). An understanding and appreciation of autism as a human difference, a valid and valuable way of being-in-the-world, is also gaining ground, as the condition has become more visible and activists and self-advocates have begun to emerge and participate in the discourse. These understandings of autism as disorder, disability and difference are not mutually exclusive or linear, rather, they inflect and impinge upon each other in a variety of ways. As the parent of a young adult with autism and a scholar with research interests

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S. Vaidya (✉)
Associate Professor and Director, School of Interdisciplinary and Transdisciplinary Studies, Indira Gandhi National Open University, New Delhi, India
e-mail: svaidya2404@gmail.com

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in the interdisciplinary domain of disability studies, I have been engaged with, and a participant in these discourses, and thus bring on board my own subjectivity and reflexivity into my analysis.

This paper will discuss the framing of autism in India in biomedical and psychiatric research and practice; activism and advocacy in civil society largely driven by family members of persons with autism, and representations of the condition through selected narratives that open up the discussion on the lived experience of autism, including poetry, parental narratives and cinematic representations. This broad sweep is intended to open up the category of disability to multiple understandings and interpretations, and through diverse yet intersecting accounts, underscore the contested nature of (dis)ability, and the power relationships that are inherent within it. They also bring to attention the evolution of the disability discourse in India and the attempts by different stakeholders to present their side of the story, create communities based upon shared experience and de-stigmatize the experience of disability.

Representations of autism have largely been in the context of discourses around personhood and sociality in highly industrialized Western sociocultural contexts; Straus (2010), for instance, interprets it as a pathological manifestation of the highly prized cultural value of autonomous individuality which then translates into painful solitude, loss of community and extreme isolation (536).

In non-Western contexts, autism presents a fertile ground for medical sociologists, anthropologists and cross-cultural psychiatrists to unpack how local understandings and cultural constructions of normalcy and ‘deviance’ interact with global discourses and practices. Such studies draw attention to the historical and sociocultural contexts within which disorders and conditions are defined and made natural. Autism in India presents a rich site for understanding how meaning-making takes place in the context of disorders and disabilities.[1] A country with a population in excess of 1.3 billion, an ancient civilizational history, a multi-cultural, multi-ethnic and multi-lingual social fabric and a vibrant democratic polity, India is, to use a cliché, a curious contradiction of tradition and modernity.

Current understandings of disability in India draw upon both deeply resonant cultural images and values, Western-inflected categories and practices as well as contemporary, global-rights-based understandings, with India being a signatory to the United Nations Convention on the Rights of Persons with Disabilities (The United Nations Convention on the Rights of Persons with Disabilities 2006). The deeply entrenched ideas of *karma-phal* (consequences of past deeds), *seva* (service, particularly for vulnerable people) and *daan* (charity for earning religious merit) rub shoulders with biomedical notions of disease and cure and contemporary rights-based discourses. This co-existence of the medical and religious models of disability

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[1] See, for instance, Daley’s (2004) study on symptom recognition and diagnosis based upon interviews with 95 families from different parts of India and her later study of adults and their families in Delhi (Daley et al. 2014; Grinker 2007; Feinstein 2010), whose books have sections on autism advocacy in India; Mehrotra and Vaidya’s (2008) comparative study of intellectual disability in Haryana and Delhi; Desai et al. (2012) and Divan et al’s (2012) study of families of autistic children in the western state of Goa; Sarrett’s (2015) research with families in the southern state of Kerala; Vaidya’s (2016) ethnography of families with autistic children in Delhi.

is reflected in the eclectic mix of remedies resorted to in order to cure disabilities, including visits to shrines and religious centres, and multiple systems of treatment.

The work of scholars like Miles (2001, 2011) draws attention to disability histories from antiquity and nudges contemporary practitioners and stake-holders to delve into the riches and insights of their society's past rather than uncritically adopting Western theories and practices. He calls for 'historical action research'; 'listening long to cultures and voices of Asian people; listening to disabled Asians; reflecting on disability ethics and choices with Asian colleagues; and strongly supporting those who are looking deeper and taking the longer view' (Miles 2009: 81–82). The edited volume by Rao and Kalyanpur (2015) similarly situates South Asian experiences of disability against the unique historical experiences of colonialism and globalization and draws attention to cultural narratives regarding disabled bodies, specific indigenous constructs and the uncritical transfer of Western expertise that creates further sites of discrimination, as in the chapter by Maya Kalyanpur which addresses the classification and assessment of disabilities of Indian children based upon Western categories. These perspectives are particularly relevant in the context of conditions like autism, particularly against the backdrop of urbanization, globalization and transnational flows of people, products, services and ideas that have contributed to and complicated the narrative around autism in India. The availability of the Internet and the proliferation of social media platforms across geographical boundaries have opened up communication and information sharing as never before. A steady stream of information about research, teaching strategies, alternative therapies and biomedical interventions has become readily available to a growing section of English-knowing middle-class people. An unregulated 'therapy market' offering untested, unvalidated treatments and 'cures' has also come into existence.[2] This may result in financial hardship for families keen on curing their children and inadvertently subjecting the person with autism to invasive and potentially dangerous procedures.

This paper focuses primarily on urban, middle-class, English-speaking spaces, within which the author is also located, and thus does not claim to represent the realities experienced by large sections of the population who still struggle to access basic social goods like nutrition, health care and education.[3] It thus will provide only a partial picture, but one which, I argue, has proved deeply influential in shaping public perception and policy. The identification and treatment of autism in India remain a predominantly urban phenomenon and access to early identification and intervention has a strong class dimension. I begin by briefly situating autism within

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[2] A recent example is the offering of stem cell therapy by some private clinics as 'treatment' for autism at extremely high costs. Medical opinion on its efficacy is divided and parent groups like the Forum for Autism in Mumbai have mobilized public opinion against its unregulated use and promotion. See https://timesofindia.indiatimes.com/city/navi-mumbai/no-proof-that-stem-cell-therapy-can-cure-autism/articleshow/58198459.cms accessed on 26 December 2017.

[3] One of the legacies of two centuries of colonial rule was the establishment of English language education, which acted both as a means of mobility and a tool of discrimination. In contemporary India, English language education accords the opportunity to break free from oppressive social hierarchies and gain entry into the 'modern' world of opportunities fostered by the Information Technology revolution.

the biomedical and psychiatric research literature in India and the genesis of the 'autism sector' in urban India.

Autism in India: An Historical Verview[4]

Tamara C. Daley's article on the website of the Delhi-based NGO Action for Autism informs us that contrary to popular belief, autism is not new in the Indian literature. This is hardly surprising, considering the history of colonial medicine and the familiarity of Indian practitioners with Western psychiatry and psychology. Daley cites a report by the Viennese paediatrician A. Ronald, working in Darjeeling at the time, and published in the *Indian Journal of Pediatrics* in 1944, which she believes to be probably the first reference to autism or the pervasive developmental disorders. Presenting an overview of the detection, causes, types and treatment of 'abnormal' children, Ronald discusses various types of difficult children, including 'deviant' and 'frightful' ones. He also offers a description of a particular kind of difficult child, and its 'precocious' behaviour which has a strong resonance with some of Leo Kanner's case descriptions in his landmark paper in 1943 Kanner (1943).

> The precociousness of a child is not always limited to specific spheres…it extends to the whole of mental personality…such children are quite different from others in respect of behaviour, speech, movements and work. The child-like conduct has partly or fully disappeared, the mental attitude of such a child becomes somewhat strange and repulsive…such children are no longer child-like; they do not play and are not cheerful. Partial precociousness shows itself in the development of a particular sense, for example, musical sense, calculations, mechanical handling and so on. In this group is included the so-called prodigy…[5]

Whether the above account refers to the cluster of symptoms that define autism is a matter of speculation. From the late 1950s onwards, articles on the pervasive developmental disorders, using the terminologies of the day, began to appear. Daley (2004) notes the multiplicity of terms used to denote the condition, including childhood schizophrenia, infantile autism, early infantile autism, savant syndrome, childhood psychosis, pervasive developmental disorder and disintegrative psychosis (1325). Malhotra and Shah (2017) cite a publication by Bassa (1962) as the first Indian case report on autism. They observe that the 'history of autism' in India is marked by 'initial sporadic efforts at clinical descriptions and research followed by a more sustained progress in clinical services, research, and policies' (1). They note that while there were a few publications referring to 'infantile autism' in the 1960 and 1970s, a steady flow started only after the 1990s. A report of 17 children diagnosed autistic by Erna Hoch (1967) is regarded as an important early study. According to Kapur (2011):

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[4] Some of the ideas in this and the following section have been discussed in Vaidya (2016).

[5] Quoted from Daley, n.d. http://www.autism-india.org/research-autism-india.php accessed on 20 December 2017.

> This classic report consisted of acute phenomenological observations and aetiological speculations. To paraphrase Hoch, disturbances in the close relationship between mother and child may occur either because of the child's excessive sensitivity or a faulty maternal attitude. As such disturbances occur fairly early in infancy, they may leave a permanent weakness of what one calls the 'ego boundary', which is the ability to identify oneself as a separate unit which faces the outside world (p. 110).

Kapur also cites her own research with six children, conducted in 1986, in which she refers to their autism as an 'illness precipitated by severe psycho-social stressors' (2011, p. 110). Malhotra and Vikas (2005) and Naik (2015) indicate that autism as a diagnostic category has had a presence in the Indian medical landscape, citing a number of research studies mainly in hospital settings and with cohorts from special schools. Daley and Sigman's (2002) study of the diagnostic conceptualization of autism among Indian psychiatrists, psychologists and paediatricians also indicates the presence, albeit marginal, of autism in medical circles.

However, the lack of familiarity of family physicians and paediatricians, usually the first port of call in the case of any developmental delays, with the diagnostic category and nosological systems like the ICD and DSM, is believed to be reason why the condition is routinely undiagnosed or misdiagnosed; even to this day, it is routinely subsumed in the category of 'mental retardation' (a term still in use in India) or mental illness. The perception that autism is a rare, 'Western' condition that did not merit any serious attention or policy intervention was also well entrenched until recently, and efforts to introduce autism-specific policies and services met with resistance by those professionals who continued to view it as a subset of intellectual impairments or mental retardation.

The period from the late 1980s and early 1990s onwards saw an intensification of interest in the category of autism globally, as growing numbers of children were diagnosed with the condition, particularly in the Western countries. This had an impact upon autism awareness in India as well, as information about the condition became more readily available. This resulted in an intensification of activities in terms of awareness raising, creation of services, legislation, policy and capacity building. The driving force behind these developments was the emergence of parent-led organizations primarily for advocacy for children and adults with autism and other developmental disabilities, and their families. Bound by the common circumstance of a loved one's disability and the lack of availability of services and social supports, some parents and caregivers started to come together to help their children and build their own capacities. Much like parental activism elsewhere, these parents-turned-activists donned the mantle of teachers, trainers, advocates, lobbyists and institution-builders, and inaugurated the 'developmental disabilities sector' in India.

From ‘Disorder’ to ‘Disability’: Autism, Families and Advocacy

Expanding what Ginsburg and Rapp call the ‘social fund of knowledge about disability’ (2010: 239), family-driven organizations extended the scope of kinship outside the ambit of the biological family to the larger realm of public culture, and made their experiences and learnings available to the wider community. Action for Autism and Tamana, both based in Delhi, were amongst the first organizations to address the needs of persons with autism; since then, nearly 80 centres and special schools working with persons with autism and developmental disabilities have come into existence (www.autism-india.org). One of the important goals of these organizations is the provision of education and training for children with autism, as they are routinely denied admission to regular as well as to special schools catering to children with other disabilities. The social stigma that surrounds conditions like autism also extends to the family; therefore, it is quite common for parents to ‘hide’ children from public view and keep them confined within the home, further exacerbating the stigma and shame. The mother, in particular, is subjected to judgmental attitudes and blame, especially if she happens to be in outside employment (Vaidya 2016).

Action for Autism in Delhi, established in 1991, is widely regarded as a pioneer in the field of autism advocacy and service provision in South Asia (see Grinker 2007; Feinstein 2010; Mehrotra and Vaidya 2008; Vaidya 2016). From its birth as a small group of parents struggling to find a place for their children with autism to learn and grow, it has developed into a multi-tasking centre of activity which conducts early identification and assessment, parental counselling and training, awareness raising and service provision, and research and advocacy. It conducts teacher-training programmes, runs a model school, a vocational training centre for adults and has recently started *Ananda*, a home for adults. It has played an important role in the formulation of legislation and policy concerning autism in India. In the process, it succeeded in creating awareness about the disability in both professional and lay circles. One of the early projects undertaken by the organization in 1998 was an ‘awareness project’ with paediatricians all over the country, providing them with materials and information that would help them in early diagnosis and intervention.[6] Much of the understanding around autism that organizations like AFA helped to create came from their hands-on experience as parents and teachers, and their efforts to obtain information and expertise at a time when both were in scarce supply. Recognizing the crucial role of the Indian family as the sole source of support for the person with autism, AFA started an intensive training programme for parents to help them better understand their child’s autism and advocate for their child.[7] Some of these parents would go back and establish schools for unserved children with autism in their own home towns.

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[6] Details of the project are available on http://www.autism-india.org/professional-awareness.php.

[7] See Brezis et al. (2015) for an analysis of parental attitudes before and after attending the 3-month Parent-Child Training Program (PCTP) at action for autism.

The 1990s was also the period when the Disability Rights movement (DRM) gained traction in India, influenced by rights-based discourses established in other social movements like the women's, environmental and Dalit movements (Mehrotra 2013). One of the major landmarks in this period was the enactment of a comprehensive legislation to safeguard the rights of persons with disability, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1995, which identified seven categories of disabilities that qualified for state support and entitlements. However, autism was not included in the list of identified disabilities, even though the categories of 'Mental Retardation' and 'Mental Illness' found a place.

Autism found inclusion in The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999) which essentially dealt with the issues of social inclusion and provision of care within the community for persons with high support needs, and the issue of guardianship for individuals who may require support and assistance take care of their needs or make decisions.[8] However, on the ground, the status of autism continued to remain that of an outlier in the disability sector; children with autism continued to be denied placements in regular as well as special schools and were routinely denied an official disability certificate unless they met the specified degree of 'mental retardation', which was included in the PWD Act. The lack of this document deprived many people of access to the minimal facilities provided by the state, causing further hardship to affected individuals and their families.

Meanwhile, in 2006, the United Nations Convention for the Rights of Persons with Disabilities was adopted, and India became one of the signatories. It was thus duty bound to enact legislation in compliance with the convention, and so the process of drafting the new legislation was initiated in 2009, with a considerable role played by parent activists. After several rounds of drafts and considerable delay on account of a change in the national government after the General Elections of 2014, The Rights of Persons with Disabilities Act was passed by the Indian Parliament in December 2016. It incorporated a list of 21 disabling conditions, including autism. The inclusion of autism within rights-based law is a major moment, securing recognition and creating the conditions for service provision and social inclusion. At the same time, the inclusion of such a diverse range of disabilities within a single legal framework presents a host of challenges, as the debate around legal capacity and guardianship testified.

There has also been a growing international interest in autism research and advocacy in India. International charities like *Autism Speaks* have registered their presence in the Indian autism sector, funding research projects and conferences and partnering with governments and other stakeholders across South Asia. 'Light it up Blue',

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[8] The debates around guardianship of certain categories of persons with disabilities and the issues of legal capacity and decision-making have been ongoing ones within the disability movement, and these assumed a particularly sharp edge during the drafting of the new disability legislation in response to India's ratification of the UNCRPD (see Ghosh 2016, p.15 and Vaidya 2014 for different viewpoints).

Autism Speaks' initiative to commemorate the UN sanctioned World Autism awareness day on April 2, elicits an enthusiastic response amongst local autism groups; the 'lighting up blue' of public buildings and the social media campaigns on the day are seen as opportunities to create public awareness and gain visibility.

The 'internationalization' of autism advocacy raises important issues with regard to the import of Western perspectives which may be losing traction in their own contexts.[9] At the same time, these engagements provide opportunities and research grants to local professionals and researchers to develop good practices and strategies for their own communities. While there is an urgent need for more research, global collaborations and cooperation, the opportunity to develop a uniquely South Asian disability discourse and practice runs the risk of being subsumed within global trends. Within the autism sector, in particular, Western templates for identification, intervention, education and care need to be revisited in the light of cultural and social realities. Developing materials and methodologies keeping in mind local needs and understandings is critical. For example, Grinker et al. (2015) demonstrate a methodology of cross-cultural translation of outreach materials (Autism Speaks First Hundred Days Kit) into Korean through a careful study of local explanatory models of the condition, causation and care. In the Indian context, structural factors like poverty, caste, class and gender also play a critical role in determining who gets access to scarce resources and who falls through the cracks.

Having provided a broad overview of the trajectory of autism as a salient category, the following section will present selected literary narratives that represent the experience of autism. The devaluation and objectification of the disabled person and the family as broken and flawed can only be resisted by an empathetic understanding that foregrounds their positions as subjects and respects difference.

Life with Autism: Some Experiences and Expressions of 'Difference'

There is a large and growing corpus of autism narratives in the West, and increasingly, narratives from India are finding their space, both in print and online. In this section, I look at two parental narratives on the experience of raising a child with autism. The first is by Merry Barua (2007), founder of Action for Autism, reflecting upon her journey with her son who was diagnosed when autism was virtually unknown in India. The second is by Madhusudan Srinivas (2016) father of a young adult with autism, which highlights the challenges of raising a child with significant impairments in contemporary urban India. I then introduce the poetry of Parul Kumtha, a parent-activist from Mumbai, who attempts to put herself in the shoes of the autistic subject

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[9] The trenchant criticism of Autism Speaks by self-advocates and families of adults with autism in the U.S. is unlikely to find a resonance in low resourced countries where the issues of early identification, appropriate intervention and parental empowerment are the major concerns, and where self-advocacy is at a nascent stage.

and give voice to their experiences. The fourth writer is an autistic individual, Tito Rajarshi Mukhopadhyaya, whose poetry takes the reader into the realm of embodied autistic experience and opens up new ways of looking at (dis)ability. These four sets of narratives reveal multiple dimensions of the experience of autism from different standpoints.

Merry Barua's (2007) reflexive account of her experiences in bringing up her son Neeraj, diagnosed with autism in the 1980s, when the condition was virtually unknown to all but a selected few doctors, takes the reader through the slowly dawning realization of a child's atypical development, the confusion and self-doubt about one's own capacities as a parent and the helplessness and powerlessness of being handed a diagnosis without any guidance on how to help the child. She describes her journey towards 'complete acceptance and unconditional love' (36) through some of the most difficult phases of her son's growing years, especially during his late teens, when he experienced "a rage, depression, anger that he was helpless to control, and which expressed itself in exceptionally challenging behaviour". For six months it was like living with a caged tiger' (36). Her account does not demonize her son, rather, his humanity is emphasized at every stage. His difficulties in controlling his feelings or understanding clearly the consequences of his actions are viewed by Barua with the lens of acceptance of the person that he is, rather than judgment on what he ought to have been. She acknowledges her son as a complete human being in his own right, a source of love and joy, and the motivating factor for what was to become her larger mission, the creation of the organization Action for Autism (referred to earlier in the chapter): 'I started the work that I do now knowing that I did not want other parents to go through what I did after Neeraj's diagnosis: the uncertainty, the blame, the misinformation, the lack of services' (39). Barua ends her account by highlighting both, the uncertainty around autistic futures and the hope that she would be able to set up services that would look out for her son and others like him. The account highlights not just her own tolerance and acceptance of her son's challenging behaviours but also the domestic and social contexts within which they are expressed and resolved. Neeraj has a social life, albeit through his mother; he attends picnics and enjoys community events like the crowded Durga Puja. It also underscores the pervasive mother-blaming in the context of parenting a child with disability, and the role of faith and spirituality in coming to acceptance and equanimity.

Jerry Pinto's edited anthology 'A Book of Light' (Srinivas 2016) comprises essays by family members of persons with psychiatric disabilities. Questioning the myth of the 'normal home' the book looks at families whose lives are centred around a single member, a loved one 'with a different mind' (the subtitle of the book). One of the authors, Madhusudan Srinivas, writes about the everyday challenges of parenting an autistic child with severe impairments, as he lets the reader get a look into life with Abhimanyu, his son, presently in his 20s. Srinivas (2016) writes with candour of the early years when the child's inexplicable bouts of crying would be so intense that they would put him in the car and drive all over the city just to calm him, the 'crippling embarrassment' at his odd behaviour in public places, and the consternation caused by his seizures and loss of bladder control. He writes of the setbacks when Abhimanyu experiences a seizure; the anxious re-jigging of medications and change of doctors; his own exhaustion and sleep deprivation.

And yet the life we lead, bringing up our child, a young man who hasn't spoken a clear full sentence to us in all the years since he was born, and then diagnosed with autism at nearly three—our precarious life together—is also supremely happy. I would not trade it for any other even if he is not and will never be like other children; in some ways, he will always be a child (99).

However, despite this framing as a permanent child, Srinivas points out that Abhimanyu is a young man, and does show 'flashes of his growing will' (100). His taste in music is well developed, and he shares a love for it with his parents. He questions the stigmatizing of the disabled other and the homogenizing tendencies of society which attempts to eradicate difference. He writes.

Most of our children haven't demanded anything of us, ever. It's we who end up demanding a hell of a lot of them in our endeavour to meet society's norms. To make the differently abled as non-different and as indistinguishable as we can. To gain 'acceptance'- in the family, the home, the housing society, the mohalla, the street, the main road, the mall, the multiplex, the metro line, the market, the world at large (100).

The essay addresses the critical question of what constitutes a good or worthy life, and the need for an ethics of care. Importantly, it highlights the need for a caring community- family, friends, neighbours and domestic staff-and the wider world in which the father makes conscious attempts to include the son, "making bridges online and off: journalism and autism for me, have gone hand in hand" (99).

While Srinivas's narrative is from the perspective of the caregiver attempting to assert and affirm the personhood of a vulnerable child, Parul Kumtha's 'performance poetry' assumes the voice of the silenced autistic subject. Kumtha, the mother of an adult with autism and one of the founding members of a Mumbai-based parent group, attempts to gain an insight and represent the experiences of persons with autism in a world determined to discipline, regulate and crush their selfhood. The poems, extracts of which are quoted below, begin with the question 'Why' and are based on incidents faced by persons with autism and their families, while negotiating the world of therapy centres, schools and other institutions in Mumbai.[10]

The poem '*Why I cling to you*' explores the anxieties of a young man and his attachment to his mother.

> *I am a man now, taller than papa, broad in the chest and deep in the voice.*
>
> *Do you remember when I was little and I crawled to sit outside the toilet door*
>
> *while you bathed or crapped or peed?*
>
> *Do you remember how I howled until my lungs ached and my body racked? I do.*
>
> *I remember that you spoke to me from the other side of the door, tried to calm me…*
>
> *but I did not know that you existed on the other side - I couldn't see you, so you didn't.*
>
> ……………………………………………………………………………………
>
> *I always wait for you, mama and I can't be at peace, not knowing when you will be back.*

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[10] Extracts of Parul Kumtha's poems are reproduced with the permission of the author.

Because you know what I eat and when, what I wear and how, what I do and why.
You are my interpreter to the world…and so, I can't let you out of my sight.
It worries me… It worries me ---- what if you are gone too?

The final lines of the poem respond to the advice often given to mothers to 'distance themselves' from adult children because they have 'men's needs' and thus potentially constitute a sexual threat.

Mama, please don't distance yourself from me - you are my bridge to the world!
That is why I cling to you, despite being broad of chest and deep of voice.
Not because I crave carnal, physical proximity.

In the poem *Why am I not ME by any other name?* the issues of choice, identity and selfhood are raised. The subject pleads for the right to be known by the name of her choice, 'Bubbly', her family's loving name for her, and not 'Jui', her 'official' name, which she associates with being sent away to an institution.

My family couldn't cope with me last year.
That's when I was sent to an institution to calm me down. I hate the place.
It was full of 'don'ts'. "Jui, don't do this, don't do that, don't, don't, ---- don't…."
When I returned home, mama and papa cried.
They said that I was a third of myself, sunken eyes and furtive look
when I surfaced from the drugged stupor in which I was maintained at that place.
"Bubbly", my mama said and hugged me tight as she sobbed into my shoulder.
Yes mama, I am your Bubbly and I want to always be your Bubbly.
Please don't send me to the Jui prison again.
I am not Jui anymore. I can't be Jui anymore. Don't anybody, ever call me Jui again.
…………..
I read the tabloids you know,
I read the tabloids you know? full of stories about rich and famous people who have changed their names to change their destinies!
Why won't you allow me to change mine?

Kumtha's poetry offers a powerful critique of the dehumanization of the disabled subject and the relationships of power and control that obtain between persons with disabilities and the 'professionals' who deal with them. The following excerpt from '*Why I sit under my desk and not at it*' underscores the lack of understanding about disability, and the often abusive disciplining strategies to extract compliance and enforce order.

Every day I come to school, clutching my fear to my heart, afraid that it will be my turn today
Every slap that whistles past my ear and lands on my classmate's cheek resounds in my brain
Every command that you bark at others ricochets off the walls and booms at me
Every day I struggle with my autism: struggle to make sense of your world

Perhaps one of the most powerful voices to emerge from the autism spectrum and profoundly challenge received understandings about the abilities of 'severe' autistics is Tito Rajarshi Mukhopadhyaya. Born and raised in Mysore and Bangalore, Tito, who has fairly severe impairments, was taught by his mother Soma through a unique teaching method, the Rapid Prompting Method, that she devised. This strategy enabled Tito to communicate and write independently. By the age of 12, Tito had published his first book, *Beyond the Silence*, which was later published in the US as *The Mind Tree* (Savarese 2010). Tito and Soma were invited to the US at the instance of Portia Iverson, the parent of an autistic son, and co-founder of the organization Cure Autism Now (CAN), which later merged with Autism Speaks, to demonstrate her unique teaching methods and help other non-verbal children. Eventually, they parted ways, but Tito and Soma continued to live in the US. Tito's prolific writing has received much critical appreciation; Savarese (2010) locates his oeuvre squarely within the neurodiversity movement, demonstrating how he pokes fun at the reigning hypotheses around autism.

The liberative possibility of his autistic identity is articulated by Tito in his ironic account of his experiences in a special education class in the US. Tito sums up the lessons he learned from the 'humiliation' of having his intelligence doubted.

> Humiliation also made me a scientist! I am the scientist who knows why I have autism: to experience the captivity of intellect by one's body and to endure it with absurd aplomb, while others struggle even to fathom such captivity. As a social scientist, I know, however, that nobody is free from captivity. One is captive to one's ego, for example, social obligations, job requirements, et cetera. Which of you neurotypicals is free to sniff a book in public? I have freedom from customary comportment, and as a sniffing scientist, I remain outside the box we term *social norms*. The rest of you purportedly free people are trapped inside the social box (Mukhopadhyaya 2015, 8).

Mukhopadhyaya represents an embodiment and politics that radically reconfigures the certitudes of the neurotypical world and its assumptions about what constitutes the normal. Savarese (2010) writes:

> By examining the work of Tito Mukhopadhyay, we can see not only evidence of a postcolonial neurology but also intimations of a very different politics. How the autistic subject understands his relationship to himself and others (both human beings and natural objects or animals) suggests are joinder to neurotypical assumptions and arrangements. That subject literally decenters and deterritorializes. Though marked by a history of exclusion and degradation, he has begun talking back to the empire of science. The subaltern has learned to speak, and he has most certainly learned to write in the master's tongue. He is a cross-cultural, cross-sensorial migrant, a cosmopolitan armed with metaphor in a world that is often quite hostile to the neurological other (276).

The representations discussed above reveal multiple dimensions of the autism experience from the perspective of both the person with autism and their families. They hold out productive possibilities for re-imagining autistic personhood and an ethics of care, and the promise of neurodiversity in radically altering our understandings of what it means to be human. These themes are also being increasingly explored in popular cinema, albeit with far less subtlety and insight than the literary representations discussed above. In the following section, some cinematic representations of autism and other disabilities will be reviewed, to make a case for the growing salience of 'difference' in mainstream cinema.

Autism in Hindi Cinema

While mainstream Hindi cinema ('Bollywood') has always engaged with disability, these representations have generally deployed the lens of tragedy and pity. While it is fair to say that many of these portrayals are caricatures, fantastical and downright outlandish at times, they do offer insights into societal attitudes about disability and difference, and, as in the case of films like Aamir Khan's *Taare Zameen Par* (2007), R. Balki's *Paa* (2009), Karan Johar's *My Name is Khan* (2010) and most recently Siddharth P. Malhotra's *Hichki* (2018), bring to public view disabilities that are relatively unknown to viewers. The films mentioned have protagonists with dyslexia, progeria, autism and Tourette's syndrome, and are represented in comparable ways as confounding and deeply stigmatizing conditions that profoundly challenge the 'normative'. For the purpose of this discussion, I shall focus on 'Bollywood' films that reference intellectual disability and autism. These films feature popular Bollywood actors ('heroes' and 'heroines', as they are referred to in India) and deploy the cinematic language of the mainstream Hindi film that generally has a much larger audience than the more serious offerings in experimental or alternative cinema.

The infantilization and denial of normative masculinity to the intellectually disabled male discussed elsewhere (Mehrotra and Vaidya 2008) is a theme that features prominently in the fantasy drama *Koi Mil Gaya* ('I found somebody') (2003, dir. Rajesh Roshan) which narrates the story of Rohit, a 'man in a child's body', and his relationship with Jadoo, a rather endearing alien from a distant galaxy. Rohit, framed as the eternal child by his mother, continues to study in a lower grade at school with children much younger than him. His disability, indirectly caused by aliens, is also remediated through his encounter with Jadoo, the extraterrestrial, who endows him with the physical and mental strength that is the marker of a competent masculine identity, and thus qualifies him to enter into an adult relationship with the young woman who befriends him. However, it is in the relationship between Rohit, his young friends and Jadoo that we see the possibility of an alternative way of being that is different from the worldly and instrumental discourse of normalcy. This depiction has a resonance with the parental narratives reported by Vaidya (2016: 70–71) in which the autistic child is constructed as lacking *samajhdaari* (Hindi for 'understanding') and therefore uncorrupted and untainted by the demands of the material world. The narrative by Srinivas (2016) in the previous section also hints at this.

Karan Johar's *My name is Khan* (2010), with Shahrukh Khan playing the protagonist, addresses the complex issue of Islamophobia in post 9/11 America, through the story of Rizwan Khan, a man with Asperger's syndrome. Rizwan migrates to the US after the death of his mother and builds a life in America, marrying a young Hindu woman, Mandira, and adopting her son Sameer (Sam). Sam is killed in a schoolyard hate crime, and Mandira holds Khan's Muslim identity as the reason behind the crime. Their relationship collapses, and Khan sets off on a journey across America to meet the President face to face and convince him that though his name is Khan, he is not a terrorist. By declaring his innocence to the President of the United States, Rizwan hopes to win back the trust of his grief-stricken wife. Khan's autism is a metaphor for a mind that is unsullied by the viciousness of identity politics and believes that the only difference between human beings is their capacity to do good or evil. This 'simplicity' lands him into all kinds of trouble, even puts his life in danger, but ultimately redeems him; holding out the possibility of hope and healing in a world rent by prejudice and hatred. However, the real issue of Islamophobia in contemporary America is rather conveniently elided. Khan's narrow focus on fixing his broken domestic relationship depoliticizes the contexts of racial and ethnic profiling and prejudice, even though these are portrayed in the film through his encounters with law enforcement and security agencies. Once again, the tendency to view autism as a thing apart from the sociopolitical contexts in which it is embedded renders the narrative as a rather syrupy 'love story' in which the 'hero' ultimately regains the affections of his 'heroine'. And yet, it does bring home the possibility of a politics that is grounded in a sensibility and subjectivity that is 'different' and more humane that distinguishes between good and evil, irrespective of community identity and political affiliation.

A film in which both protagonists have a disability is *Barfi!* (2012), directed by Anurag Basu. The fairy-tale-like story of a deaf young man, Barfi, and a young autistic woman, Jhilmil, is an interesting take on how persons with severe communication challenges do manage to 'communicate' affection, friendship and caring. Their relationship assumes a particular quality of playfulness that is of a piece with their embodied differences, even though the depiction of autism in the film is simplistic and superficial, to say the least.

These films have played a role in bringing conditions like autism and intellectual disabilities into public view, albeit in a formulaic style, replete with the stereotypes that surround disability and couched in understandings of the disabled person as being somehow apart and not enmeshed in the routine, quotidian messiness of everyday life. Liberally seasoned with the 'masala' that lends Bollywood its unique flavour, they have nonetheless opened up conversations around disability and foregrounded the possibility of viewing it not as a pitiable tragedy, but a dimension of human difference and diversity.

Concluding Observations

In the above, we have looked at the development of the discussions around autism in multiple domains; from clinical research to service provision, parental advocacy, legislation and representations. What does the 'autism scenario' look like in India today? As compared to the situation two decades ago, it is clear that there is considerably more public awareness and recognition, at least in urban India. Disability has come out of the closet and has become more visible in public spaces. 'Disability stories' are being told in the media, often in tokenistic ways (e.g. special programmes and features to commemorate World Autism Awareness Day on 2 April or World Disability Day on 3 December). An ecosystem around rehabilitation and special education has also grown, and the 'helping professions' are now being seen as viable livelihoods, rather than 'social service' exclusively rendered by family members. 'Inclusion' has become a buzzword in theory, if not in practice, and mainstream schools are slowly but surely opening their doors to children with autism.

From being a virtually unknown category amongst medical professionals, autism has become an increasingly common diagnosis. A special issue of the *Indian Journal of Pediatrics* in January 2017 carried papers on early intervention, social and communication issues, educational and behavioural interventions, governmental schemes and the rights of children with autism.[11] This indicates that professionals across the medical and advocacy domains are in conversation with each other. Indigenous screening tools for autism in India (the INCLEN Diagnostic Tool and the Indian Scale of Assessment of Autism) have been developed and notified as the instruments for assessment and quantification for issuing the all-important disability certificate, which was earlier not available for persons with autism. The requirement of medical certification and expertise to enable access and equity to social-economic goods testifies the ubiquity of the medical model, an irony that has been critiqued by disability rights activists.

However, in the larger sociopolitical context, polarization and the demonization of the 'other' have become widespread. Disability is still seen as an apolitical category in India, and thus treated with a benign condescension that reflects in new terminologies like '*divyaang-jan*' (divine people) to replace the earlier term '*viklaang*' (impaired) to denote persons with disabilities. The representations discussed above demonstrate this, to some extent; the stereotype of the compliant and docile disabled person is however being challenged in academic and activist circles with the emergence and growth of disability studies in the academy and the rights movements in the public sphere.

Within the new economy, participation of persons with disability is also receiving attention. The disabled body as a source of 'value' in the new economy has been discussed by Friedner (2015), among others. Persons with autism and intellectual disabilities are also being recruited into open employment as part of CSR initiatives; however, some of the placements offered conform to stereotypes of the disabled worker as a low-value one, fit only for those dead-end tasks that a non-disabled worker may not want to do on a long-term basis.

A quarter of a century after autism made inroads in the disability landscape of India, issues of adulthood, employment and residential options have become important. There is also a qualitative shift in the envisioning of autistic futures with the possibility of independent living being a realistic and attainable goal. The activism of parents' groups two decades ago laid the foundations for creating social spaces and opportunities for persons with autism in India. Hopefully, the discourse they

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[11] The Indian Journal of Pediatrics, vol. 84, no.1, January 2011, https://link.springer.com/article/10.1007/s12098-016-2262-4, accessed on 20 December, 2017.

opened up will develop in enabling and productive ways to foster inclusion and human rights of all persons with autism. Interdisciplinary scholarship that attempts to integrate medical, social, cultural, legal, etc. perspectives to foster a holistic understanding of the manner in which individuals and communities understand and live the experience of disability is the need of the hour.

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Chapter 4
Disability and Public Spaces: Universal Design Approaches

Shilpa Das

Abstract This chapter is located at the intersection of disability, society and design in the Indian context. Beginning by examining the systems model of disability, it explores how this model, like other models such as the medical model and the social model of disability, is underwritten by different kinds of cultural and historical determinants and is a powerful ideology that constructs categories of identity. Further, the paper explains how information available and conformity with the model and a universal design approach may have a critical bearing on design decisions, processes, the action that is taken and even social policies that are framed. Designers could substantially gain from these insights, but often falter because the concerns of disability studies are every so often rendered invisible in ableist design thinking. The chapter illustrates how the canvas of design is often limited in its interface with disability. It also underscores the need to incorporate the unique concerns and experiences of disabled people in design thinking and practice, and having a universal design approach to enrich the fields of design practice, design education and the field of Disability Studies in India.

Keywords Disability · Accessibility · Systems model of disability · Universal design

This chapter seeks to provide an overview of the linkages between the personal experience and social construct of disability, the field of design and the field of disability studies. It is informed by the World Health Organization's new International Classification of Functioning and Disability (WHO-ICF),[1] which states that disability is the 'outcome of a complex relationship between an individual's health condition and personal factors, and of the external factors that represent the circumstances in which the individual lives (Erlandson 2008, p. 30)'. This definition views disability as an outcome of a relationship between the person and the physical, cultural and social

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[1] 'Towards a Common Language for Functioning, Disability and Health: ICF', published by WHO in 2002 reiterates this point.

S. Das (✉)
National Institute of Design, Ahmedabad, India
e-mail: shilpadas@nid.edu

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environments. The conceptual model of disability that aligns with this definition, the Systems Model, combines elements from both the medical and social models of disability. It sees disability as ‘a broadly based distributed phenomenon with its central focus of maximizing an individual’s functional capabilities within a spectrum of environmental conditions’ (Erlandson 2008, p. 34). Like the medical model, this model focuses on the individual and like the social model, the person is an active agent rather than a passive agent for whom and to whom things are done. In this model, stakeholders (individuals or communities) must assume responsibility for those elements over which they can exercise some control (for instance, utilizing the resources available to them in their environment such as schools, transportation, etc.). At the same time, culture, society and governments need to ensure that individuals get these resources and opportunities to maximize their functional capabilities within the given environment, remove barriers and significantly promote varied alternatives for personal actions and personal choices.

Erlandson (2008, p. 34) points out how the medical, social and systems models of disability perceive design, the design process and the role of the designer in different ways. Since the medical model considers disability as an individual pathological problem, it looks for ways to restore the person’s functional ability largely through assistive aids and appliances, prosthetics and orthotics. The social model, which places the onus of disability on society and the environment surrounding disabled persons, urges using products, facilities and services based on accessible design principles to reduce or remove accessibility barriers. Titchkosky defines access as ‘a way to orient to, and even come to wonder about, who, what, where, and when we find ourselves to be in social space…(it is) tied to the social organization of participation, even to belonging…Access not only needs to be sought out and fought for, legally secured, physically measured and politically protected, it also needs to be understood—as a complex form of perception that organizes socio-political relations between people in social space (Titchkosky 2011, p. 4)’. The systems model advocates using universal design as a way to increase accessibility for everyone. Considering the sweep of global markets and a booming consumer base, it demands of all segments of the economy to deliver more accessible products. Thus, it considers accessible design and universal design to be tools that diminish disability brought about by the built environment because they compel designers to constantly reflect upon the enabling and disabling aspects of the environment. This model is also less stigmatizing than the other approaches mentioned above, which continue to accentuate disability and segregate the disabled in one or the other way. However, and this is the first problem of design education with respect to disability: it is still focused on the medical model of disability which in turn impacts both the design process and the final product or outcome.

Participation in social life is a basic human right for people with physical, mental or sensory impairments. Reinhard (2009, p. 127) says, ‘A sense of orientation, the ability to perceive dangers, process information, and move around physically are basic prerequisites for today’s mobile society.’ Accessibility ‘describes the degree to which a location or a service is accessible to all its possible users. This captures the availability of transport, access to services and goods as well as access to the means of social and economic participation in a community' (Erlandson 2008, p. 18). Accessible design, therefore, means that products and environments are designed and constructed so that disabled people may access and use them (Pirkl, 1994 cited in Nussbaumer 2012, p. 28). An example of accessible design is curb cuts on footpaths or ramps that provide access to public spaces. From a social theory perspective, accessibility enables a shifting to the social model of disability and away from the individualized morality and medical model approaches, which consider the individual as a locus for a lack of ability. Accessible environments enable disability to be viewed positively, social stereotypes and stigma of disability to be dismissed because they allow disabled people to be seen acquiring education, working, commuting, marrying, running households, having children, having a social and community life, and carrying out their daily lives in a dignified manner.

Going a step further leads to the inclusive design approach where designers simply ensure that their products and services address the needs of the widest possible audience, irrespective of age or ability. In the West, developments in inclusive design have taken rapid strides in the last 50 years as they were faced with the reality of an ageing population and the inadequacy of mainstream design to address the issue of disability and address the needs of this population. Inclusive design is progressive in spirit because it is about culture, social values and social justice, not just about mobility and dexterity. It places people at the heart of the design process. Greater attention began to be paid in mainstream product development towards the 'softer, more human aspects of emotional engagement, lifestyle and aspirations' which were more destigmatizing aspects of design promoting social integration (Coleman et al. p. 9). This led directly to the philosophy and practice of the 'universal design' approach in the US and 'design for all' in Europe and Canada[2] which understand and respect the needs of a diverse range of users.

Universal design refers to the design of products, systems and environments, which are usable by people with the widest range of abilities without the need for adaption or specialized design within the widest possible range of situations.[3] They

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[2] Architect and product designer, Ron Mace promoted and championed the cause of universal design in the US. He urged for a shift in design from accessibility of buildings towards designs usable by people of all ages and abilities, therefore more universal. The seven principles of universal design as laid out by the Center for Universal Design which Mace established are equitable use (the design is useful and marketable to people with diverse abilities); flexibility in use (the design accommodates a wide range of individual preferences and abilities); simple and intuitive to use (use of the design is easy to understand regardless of the user's experience, knowledge, language, skill or current concentration level); perceptible information (the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities); tolerance for error (the design minimizes hazards or the adverse consequences of accidental or unintended actions); low physical effort (the design can be used efficiently and effectively with a minimum of fatigue) and size and space for approach and use (appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture or mobility). Thus, universal design can be defined as 'the design of entities that can be used and experienced by people of all abilities, to the greatest extent possible, without adaptations (Erlandson 2008: 17)'.

[3] This definition fuses the CUD definitions given by Ron Mace (2008) and Vanderheiden (2009) which is cited in Nussbaumer, 29).

broaden the understanding of accessibility from mere wheelchair access to apply to the design of products and services, and the way people (of all ages and abilities) interact with them. Thus, the focus is not on age or disability alone but on inclusivity at a social level which meets its objective without stigma. An example of universal design is automatic door openers at malls and other public places (Rose and Stonor 2009, p. 79). Thus, Steinfield and Maisel (2012, p. 189) say ‘it includes goals beyond basic accessibility such as health and wellness, social participation and safety, and a much higher standard of performance than accessible design. Universal design is aspirational and evolutionary-continuous quality improvement. Accessibility laws do not have this purpose’.

Design is ‘the thought process comprising the creation of an entity’ (Erlandson 2008, p. 23). If we were to draw a Venn diagram that showed the relationship among general design, universal design, accessible design and adaptable design, then universal design would be a large subset of general design, with accessible design and adaptable design intersecting with universal design. The way we design our houses, schools, cities, transport systems, products and services reflects ableist design principles that consign populations such as the ageing and the disabled into the margins of society. Such a mindset has also led to a big problem of design education—the study of anthropometry and establishing it as a standard tool for designers, thus feeding into stereotypes of normality and normativity, and led to a further distancing of these communities from mainstream society. Design education, particularly industrial design, continues to be mired in assistive design and has not integrated in a meaningful way the approaches of inclusive or accessible design. Assistive design products typically assist in augmenting the functionality of impaired body parts.[4] The final product would typically uphold as its USP aspects such as ‘provision for disassembly’, or ‘modularity of parts, ease of maintenance, storage and transportability, structural strength and ruggedness, accessibility and ease of operation, and comfort and feature enhancement’. Small wonder that design practice, a direct outcome of design education, primarily considers designing for the disabled inappropriately as for ‘special need’ rather than lifestyle aspirations and so has remained ‘trapped in equally narrow markets where turnover and profitability are too low to justify adequate investment in design itself, giving rise to a plethora of stigmatizing and poor quality aids and adaptations’ (Coleman et al. 2003, p. 3). When designers look only at the clinical aspects of disability in designing for the disabled, they are still relegating design to the medical domain. It is as if one is saying that disabled people are circumscribed because of the functional or psychological limitations imposed by their individual impairments rather than by the social restrictions imposed by society. More importantly, one is designing for the impairment and the person with the impairment rather than holistically looking at the shortcomings of the societal

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[4] Assistive devices help people with disabilities achieve independence. These include mobility aids such as wheelchairs, walking sticks, crutches and walkers and toileting aids like raised seats and grab bars. Generally developed as healthcare products, assistive devices often have a clinical appearance. Industrial designers, in such projects, tend to have a medical approach to disability and focus on formal aspects, material selection, technical detailing, simplifying the technological aspects, motion dynamics or work on ergonomical aspects.

framework that impede their lives. What disabled people may challenge in terms of design are their inability to consider the social conditions and relations in which such encounters take place, the enveloping of their identity in medical terms, the importance of their voices being heard and a much more effective participation in decisions which affect them. But if they were to follow the approach of disability studies and keep a disability rights' perspective, then the medical model's shortcomings could be considerably reduced and they would be able to reinterpret disability as a political category leading to a more holistic and humane approach.

Further, the approach itself may be very 'designerly' emphasizing not really on research, or analysis, but on the generation of an innovative design solution. This may be admirable from the point of view of a student/studio project, but can of course be a two-sided coin in the view of the end users. The area of work is definitely one that needs some attention, especially in the light of our context: economic constraints and complex terrain in developing countries.

The emphasis is quite obviously on the appropriate application of technology. Such a laborious analyses and evaluation of each technological innovation may be appreciable; the special attention paid to the independence of the wheelchair user in basic activities, such as picking up dropped objects, sitting at tables: small areas that are not normally considered, be praiseworthy; and the ability to draw precise inferences and apply them directly to the final design may be a good thing. Sometimes, the project may have gone through multiple iterations and the product itself may have incorporated many interesting features. The user testing may also seem to have been reasonably positive and the product a definite improvement over the existing models. The final features of the design are obviously informed by these, but they sometimes lack a spatial analysis. Again, is the product intended for domestic interiors? For outdoors use? Has the usage environment been considered? Where are the ramps and kerb cuts in our built environment in India? Has a thorough analysis of this with a systems-level approach been undertaken? Sometimes, the project ends with a computer-generated model, and no user testing has been done, even of a basic mock-up or prototype. For projects of such nature, this is really unfortunate and seems to negate the laborious detailing and the potential that product holds.

It must be underscored, however, that technology itself in terms of machines, gadgets, appliances and prostheses will not necessarily lead to greater satisfaction levels for the disabled people as users of these aids and appliances, or even for the healthcare domain if you eclipse the user/disabled person in the design process. Again, considering the aspect of 'care' that is important to us in our sociocultural context: the way we are looking at design right now, while it is good for us to keep in mind that we wish to ease the user's needs for mobility/assistance or whatever, it depersonalizes the objective of the design product and may be invalidating of disabled persons themselves. In fact, we may be actually taking a step in the wrong direction by doing too much of what is often called 'an over-technicalization of care'.

User studies in classroom design projects are often limited. The user is usually completely reduced to design-specific data (ergonomics, space utilization, etc.), and may disappear in the process! Gender differences are only considered through anthropometric data in the ergonomics study. The position of the user study is primarily concerned with strictly functional problems: manoeuvring, stability, physical fatigue of the user and bodily safety. These are no doubt critical concerns, but psychological or social aspects are not considered; studies on disability models and in-depth interviews with disabled persons to understand the phenomenological aspects of disability are lacking. There is usually a techno-medical feel even in mobility aids that are designed for the needs of children with disabilities. Such devices have straps and ties, and multiple parts. No effort is made to humanize the aesthetics. At a formal level, it is at the same level as crutches and callipers: an association many disabled people and especially disabled children will perhaps not fail to make. This has obvious consequences with regards to the perception of people with disabilities, but little has been done to mitigate this. These lacunae are often reflected in findings from the user testing even if they are mildly empathetic.

As mentioned earlier, participation in social life is a basic human right for disabled people. One significant determinant of who can play an active role in society is the design of public areas and the way public life is organized around them. It is a foregone conclusion that disabled people find it difficult to access public and private buildings and public utilities and facilities in cities, especially in India. They have to confront a hostile built environment replete with ableist design principles and face what Imrie (1998) terms 'design apartheid where building, form and design are inscribed with the values of an "able-bodied society"' in the course of their daily lives (Imrie 1998, p. 120). Over 40 years ago, Goldsmith (1976) observed that 'buildings have always been, and always will be, geared to suit two-legged able-bodied people and not people propped on sticks or rolling about in chairs or wheels'. Ableist spatial design education and practice manifest in a disablist built environment, which 'projects "able-bodied" values which legitimize oppressive and discriminatory practices against disabled people purely on the basis that they have physical, sensory and/or mental impairments (Imrie 1998, p. 145)'. They overlook the fact that all our 'public accommodations' including public and privately owned buildings including schools, colleges, banks, post offices, police stations, municipality offices, outdoors spaces such as amusement parks, parks, gardens, public facilities such as malls, stores restaurants, cinema halls, exhibition grounds and other recreation spaces, and transportation systems are barrier ridden. Public accommodations enable people to participate in key social and cultural activities, engage with civic affairs, education, employment, recreation and the community network. But a hostile built environment significantly restricts their ability to make contact with others and makes even routine daily tasks such as shopping, going to banks, going out to eat at restaurants, watching films in cinema halls, visiting places of worship difficult and even impossible to negotiate.

Mobility barriers are seen in the constructed environment, for instance, in the form of changes in ground level, inadequate area for movement or overtly narrow corridors. Overcoming differences in levels is a major difficulty in the daily lives of people with motor impairments. Using public transport is impossible without special unobstructed access. A high curb or step may be a barrier for people who have locomotor impairments and for parents with pushchairs, as well as for wheelchair users. Personal living and working environments are replete with barriers. Front drives and entrances to houses, the thresholds of doors or balconies and upstairs areas, unevenly paved roads represent 'barriers' to wheelchair users. The width and extension of transport and activity areas—hallways, doorways and window areas, working spaces and the areas around furnishings and sanitary objects all present a bottleneck for people with walking frames or wheelchairs and are made more arduous by the need to open doors. For wheelchair users, ramps and easy to open doors are scarce; getting through revolving doors is very difficult; circulation areas and corridors often have inadequate turning space and upper floors are not accessible due to lack of lifts. Those with locomotor impairments face problems in big stores or malls and they have to keep standing all the while as generally there are no seats to sit on. This causes a great deal of physical discomfort and even bodily pain. They also face great difficulty in walking or even using their crutches on the slippery marbonite type floors of malls. Wet floors are even more dangerous. Escalators also pose a problem to those with locomotor disabilities who use walking aids and appliances because they cannot hold on to the handrails to keep their balance. Additionally, banks, hospitals and other buildings have steep steps that compel some people using crutches to crawl over stairs so they tend to avoid going to such places to spare themselves from embarrassment and shame. Matters that are quite trivial to the average citizen can present a serious impediment to disabled people, who may also have limited physical strength, speed of movement, balance or coordination.

Barriers make an environment unsafe and cause a high level of difficulty to the user; cause spaces to be out of reach; deny people the opportunity of independent living, dignity and rights to full participation in education, economic, social, cultural and many other spheres of life as citizens of a country and eventually culminate in their exclusion from society.[5] This loss of opportunity is dual: on one hand, the design academia and profession loses out on an opportunity for significant design intervention. On the other, it is a loss for the disabled individuals concerned and also society's loss that misses out on their contribution. In rural areas of India, the geographical terrain has its own attendant challenges for people with locomotor impairments. Waterbodies, wells and pumps are often inaccessible places because of elevations, depressions and so on. India is going to face a situation similar to the West of an ageing population in the not so distant future, and should wisely draw lessons from those faced elsewhere in the world and take up steps to shun design exclusion, to have a user-centred approach to design (discard the product-centred approach) and address the challenges which will soon accost it.

Barrier-free living spaces should extend beyond our own homes to encompass our whole living environment and every social setting. In physical terms, the provision of a barrier-free environment can be undertaken in four complementary domains: inside buildings, in the immediate vicinity of buildings, on local roads and paths,

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[5] This problem is however faced not only by disabled people but also by many sections of society such as the elderly, pregnant women, children and temporarily incapacitated people.

Provisions and regulations for providing features of accessibility for people with disabilities are guided by two items of national regulations: the National Building Code of India and the IS: 4963-1968: Recommendations for Buildings and Facilities for the Physically Handicapped. Many states, union territories and city development authorities have provisions and by-laws.

and in open spaces and recreational areas. The aim of barrier-free design measures is to integrate into mainstream life groups such as pregnant women, children, the elderly and the disabled. Barrier-free planning, therefore, means thinking ahead and building for the future—not only meeting the present needs of users, but also creating living spaces that can easily and safely be used by children or adapted for people who are ageing or old or have restricted mobility.

Universal design strategies for public spaces mandate design of accessible walking surfaces which are stable and slip-resistant, wide enough for wheelchair use (maximum running slope and cross slope), keeping protruding objects such as overhead signboards at bay for the safety of those with visual impairments, reducing pedestrian and vehicular congestion, especially at intersections, use of photoluminescent materials to mark edges of slopes and footpaths at night, signal timing, talking or audible signals for visually impaired pedestrians and to increase situational awareness of all, measures to prevent water pooling at the bottom of ramps and slopes and so on (Steinfield and Maisel 2012, p. 199). Universal design features might include proper space planning, landmarks and proper signage at each primary entrance/exit, entrances that provide the shortest and most direct route to primary locations in the building, adequate weather protection (from sun, rain) and so on for the ramps and access routes and even waiting areas, tactile and visual/braille signage, proper ramps and stairs with safe railing and landing design, tactile, visual and/or auditory cues to indicate changes of direction inside buildings, door manoeuvering clearances, having outdoor facilities adjacent to related indoor spaces, clubbing-related services together, such as drinking water facilities and washrooms near auditoriums, classrooms and conference rooms, movie theatres and departmental stores, surfaces free of glare, surfaces and edges made from slip-resistant material without excessive friction, well-illuminated stair treads, ramp surfaces and handrails (Steinfield and Maisel 2012, pp. 205–207). It is a foregone conclusion that many different design professionals besides architects and interior designers such as graphic designers, textile designers, industrial designers, spatial designers, user experience designers and interface designers would need to be consulted in designing such spaces. Sadly, that is rarely the case in real life. Academic departments or design disciplines, despite their best intentions, remain watertight compartments missing out on the insights that a truly interdisciplinary osmotic interaction might yield.

Public buildings and spaces such as museums, exhibition galleries, hotels, theatre spaces, concert halls, malls and department stores may also need some universal design facilities to address the diverse needs of visitors. These may include installing benches or seats at regular intervals, a help desk for visitors with special needs, information provided on websites to help people know about the environmental challenges they might encounter, equipment available on request to visitors (bicycles, mobility aids and devices, toilet seat risers, transfer seats, etc.), alternative experiences for visitors who cannot participate in the regular tours or activities (e.g. tactile and audible artwork in museums or art galleries, or texts of tour guide presentations for the use of those who are hearing impaired). The National Gallery of Modern Art in New Delhi is one such building which has incorporated many accessible and universal design features in the building. Universal design of public buildings increases functionality, supports and promotes accessibility and creates a positive emotional response for those who use them. These design decisions enable dignified way finding for all visitors, personal safety, social integration, inclusion in public life, and 'affect their health and psychological and emotional well-being' (Steinfield and Maisel 2012, p. 275). In catering to the requirements and needs of different user groups within one system, you are inclusive and socially conscientious in your approach, design process and outcomes making differences in terms of abilities unnoticeable. This is a significant transcendence over even accessibility design that yet manages to draw attention to difference. Such a philosophy of design almost certainly would lead to good design. Besides, with universal design you are working on generalizing grounds, you are as if disembodying the body, so that it could be any type of body that's in focus. So, it may help to substantially raise self-esteem, homogenize identities and erase the marker of disability as something different or as something that needs attention. It may alleviate stigmatization and remove constraining barriers to perception.

If we examine the specific issues of people with partial or full sensory impairments, in particular, we see that they have problems orienting themselves when they are deprived of certain sensory information in their environment. Sight is the most important means of perception in our built environment as most information is visual. Consequently, even mild visual impairment or low vision can cause problems if public transport information such as the names of bus stops or stations, and information signs are represented in very small type. People with low vision find it impossible to move easily about in the inside spaces of public places such as cinema halls and malls. Interiors of cinema halls have dark reflective floor tiles, the glare of lights from top and the sides of the stairs, dark colour carpeted steps inside the auditorium, and mercury and yellow lights all making it difficult for people with low vision to negotiate their way inside. While people generally adjust to a dark space in 5–6 seconds, for people with low vision, it takes almost 5 minutes or more to adjust to the darkness. Huge white lights and spotlights would make it much easier for them to be able to find their way. Malls are more accessible to disabled people with low vision because they usually have white- or ivory-coloured floors. The presence of ramps, railings, lifts and escalators also helps. Big departmental stores pose a problem to those with low vision and visual impairment. More severe visual impairment makes orientation in the street or in buildings difficult, as a person may be able to perceive only colours or contrasts. Environments with extremes of contrast and colour, which are difficult to classify spatially, make information-gathering difficult. People with total visual impairment have to depend solely on hearing, smell and haptic perception to find their way. Orientation is particularly difficult in undifferentiated or unfamiliar streets and interior spaces. Any change in a space is a threat, disrupting a blind person's calculations in finding their way by memory. People with partial or full hearing impairment encounter auditory barriers in any kind of communication. In a public space, potentially dangerous events that hearing people would be aware of even if they happened out of sight will not be apparent to people with hearing impairments. They are excluded to a greater or lesser extent from auditory information such as public transport announcements, doorbells or warning signals (fire alarms, sirens). In some cases, these may make no impact or even be potentially life-threatening.

All this leads us to the crucial imperative that unless interior design of buildings is carefully considered universal design goals will not be realized. Steinfield and Masel point out how the design of interior features in such buildings can assist users in orienting themselves in space, situational awareness, negotiating space successfully, finding their destinations (such as seats in cinema halls) leading to an overall experience of enjoyment by all users. Different kinds of cues, i.e. both visual (creating textures and patterns, for instance) and non-visual (audible, tactile or aromatic prompts) can also help perceive and navigate the space well, especially for people with sensory impairments. Besides, acoustic cues and signals define an area spatially for people with low vision and visual impairments enabling them to create a mental map. Following lighting design guidelines can help to distribute light evenly and reduce distortion and disorientation, and reduce both reflective glare and direct glare. Even colour has a physiological and psychological impact on us; colour cues continuously help us move through space. So, designers need to understand colour properties and their perception well in the design of both exteriors and interiors of built spaces. The strategic use of colour with lighting effects can significantly alter the visual experience of those with low vision and cognitive impairments. The use of highly contrasting colour and lighting on floor surfaces would need to be controlled properly to avoid causing illusions for them and the attendant fear of falling. ‘Glare, light pools, or sharp shadows across a floor may appear to be holes or drop-offs, or potential falling hazards like slippery surfaces’ caution Steinfield and Maisel (2012, p. 288). The design of furniture, furnishings and floor coverings may need to factor in people with different impairments as well. For instance, the seating arrangement may need to integrate space for wheelchair users. Barriers to those with sensory impairments should be removed by providing information to two different senses. This two-sense principle, or alternative perception, makes orientation and learning easier by allowing hearing, sight and touch to compensate for each other: Instead of sight, account for hearing and touch/feel; similarly, instead of hearing consider sight and touch/vibration. This principle applies particularly to alarms, emergency services calls and alarm announcement systems. Such measures are also useful for general information giving and communication.

Toilets are an acutely vital site for the practice of accessibility and universal design. Any human being needs to conduct and complete their personal hygiene tasks efficiently and in a dignified manner. This is important not only from a health perspective but also in terms of social participation and avoidance of stigma. All disabled people speak about the poor and inaccessible design of toilets. Inside any toilet, it is difficult for the visually impaired to determine whether the tap is to the right or to the left. Second, in the squatting type of (Indian) toilet, it is difficult to know which side the step is on and which direction to face after squatting. In the absence of standardization in the design of toilets, they are attentive to other features and infer for themselves. Even in public toilets there is no signage in Braille, or a plate informing which side to face while squatting. Many visually impaired and locomotor impaired people say that they tend to avoid using public toilets and prefer to wait until they return home often holding themselves for several hours and bearing the discomfiture and even pain, which it entails. This is primarily because they are not sure how accommodating the toilet would be for them. There is also a fear of slipping and falling. People who crawl find it more difficult to use washrooms in public places. The wet floors spoil their clothes and their hands that they have to put on the floor to move forward get dirty. When women who crawl menstruate, it is even more difficult for them to use these toilets. There is little privacy for them. When public amenities such as toilets do not consider ergonomics or cater to universal/inclusive design or accessible design principles, they become inaccessible to a wide range of people with different kinds of bodies, restrict their mobility, limit the life chances of disabled people and make for social exclusion.

Minimum accessibility standards, especially for wheelchair users, include proper signage that indicates a toilet is accessible, minimum sizes for accessible toilet stalls, proper placement and design of adjustable grab bars to assist in transferring to and from the toilet or alternative configurations to accommodate different needs, minimum door clearances, availability of space to manoeuvre wheelchairs, proper mounting heights for fixtures such as taps, mirrors and bag hooks. Those using crutches or other walking aids may additionally require minimum clearances for positioning their aids and equipment. Basically, it means accommodating a full range of sizes and abilities but proper planning needs to be put in place for those who need a large space in toilets including those who may need others to help them in such spaces. Additionally, those with severe or multiple disabilities may have limitations in grip and reach including operating taps and flush levers even if they are mounted to be accessible.

Various statutory and regulatory provisions exist that encourage and promote incorporation of barrier-free features in public spaces, facilities and services to create a framework for a more inclusive society and to trigger changes in design practice.[6] However, one of the major issues in promoting access for disabled people is that of institutional coordination. Local authorities, property developers, architects and design professionals have failed to respond positively to accessibility recommendations. Particularly for the built environment, there are in most cases a range of agencies and other local authorities responsible for infrastructure. This frequently results in uncoordinated action and no single agency considering itself accountable for making the built environment accessible. In this respect, the PWD Act itself is not of great use in terms of establishing clear lines of accountability for ensuring that accessibility standards are adhered to. The other problematic aspect of legislation and standards is that they sometimes advance special provision instead of a level playing field or inclusivity, which could benefit a wider spectrum of people not strictly considered disabled by Indian law.

Design practice must also advocate taking up adaptable design features that are modifications made to standard design for the purpose of making the design usable for an individual (disabled people), as needed (Erlandson 2008, p. 18). An example of adaptable design is adding ramps to an existing public building when it is being renovated. Also called ‘Low barrier’ it aims to relate accessibility targets set down

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[6] There are also guidelines and space standards for barrier-free built environment for disabled and elderly persons issued by the CPWD, Ministry of Urban Affairs and Employment.

in the building norms to the actual situation in existing buildings, adaptation and modifications. However, this move is also fraught with problems. The design structure may be overwhelming or intimidating, spaces may be too narrow or too small and so on. When cost-cutting measures are taken in new buildings, accessibility is one of the first things to be discarded. This is where ‘low barrier’ measures come into play. They seek to remove or avoid as many barriers as possible through simple, clever and practical solutions even if the issue cannot be entirely addressed. This requires architects and planners to get an access audit of living or working spaces through disabled people themselves to examine in greater detail how they interact with these spaces and what works or does not work for them. For many disabled people, even a little reduction of barriers (handrails enable easier negotiation of steps) goes a long way in enhancing their independence in terms of carrying out daily activities.

Several mottos have come up globally in the past few decades that have equality at the core (Reinhard 2009). In the UK, spatial accessibility planning is now taking account of what is called ‘space syntax’ which requires a radical change in thinking and practice of planners, urban designers, architects and everyone involved in the development process and entails a robust cross-disciplinary integration of planning, transportation and economics. Rose and Stonor (2009, p. 79) state, ‘Space syntax is interested in how all-different scales of accessibility overlap, thereby shaping our cities and neighbourhoods into successful communities.’ Here urban layout is investigated in relation to different scales of movement (local micro movement, neighbourhood, city, region) and one identifies how cities are shaping the emerging collective patterns of human behaviour. Great cities provide an environment that is high on convenience on all scales for a majority of the people. Accessibility, in this context, is understood with a scientific approach and shapes ‘the development of sustainable communities and the long-term value of the built urban fabric’. Both design education and practice in India lack such perspective.

Promoting sensitivity to the needs of people with disability is a far-reaching social issue. Disability is ‘a complex body-space that is constantly in dialogue with culture’ states Ferguson and Titchkosky (2008). To be considered as ‘lack’ or ‘void’ means to ascribe a variety of cultural meanings and values, which privilege the lives of some people and invalidate others and more insidiously make their way into our epistemologies. What effectively happens is that the everyday lived experience of people with disabilities is erased leading to a lack of realistic perspectives and poor understanding of disability. At the same time, the normative identity is sustained, attributed with positive value, and thus empowered. The economy of visual difference creates a cultural self and a cultural other. So, the thing to do would be to just invert the binary of designer-as-expert with user/disabled person as expert. Such a scheme of things would be ‘user’ centric; in this case, disabled-person centric would incorporate a fuller account of the disabled situation, and be greatly enriched for it; we don’t need to stretch our imagination much to realize the ramifications of this approach. Since the ‘user/disabled person’ would be the expert and not the designer, the conceptual shift would be greatly empowering disabled people who would use or be affected by the product or film or space. This would also be a paradigm shift in terms of design practice.

Architectural or design education and planning play a key role in integrating disabled people into mainstream society. A minimum threshold of compliance with regulations to establish the legal basis for government regulatory actions is vital. We still need to think beyond assistive technology and go a long way in terms of transport technology and communication technology to increase mobility for the disabled. At the same time, we need to remember that design itself is a societal process influencing and being influenced by societal elements. We also need to think further in terms of sustainability and the quality of the built environment and outdoor spaces, systems design and service design. But broadly, observance of both universal design and accessible design principles in terms of the built environment will go a long way in changing society's collective notions about human functioning. The interplay of feedback mechanisms between society and design activities would help expedite the process.

The problems in countries like ours are exacerbated by oppressive social realities such as poverty, population boom and lack of resources where the disabled occupy a liminal space and governments mandate only piecemeal or incremental measures. Concurrently with design activities, increased political lobbying, advocacy and self-assertion by disabled associations and NGOs would lead to significant developments in gaining disabled people rights to access public spaces, buildings and services and thereby be more visible to the public eye. Greater campaigning by disability rights groups could underpin a dramatic shift in thinking by designers and society at large. There is also greater need to promote commitment, awareness and sensitize people in design and architecture education and practice, and planning about the experience of disability so that this in turn informs their work. In fact, disabled people should be considered as experts and equal stakeholders in any design decision-making and have greater representation in committees that work in this area.

Interestingly, seeking design solutions that meet the needs of the disabled results in a better overall design, benefitting both the disabled and the non-disabled. Access should not be viewed as a constraint on architectural design but should be conceived of as a 'major perceptual orientation to humanity (Imrie 1998, p. 145)'. The good news is that considering the needs of the disabled will ultimately lead to designs that are safer, more flexible and more attractive for all consumers. If we work towards a world where design solutions are found for people of all degrees of ability, then only we can justify the flourishing power of a strong and united society.

In conclusion, my recommendations in this paper are (1) The need for the design model to shift from the medical therapeutic/functional model to a model of social inclusion and thus establish the need for universal design in design education and practice. We need to move from a product-centric approach to a human-centric approach. (2) The need to study systems at large and place the design object/product within the larger scheme of systems design. (3) Service design is an area that could be engaged with intensively. (4) An emancipatory approach to the study of disability for designers that entails engaging with several key issues is a vital imperative. For example, you may need to establish relationships with disabled persons, listen to their voices. (5) We need to ask ourselves ethical questions such as these which throw up varied concerns and are certainly not for the faint-hearted: Why am I undertaking this design project? What responsibilities arise from the very fact of my being a designer? Am I incorporating their perspectives or filtering them out? How am I dealing with conflicts of interest that may arise? How can I use my knowledge and skills, my 'design imagination' to challenge forms of oppression disabled people experience? Does my design reproduce the status quo of domination or does it challenge it? Is it liberating for the disabled person? How am I representing the disabled person through my work? Raising such questions would be an enabling learning experience. (6) The design academia in this country has already taken cognizance of the need to include universal design but needs to quicken its steps to shape and firm up pedagogy of universal design. After all, in the ultimate analysis, the design school of today charts out the design practice of tomorrow.

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Chapter 5
Ignorance of Disability: Some Epistemological Questions

Anita Ghai

For many social epistemologists, feminists prominently among them, ethical–political questions about trust, power, epistemic negotiation, advocacy, credibility, communities of inquiry and the ethics of belief enter and shape the discourse code,[1] (2014, p. 113).

This article looks at the 'epistemologies of ignorance' regarding disability in academia in India and the ways in which disability has been ignored, denied expression or blocked from academic understanding. My understanding of disability as an epistemology and its close connection with ignorance surrounding it has been predominantly influenced by my own experiences as a disabled woman, who also has a keen interest in the knowledge of disability.

My engagement with the issue of disability began as I negotiated my sociocultural and political positioning as a woman with disability in a traditional patriarchal society. I would seek to argue that ignorance of disability is produced through the quest of a 'normal' and perfect body that results in epistemological exclusion from the academia in terms of Kristi Dotson, 'epistemic oppression refers to persistent epistemic exclusion that hinders one's contribution to knowledge production…… The tendency to shy away from using the term "epistemic oppression" may follow from an assumption that epistemic forms of oppression are generally reducible to social and political forms of oppression' (p. 116). The chapter is divided into three sections. The first discusses the meaning of disability in India. The second section looks at the understanding of ignorance with reference to disability in academia. In this, I offer reasons for the marginalization of disability that has not been freed from the confines of the traditional medical/rehabilitation/charity framework. Finally, in the third section, I suggest the possibilities for structuring disability studies in India.

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[1] Lorraine Code (2014) Ignorance, Injustice and the Politics of Knowledge, Australian Feminist Studies, 29:80, 148–160, https://doi.org/10.1080/08164649.2014.928186.

A. Ghai (✉)
School of Human Studies, Ambedkar University, Delhi, New Delhi, India
e-mail: Anita.satyapal@gmail.com

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Disability in India

For most scholars of social inequality, struggles around material conditions take place not only in the social, economic and political realm, but also in ideological realms that interact with the structural factors and processes of instituting social reality.

While tracing the historical, cultural and heritage roots of disability services over the past millennium in South Asia, Miles (2000) visualizes a 'perfect world' in which there are no disabled people. The dream fits in with the hegemony of 'normality' that characterizes societies in which any kind of difference is marginalized. Within this context, a disabled person is considered an incomplete entity. The deterministic framework of destiny/fate allows very few to escape this erosion of agency, thereby creating a situation wherein a person with disability is not accorded expert status either for his/her own life, or for that of the dominant group. While the medical framing of disability is well known, the cultural understanding of disability is based on the belief that it is a consequence of human misdeeds in previous births. Suffering the wrath of God, the notion of a 'just world' is firmly ingrained in the mind and is frequently invoked to explain whatever happens in one's life disability, therefore, is a punishment for the sins of previous births. The theory is paradoxical as one understanding is that *karma* (action) has very often led to a ready acceptance of physical disability, with little effort in the direction of improving life conditions. Since culture denies access to social, political and economic opportunities, disabled people and their families cannot help but respond to their life situations in a resigned manner. It is presumed to be a deterrent to collective efforts to assert the right of equality for people with disabilities. The religious doctrine of *karma* however, does not allow passive resignation, as potentiality of change is embedded within the religious beliefs. The possibility of repaying the debts and consequent a better rebirth induces an attitude of tacit acceptance of asserting the rights as a citizen. Belief in *karma* helps people in understanding their own and others' angst. A sense of desolation and hope is thus entertained together. In the last three decades, the lived reality of people with disabilities has changed. Reasonable accommodation and reservations in the 2016 bill have brought disabled in the 'mainstream'. For instance, media and literature are positive representations such as Firdausi Kanga[2] in his novel *Trying to Grow* and a movie *Sixth happiness*[3] and Leila in *Maragita with a straw*,[4] which follows from Malini Chib's autobiography.[5]

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[2] Kanga, F. 1991. Trying to Grow. London: Bloomsbury.

[3] Moving and humorous drama about a boy suffering from brittle bone disease who will never grow, adapted from Firdaus Kanga's fictionalised autobiography.

[4] *Margarita with a Straw* is a 2014 Indian drama film directed by Shonali Bose. It stars Kalki Koechlin as an Indian teenager with cerebral palsy who moves to America for her undergraduate education and portrays a complex relationship with a blind girl, played by Sayani Gupta. Revathi, Kuljeet Singh and William Moseley play supporting roles. Produced by Bose in partnership with Viacom18 Motion Pictures, *Margarita with a Straw* was co-written by Bose and Nilesh Maniyar and deals with themes of stigma, inclusion, self-acceptance and human sexuality.

[5] Chib, Malini (2012) One Little Finger, Sage Publications.

Disability is often conceived as eternal childhood, where survival is contingent upon constant care and family protection. The emphasis is on images of dependency that reinforce the charity or pity model. Carrying a sense of shame, disabled people find that their voices are silenced and they are always looked upon as the 'Other'. The binary of disability and ability is understood more readily as a medical issue. I underscore the fact that disabled people have not only been constructed as 'Other', but frequently as 'the other' of 'the other'. Though we have come a long way from this view, yet it continues in various ways. As Snyder and Mitchell remind us that 'disabled people must negotiate a finite repertoire of social meanings [...] there are significant stakes in the humanities-based analysis of disability' (2006, pp. 168–169). Thus, 'disability tends to be figured in cultural representations as an absolute state of otherness that is opposed to a standard, normative body'. I submit that the 'problem' is not the person with disability. Rather the difficulty is the way that normalcy is constructed to create the 'problem' of the disabled person" (Davis 1995, p. 24).

People with disability, nevertheless, are marginalized even by those who are considered to be peripheral in social contexts such as in the context of ethnicity, race, caste and gender. Thus, persons with disability for marginalized contexts are caught in multiple oppressions. However, in one sense, it is fruitful to understand the similarities and differences at the level of ideological constructions. For instance, systems of inequality based on caste, race, ethnicity and gender seem to rely on dichotomies[6] such as 'Us' (read abled) *versus* 'Them' (read disabled), implying not only difference and opposition but also superiority and inferiority. In the latter part, I interrogate the binaries and think of deconstruction. As Derrida (1978) reminds us that binary structure should be rejected, and this goes beyond the simple opposition signifier/signified.

> This structure in fact underpins the history of philosophy, which conceives the world in terms of a system of oppositions proliferating without end: logos/pathos, soul/body, self/other, good/evil, culture/nature, man/woman, understanding/perception, inside/outside, memory/oblivion, speech/writing, day/night, etc.

Historically the work of Albert Memmi on *The Colonizer and the Colonized* (1967) serves as a useful benchmark in understanding the process of alterity in the context of disability. The concept of alterity is sometimes a very palpable presence, while at other times only a significant trace in so far as it is implied in discussions of identity, domination and subordination, oppression, binary oppositions and in claims made by a variety of social groups and movements.

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[6] Janet Price (2011) reminds us of fluidity in moving away from binaries working with an understanding that we are all vulnerable, and that we all live with unstable, potentially out-of-control bodies, could we dare to displace the able-bodied/disabled binary, drawing on the recognition that we are all, at best, temporarily able-bodied. For we will at least all get old, if nothing else? An acceptance of this inevitability breaks down some of the great divides that have been instituted through identity politics and brings us all to a recognition of the temporary, and highly contextual nature of our identities, and of the embodied self.

Nullification of disability therefore marginalizes people whose disabilities are either more extreme/noticeable or rare, which puts some people at a major disadvantage from birth. This marginalization not only puts disabled people at a disadvantage but also prevents society, in general, from directly experiencing the lives of the disabled. Reading Memmi strengthens the argument that those of us, who have been marginalized by our respective disabilities, enter the life space of the more complete 'Other' from the position corresponding to that which the colonized holds in relation to the colonizer. Taking over from the portrait that he draws of the 'Other' as it means to the colonizer, the colonized emerges as the image of everything that the colonizer is not. Every negative quality is thus projected onto her/him. Most fundamentally, my contention is that the creation of a devalued 'Other' is a necessary precondition for the creation of the able-bodied rational subject who is the all-pervasive agency that sets the terms of the dialogue. There are many significant aspects that need to be noted in this description by Memmi. In fact, they may seem familiar to many of us who share a disabled existence. First, the 'Other' is always seen as 'not', as 'lack', as 'void', as someone lacking in the valued qualities of the society, whatever those qualities may be. Second, the humanity of the 'Other' becomes 'blurry'. Third, the 'Others' are not seen as belonging to the human community, but rather as part of a muddled, confused and nameless collectivity. They carry, according to Memmi, 'the mark of the plural'. In other words, they all look alike. This is indicative of the cultural hegemony that strives to posit an autonomous able-body.

All binaries, in psychoanalytical parlance, operate in the same way as splitting and projection. Thus, the Centre expels its anxieties, ambiguities and irrationalities onto the inferior term, filling it with the converse of its own identity. The other in its very strangeness simply mirrors and represents what is deeply familiar to the centre, but projected outside of itself. It is this process of marginality that produces the resentment, enmity and repugnance for the one who is sensed as the other. Disability provokes fears and anxieties about 'able-body' mortality, and very easily renders itself as the 'Other' (Ghai 2018).

Ignorance of Disability in Intellectual Scholarship

Most scholars still consider disability an anamorphic lens displaying distorted or grotesque subjects who are rather more "them" than "us"' (Davis (2002, 44). As May and Ferri (2005, 127) remind us that "This inability to analyse disability through a critical lens further indicates that the problems with passive empathy or analogic bridging, and assuming of the reversibility of experiences". It is here, in this connection, that I underscore the epistemology of ignorance in academia. As a first-generational learner, a key goal of my life was to be connected to the university as the site of 'legitimate' knowledge. Indeed, the close relationship of 'legitimate knowledge' with politics has been an ongoing challenge that is faced by those who are marginalized and disfranchised.

To understand knowledge and ignorance, I turn to Charles Mills' book *The Racial Contract* as methodology to generate insights on understanding disability and for conceptualizing ignorance. According to Mills, [o] n matters related to race, prescribe for its signatories an inverted epistemology, an epistemology of ignorance, a particular pattern of localized and global cognitive dysfunctions (which are psychologically and socially functional), producing the ironic outcome that whites will, in general, be unable to understand the world they themselves have made (1997, 18). Gaining insight on Mills' premise, my understanding is that the way *The Racial Contract* excluded many categories of the world's human beings especially people with disabilities too get excluded from the discourse of the abliest contract. For Mills, the epistemology of ignorance is part of a white supremacist state, for me, the division between ability and disability is very clear to the society. Though abled people tend not to understand the world in which disabled live, able people do benefit its cultural hierarchies, ontologies and economies. Indian academia still fails to present an understanding of disability as legitimate knowledge. Ignorance is often an active social construction. Both abled and disabled people's knowledge is shaped by their social location. From positions of normality and consequent dominance, ignorance can take the form of those in the power either repudiating to allow those who are at the margins to know, or of actively erasing knowledge that creates conscious and unconscious anxieties about knowledge that can create vulnerability. The study of knowledge of disability and consequent epistemology addresses the questions of how we come to know and what we can know. It took me time to understand the connections between knowledge, authority and power. As I grew up, I realized that discourse of power with its nuances of constraint and repression are always contested in the institutions and academia. Indeed, the close relationship of 'legitimate knowledge' with politics has been an ongoing challenge that is faced by those who are marginalized and disfranchised. I am drawn to a very critical epistemological question as to 'What counts as knowledge?' This epistemological question matters greatly in the university in which there was no public debate and academic reflection on questions related to disability. The absence of epistemological debate in disability resonates with what Dewey (1969, 6) called 'the weary treadmill which [philosophers] pursue between sensation and thought, subject and object, mind and matter'. The treadmill runs repetitively onward, spinning out theories of knowledge but with no understanding of disability.

According to Dewey, 'The epistemologist's problem is, indeed, usually put as the question of how the subject can so far "transcend" itself as to get valid assurance of the objective world' (Dewey 1976, 122). I believe that disability studies scholars are keen to grasp the epistemological questions on disability. For instance, the progression of knowledge construction is bounded by questions of authority and authenticity. Michalko (2002, 175) laments the suppression of knowledge stemming from blind experience, which are even actively fought because they are 'not only irrelevant, but are detrimental to the acquisition of objective (real) knowledge, knowledge's that come *from within sight*' Michalko (2002, 182). Therefore, he advocates for recognizing the located knowledges emerging from disability experience. In this view, disability becomes an analytical category of scrutiny. However, the tragic part is that there is no constant debate over the production of knowledge about disability and whether it should be privileged within the academia.

As I state elsewhere (2015), a teacher who taught me epistemology narrated a famous story told by various Eastern religious traditions about six 'blind men' '(sic) who encounter an elephant. One blind man (sic) feels the elephant's trunk, another one encounters the tail, another one feels its side, and so on. As a result, they come to widely diverging accounts of what an elephant is like'. To me this story can understand disability completely different from the vantage point of academics that tend to explore the surfaces of a complex phenomenon like disability, while largely disregarding others. For instance, Linton (1998, 120) emphasizes [that] if we want to introduce disability as a critical category of analysis, we need to reinforce its epistemological base: 'A goal right now for this field [disability studies] is to formulate the epistemological foundation for viewing disability as a critical category of analysis, the absence of which weakens the knowledge base'.

The epistemological ignorance therefore means that the dominant and the power of an elite group cannot understand the non-dominant positions such as disabled. To be disabled is to be located in the brinks, and thus from the privilege and power found at the epicenter. For instance, Latin[7] observes that '*"Marginality" is so thoroughly demeaning, for economic well-being, for human dignity, as well as for physical security. Marginal groups can always be identified by members of dominant society, and will face irrevocable discrimination*'. Such a location results in the non-dominant group being subjected to a form of unknowing, by the dominant group. In other words, manifestations of epistemic ignorance are not random offshoots or isolated incidents but rather a reflection of a structural and systemic problem which 'are endemic to the social, economic, and political order, deeply embedded in all of its self-reproducing institutions' which the academy is part of McIntyre (2000, 160).

Ignoring the margin might indicate an apolitical stance of academic environment which contains an implicit political ideology, and silence or denial of their involvement is no less a political act than explicit political action. For instance, education of the disabled students is a critical issue that is not deliberated in the academia. They might be included in the university because of a policy stipulation. A host of scholars would talk about a myriad of systemic problems such as political systems, economic injustice, corruption patriarchy and global warming. Engaged with a more or less taken-for-granted set of values, norms and expectations, the academia at large usually knows very little, if anything, about knowledge of disability, preserving discrimination against disability. While the presence of Equal opportunities cells are there in the university, but the discourse is largely in terms of concessional issues. Notwithstanding the problems intrinsic to access, disability as knowledge system is not part of academic discussions. As a token gesture, the only response is that understanding disability is critical.

Many such aborted interactions result in silencing of the disabled. As Minow (1989) reminds us that the 'largely silent response' to feminist scholarship 'may

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[7] https://www.lawctopus.com/academike/problems-marginalized-groups-india/ accessed on 4 August 2019.

represent a form of significant criticism'. Silencing to me is aggressive when lived reality of disability is ignored. Though disabled people are 'given' a voice but urged to speak and express their views and perspectives in the name of tokenism/diversity. Trinh Minh-ha aptly calls this phenomenon 'the voice of difference that they long to hear' (1989, 88).

I realized that understanding of disability is intimately connected to study of ignorance, as academia has not evolved tools for understanding how and why various forms of knowing have 'not come to be', or disappeared, or have been delayed or long neglected, for better or for worse, at various points in history" (Proctor and Schiebinger 2008, vii). Most of the universities like others remain sites where not only knowledge but also a patriarchal, neoliberalism and normative values are produced and reproduced.

As I state elsewhere, (Ghai 2015, 312) an enlightening example is provided in the conversation between Bryan Magee and Martin Milligan, in which Magee simply disagrees with Milligan's report that, although almost blind from birth and without visual memories of experiencing specific colours, he fully understands the meaning of 'red' (Magee and Milligan 1995). Thus, Magee depicts Milligan as a 'defective' knower because of his impairment an understanding that Milligan's experiences with redness are not exactly like Magee's own. Yet it is provocative to point out that blind-from-birth individuals do not develop visual processing skills, and then to intimate that they must be epistemologically inferior to, or that their modes of knowing cannot rise to the epistemological significance of sighted people. Foucault clearly points out that there are many forms of subjugated knowledges, which are unearthed by lineage, those that represent the individual voices silenced by hegemony. Says Foucault, '…a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity… It is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work (1980, 81–2). These are the suppressed voices of 'the psychiatric patient, the ill person, …the delinquent', etc., which are representative of 'a popular knowledge …a particular, local, regional knowledge, a differential knowledge incapable of unanimity and which owes its force only to the harshness with which it is opposed by everything surrounding it' (ibid, 82).

Sullivan and Tuana (2007, 1) remind us that ignorance often is thought of as a gap in knowledge, as an epistemic oversight that easily could be remedied once it has been noticed. It can seem to be an accidental by-product of the limited time and resources that human beings have to investigate and understand their world. While this type of ignorance does exist, it is not the only kind. Sometimes what we do not know is not a mere gap in knowledge, the accidental result of an epistemological oversight. Especially in the case of racial oppression, a lack of knowledge or an unlearning of something previously known often is actively produced for purposes of domination and exploitation.

I quote these scholars to understand knowing and not knowing. A very clear example of socially constructed ignorance is disability that make able-bodied as privileged knowers who are unconscious to systemic injustices. It is therefore not surprising, then, that the difficulties of disabled people are often termed as 'differently abled' and 'differently challenged'. As per Tuana's (2006) taxonomy of ignorance, what is really critical is the *Ignorance produced by the construction of epistemically disadvantaged identities.* In particular, Tuana is curious about the 'epistemology of ignorance', or the 'what we don't know and why' when it comes to disability.

The fact that disability as knowledge and can be understood by the stakeholders is not considered in the academia. For instance, 'the devaluation of the non-verbal testimony/testifier in rape trials, is not independent of the overall gendered structure of rape law, which assumes that the testimony of the prosecutrix is irrelevant and that the "facts" could be inferred from other sources, such as her behavior or medical examination'. *Thus*, disability discourse actively rejects the dominant episteme and refuses to seriously anticipate their way of understanding. Such ignorance in so doing is a form of understated violence. Thus, the reality that they attempt to represent is erased and destroyed (Shiva 1993, 12).

Another scholar who brings in intentionality is Spelman (2007) who emphatically argues that the ignorance at work in instances of systematic racism is not a simple 'not knowing', but rather a triumph, and one that must be managed. She questions Baldwin's assertion that 'This is the crime of which I accuse my country and my countrymen, and for which neither I nor time nor history will ever forgive them, that they have destroyed and are destroying hundreds of thousands of lives and do not know it and do not want to know it' (cited in Spelman, 119). Spelman manages ignorance and highlights the notion of willful ignorance. Thus, intentional ignorance is a ruse that we enforce upon ourselves so that we do not recognize the dissonance. She makes us aware of inconsistent beliefs and commitments involved in ignorance. Thus, the ambivalence of being a self is always tied with an act of division. As a disabled person, I find that an attitude of willful ignorance of defenselessness. This underlies the tyrannical denial of the possibility of responsibility in disabled persons manifested in a tendency to take away work from them.

In this light, it will not be out of context if we were to ask 'whether the Subaltern (read disabled) can Speak or be taken as academic? Historically, the very infamous question was a result of the subaltern studies group, a project led by Ranajit Guha. Having borrowed Gramsci's term "subaltern", the objective was to locate and reinstate the marginalized by giving them a "voice" or shared locus of agency in postcolonial India. From Spivak "Subalternity" is the name I borrow for the space out of any serious touching with the logic of capitalism or socialism? Please do not confuse it with unorganized labour, women as such, the proletarian, the colonized … migrant labour, political refugees, etc. Nothing useful comes out of this confusion' (Spivak 1995, 115). Thus, to Spivak the very definition of the subaltern is entailing 'stillness', whereby the cultural space of subalternity is cut off from the lines of mobility producing the class- and gender-differentiated colonial subject. However, the quandary is whether the subaltern has no agency or is fated to silence. Spivak's argument is that elite or hegemonic discourses are 'deaf' to the subaltern, even when s/he does speak or resist (1996, 289). My submission is that knowledge of disability is ignored, forgotten or not considered human enough by the academia. Following

Spivak's argument, Rauna Kuokkanen concludes that, 'the academic conditions of intellectual representation—liberal multiculturalism, tolerance, diversity—preclude the recognition and hearing of indigenous epistemes' (2008, 65).

For instance, ignorance is discussed by Maria Lugones's *Pilgrimages/Peregrinajes: Theorizing Coalition against Multiple Oppressions* (2003). She focuses on the non-white voices and records the flow from them rather than trying to interrogate the non-white into existing white-created frameworks. Rejecting recognized political frameworks as a means of interpretation, she begins in 'a dark place where [she sees] white/Angla women as "on the other side," on "the light side,"' and where she sees herself as 'dark but [does] not focus on or dwell inside the darkness, but rather focuses on the other side'. (2003, 12). Thus, if we cease to think of disabled people as victims annihilated and exhausted by systems of subjugation and conceptualize how disabled can resist systems which aim at imprisoning, interrupting and obliterating disabled, different ways of making sense can emerge. Lugones's theory has an aim, which would develop an exciting and creative substitute to modern subjectivity. It is this aspect of her work that I think offers a way to expanding visions on ignorance of disability. Given these realities, a significant question to my mind is regarding the fate of those who are marked with 'multiple categories of difference'. Is a Dalit [lower caste] disabled poor woman, first a Dalit, then poor and then disabled? With whom should she seek a political alliance that would profit her the most? This is where identity which is understood in terms of fixed nuances creates the greatest trouble. Perhaps at this stage, it would be wise to recall a feminist scholar Nivedita Menon who points out, 'we must go much further than saying that "women" mobilize as upper caste/Dalit and so on. Rather we need to come to the more complex recognition that under different circumstances, and given different kinds of political mobilization, "people" identify and come together as Dalits, [lower caste] Muslims, working class, or much less often, as "women" This is the difficult political [and in my case academic] face to face-that women coming together as upper caste/Dalit *women*' (*p. 179*, Italics in original). Thus, it is critical that we account subjectivity of the disabled that centres on multiplicity.

Historically, humanizing people with disabilities has been established on the premise of 'creating special groups', that is, 'Ignorance in the realm of social sciences in India' is not depicted as a gap in knowledge: something that we do not (yet) know. My university provides an intriguing case for a close inspection of the emergence and prospects of disability studies. The academia evinces deep concern for what are conceived as interdisciplinary based on many societal issues. These include poverty, class and caste inequalities, labour-related injustice, wages and employment, population technologies, violence, dowry and preference for a male child resulting in skewed gender ratio. With time, many other issues such as domestic violence, childhood sexual abuse and sexuality have became dominant concerns of both theoreticians in the academy and activists in the social movements. First, disability-related issues have a rather specific orientation and are strongly influenced by medical and rehabilitation perspectives.

For the disability scholars, in the academia, establishments and their interpretation have been mostly normative and patriarchal. The knowledge-makers were and are predominantly able-bodied males and also positivists. Thus, scientific rigour and rationality were defined as knowledge. The disabled are largely, therefore ontologically 'strangers' [cited from Sharmila Rege[8]], functioning as 'marginal intellectuals' in the academy. There was much intellectual excitement as disability critique of the discipline challenged the absence and distortion of disability experiences in psychological knowledge. The history of the many disciplines was read more as absences, constituting thereby and ignorance of epistemology. My University is perhaps one of the few in the country whose undergraduate degrees still command respect within and outside the country. With a shift in the curriculum, all students will be forced to take foundation courses, which include two courses on 'Language, Literature and Creativity' ('Information Technology', 'Business, Entrepreneurship and Management', 'Governance and Citizenship', 'Psychology, Communication and Life Skills', 'Geographic and Socio-economic Diversity', 'Science and Life', 'History, Culture and Civilization', 'Building Mathematical Ability' and 'Environment and Public Health'.

Nonetheless, the fact as to whether the course would be successful or not, my concern is about the nature of academia which supports and reproduces certain systems of thought and knowledge as well as structures and conventions that rarely reflect issues of disability. To me it is inexcusable that students and teachers can in most cases navigate through postgraduate and research degrees in social sciences and understand interdisciplinary courses in the academia without engaging with the issues of disability. Since the late 1990s, this picture is changing as scholars with an interest in disability in the academy have been integrating the writings of many scholars in psychology, law, political science and literary studies curricula.

Notwithstanding the ambivalent relationship between disability and feminism, women's studies have engaged with issues of disability. Sometimes it had has tokenistic connotation, but all along a certain sensitivity and perhaps a political correctness have been there. However, the generic discourse has included the reality of disability in formulating the generic courses on women studies or feminist methodology. Initially, I always thought of women's studies and the feminist movement as a model for creating a field of disability studies, established after extensive discussions and dialogue that have enabled the achieving of academic excellence and practical emancipatory objectives. However, such endeavours do not check the authenticity and subtleties of experience of women with disabilities. Thus, even the conscious production of knowledge about the experience of gender issues of disability goes hand in hand with ignorance. The result of this ignorance is that disabled people can be misunderstood, underrepresented, regulated or subsumed under the experience of 'universal sisterhood' while 'knowledge' about disabled is being encouraged and disseminated. While there are innumerable courses on issues of women, the university funding agencies have sponsored women's studies centres,

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[8] http://www.india-seminar.com/2000/495/495%20sharmila%20rege.htm accessed on 4 August 2013.

seeking to include/incorporate/integrate feminism in various courses. Despite their own ambiguous location disability finds more space within women studies centres. However, even within the academic understanding of embodiment and its related issues, the recorded exclusions of women with disabilities remain as an add-on category, creating marginality yet again. My suspicion is that non-disabled women's potential susceptibility of their own bodily pain to less than 'picture-perfect' functioning—precipitates a denial of rationality in which one dissociates oneself from another who is a reminder of this vulnerability. As Bordo reminds us, 'This ignorance means that we do not conceive of ourselves as "culture makers as well as culture consumers"', that we abdicate responsibility for the selves that we make, and thus perpetuate oppressive ideals by denying our complicity in doing so (Bordo 1999, 50). Ability epitomizes the opposite of the invulnerable self one seeks to be, and one's response of avoidance is intended to stay away from the sense of defenselessness. A serious question is whether feminism/women's studies will ignore the disability concerns? Anita Silvers raises a question as to whether feminism will privilege the purposeful competencies and social and cultural roles characteristic of 'normal' women. Silvers finds that feminist theories are guilty of 'magnifying these until they become standards of womanhood against which disabled women shrink into invisibility' (Silvers 1998, 331).

It is not so difficult to understand that normative and abliest hegemony stands to lose if they give up their unconscious selves. However, I have always been uncertain about the merging or separation of 'us' ('disabled') and 'them' ('able'). A significant issue for me is that though binaries reflect the opposition against normative hegemony, I do believe that binary constructions served a political purpose. The lived reality of the disabled offers a far more complex picture. I do understand that a binary and essentialist approach to identity is conceptually flawed, inconsistent and has undesirable moral and political consequences (see Sherry 2007). In one sense, the disabled/non-disabled divide is also extremely knotty and theoretically limited. For instance, the division between black/white is ineffective for conceptualizing disability, ethnicity or caste. As Sherry (2007, 19) says, 'people often position themselves somewhere in-between or outside these binary categories, and this positioning is fluid and contextually dependent'. In my opinion, academia should read disability not in terms of a monolithic 'third world woman', at once 'homogenized' and 'systematized' under oppression, but instead with attention to the contradictions and conflicts that can arise from their distinct historical and material relationships to class, religion, culture and patriarchy (Mohanty 1991, 214). Yet, many binaries remain hard-hitting. Dissolution of categories dis/(ability) can unconsciously underpin the established academia. While deconstruction can assist in breaking down the binary oppositions, the task of academia does not end there. The idea of TABs, i.e. temporarily able-bodied, though intended as an indicator of the precariousness of human existence is extremely helpful in destabilizing the binaries of health/ill health, non-disabled/disabled. Thus, the boundaries, which divide us into categories, are tangentially wobbly, such that constant replication is needed to keep them in check. However, we have to be extremely cautious that erasing the binaries is not a one-time attempt.

Possibility of Disability Studies in India

The centrality of disability studies in the quest for creating and enabling theoretical advances, academic morality and transforming disability advocacy cannot be stressed enough. The purpose of making disability studies as an academic discipline is to create a body of knowledge, which can provide challenges for rethinking and reflecting upon aspects of our comprehension of disability. There are many scholars who have sketched the history of the disability movement. Scholars have done notable work in disability studies from UK, USA and Australia. Though this corpus on disability studies might have come from the developed countries, advocacy was the key in introducing knowledge production. It is important to state that advocacy/activism on disability is critical in creating an enabling environment for the study of disability. As Goodley (2011, 4) says, What is important to keep in mind is the breadth of disability activism that continues to influence debates within disability studies. The slogan which guided activism 'Nothing about us, without us' (Charlton 2000) should ask germane questions about disability studies. Thus, disability is an understanding of theory about knowledge, about who can know what and under what circumstances. This is critical as disabled people are often seen as 'objects of knowledge' rather than knowledge producers in their own neither right nor are they seen as capable experts who have the capacity to produce and interpret knowledge from their own particular standpoint. It is such asymmetrical power imbalance in the production of knowledge that reinforces the image of the disabled as the 'Other'.

Ignorance of disability is not limited to disability studies as a major discourse. It is a much more fundamental concern questioning the foundations of the academy which silences the voices of the 'vulnerable'. Shefali Moitra, as feminist philosopher reminds us that, 'There is a fear that the admission of heterogeneity in epistemology will lead to anarchy as well to a communication breakdown. This is a common bogey raised by the main stream disciplines The point to be remembered is that pluralism is not synonymous with anarchy' (2002, 137). In other words, understanding ignorance is an echo of a structural and systemic problem which 'are endemic to the social, economic, and political order, deeply embedded in all of its self-reproducing institutions' which the academy is part of (McIntyre 2000, 160).

It was when I joined Ambedkar University in 2015, I was given this opportunity of bringing Disability Studies became a reality. School of Human Studies, provided a context for understanding human predicament in an interdisciplinary approach through which disability studies have emerged as creative and dynamic field of intellectual inquiry and creative action. Though floated, but a full course on Disability Studies has not seen the light of the day. All the same, there are voices of the disability community and academic scholars who are attempting to speak together, we can hope to create guiding posts to formulate the content and methodology of disability studies. Such an approach would be interdisciplinary in more ways than one. This is not to say that I wish to create a new kind of hierarchy, as it is not important that only the disabled know the reality. Rather the idea is that there would be many non-disabled scholars who take a greater interest in framing of disability as an epistemology.

Such a consciousness can also pursue to unmask and deconstruct the dominance and power of the 'perfect' able-body by directing on the way that disability is fashioned by society.

Thus, the societal assumption is that the disabled are incapable of mutuality and consequently fail to interrogate societal barriers, able-bodied standards and prejudice as the causes of disenfranchisement of disability. The challenge of leaving the comfort zone of our original epistemology formed under the taken-for-granted dominant academic discourses therefore is always perplexing. It is even more disquieting to turn our own beliefs upside down and critically analyse the assumptions behind these. What is significant to perceive is that as soon as we become alert to confront the anxiety of stereotypical beliefs, we create an unconscious so that we tend not to venture into such anxieties? When both non-disabled and disabled can go through a creative understanding of disability, i.e. a journey of self-examination, then we can reframe the disability perspective. It is clear that disabled people do understand that perfection is a myth. People with disabilities therefore would not conceal from others and themselves that they are disabled. According to Siebers (2008), 'embodiment seen complexly understands disability as an epistemology that rejects the temptation to value the body as anything other than what it was and that embraces what the body has become and will become relative to the demands on it, whether environmental, representational, or corporeal'.

While I am concentrating on the question of disability in my university, I underscore the imperative that can question the academy responsible for its ignorance. Such a cross-examining of the academia can create spaces for knowledge of people with disabilities. This demands that the academy is accessible and ready to stretch into a 'learning to learn' mode of understanding and observing the disabled's world view.

I am reminded of Gilles Deleuze and Félix Guattari, *A Thousand Plateaus* who conceptualizes a rhizome which has no beginning or end; it is always in the middle, between things, interbeing, intermezzo. The tree is filiation, but the rhizome is alliance, uniquely alliance. The tree imposes the verb 'to be', but the fabric of the rhizome is the conjunction, and… and … and …As I state elsewhere (Ghai 2018), 'The quote above brings us to the understanding of the Deleuzoguattarian rhizome whose meaning offers a chart and metaphor for the field of disability studies, as it grows outside the boundaries of a defined discipline or programme'. Within the university, we are always confronted with the parlance of connotations such an inquiry in a field, as to that of discipline, department or programme. When we think about rhizomatic thinking and growth, we are reminded of Deleuze and Guattari: 2 'Don't sow! Grow offshoots! Don't be one or multiple, be multiplicities!' (24).

I believe such an approach will open disability as an exciting and valuable site of analysis for the social sciences and humanities, redeeming it from its traditional rehabilitation and social approaches. Introducing disability as a counterpoint to the medicalized perspectives on disability springing from the applied fields and in response to the marginalization and deceptions across the notion of disability may seem like a daunting journey for many intellectual researchers and scholars grounding their knowledge in the positivist paradigm. Disability studies are understood by scholars who find that mainstream academia has excluded the disability perspective. However, mainstream scholars have been reluctant to the new voices. Perhaps because academia's issues are rarely resolved, there is little room for new posers such as disability or perhaps the able-bodied academia resists the notion that it has not always spoken for all people—Dalit ('lower caste'), tribal, or disabled. This dogmatism is found not only in the traditional understanding of my university, but also in all universities. This exclusion therefore has to be interrogated.

My experiential reality of disability affirms the need to reformulate our epistemic understanding of disciplines and knowledge production, so as to learn from hitherto invisibilized experiences. Historically, most of the progressive changes which have come about politically and socially have been rendered possible only on account of collective action of women's movement which for some strange reasons we have not been able to reconstruct post the 1970s and 1980s.

Perhaps creating academic spaces for conjecturing on lived realities and experience is one step amongst the many strategies, which we need to constantly work on. I state further (Ghai 2018, p. xvi) to reference Raymond Williams, if disability studies are a field, what are our keywords or search words? And if we don't have any, or if we have only insufficient ones, then how can we be found? One of the main concerns with scholarship in keywords in DS is the absence of a lexicon of disability typical of the Global South. If disability studies are a field, or better still, a field of energy, where does it happen, especially in non-Western contexts? The inconspicuousness of disability studies on some campuses may be a result of the critical ways the field departs from how disability has been treated historically. So much of disability history has entailed the grouping together of disabled people through techniques of surveillance, identification and nomenclature.. Struggling for issues of disability is important in putting up a fight for inclusion in academia. I find such a fragmentation of identities in academic scenario as troubling, as hierarchies are vicious, discordant and immobilizing. Simply removing add-on categories to the new courses are not going to work unless intelligentsia's abliest attitudes have acknowledged that disability is a part of social and academic psyche.

Disability is mentioned in all cultures/texts, ranging from the Indian epic Ramayana to the Greek myth of Oedipus and the more recent Human Genome Project. It is a narrative about human differences that we can chart over time. If we can excavate, a fiction about bodily variation can be revealed. Critically, these narratives shape the material world, inform human relations and mould our sense of who we are. In short, then, Disability Studies interrogate humanity as it challenges our collective stories about humaneness, redefining it as an integral part of all human experience and history. The lens of disability therefore can enrich the knowledge of body, inequity, identity, literary theory, art poetry, music, literature and sexuality, through understanding disability studies.

The study of disability infuses into the academy a perspective of those who are routinely made invisible and marginalized, just as woman studies and caste studies did before it for other groups. When the issue is gender, men are always acknowledged, as the norm, and women are considered the deviation. When the issue is disability, the able-bodied, seeing, hearing, mentally healthy person with a certain score on an intelligence test is treated, but never acknowledged and understood as the norm, while people who communicate through sign language, use wheelchairs, or speak, think, or hear differently, are considered the deviation. The understanding of disability as knowledge helps us to understand insinuations of these preferences.

Disability as knowledge not only adds to existing disciplines, but also creates new scholarship by posing questions about the place of diverse human realities in society that conventional disciplines have ignored. Understanding the epistemology of disability as a social, cultural and political phenomenon externalizes the issue and helps counter the notion of disability as an inherent, immutable trait located in the person. The study of disability considers the sociocultural dynamics that occur in interactions between society and people with disabilities. Such an understanding rejects the view that disability is solely a medical problem or a personal tragedy. Instead, disability studies place the responsibility for re-examining and repositioning the place of disability within society not on the individual, but on academia as well as society itself.

Disability Studies will confront the way in which disability is constructed in academic society. The critique[9] by Tremain indicates that the university will involve in the development of the theoretical, research, educational and advocacy models necessary to remove the legal, physical, policy and attitudinal barriers that exclude people with disabilities from society. Disability Studies, therefore, have the potential to benefit people with disabilities as well as society by the participation and presence of people with disabilities in our schools, our neighbourhoods, our workplaces and in our lives.

Conclusion

Ignorance of disability from the mainstream academia creates and maintains a status quo where the ‘disabled’ is incorporated with the existing social patterns [as special], while arbitrating the normative hegemony. In this sense, the representation of disability is trapped in a metaphorical understanding. Although race and sexism are seen as constructions, disability remains as an out-and-out state, both politically and academically—it is the source of its own oppression. Such a reading suggests that more is at stake than a problematizing discourse of specific categories (Spivak 1990, 42). For instance, we need to be engaged in ‘the unlearning of one’s own privilege. So that, not only does one become able to listen to that other constituency, but also one learns to speak in such a way that one will be taken seriously by that other constituency. Also the hope is academia can rewrite the relationship between the margin and the centre.

Disability Studies can enable the academia to think critically not only about disability, but also about oppressions that affect all historically marginalized groups.

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[9] https://philosophycommons.typepad.com/disability_and_disadvanta/2016/11/whose-epistemology-why-ignorance.html#.

Scholarship in the universities has become knowledgeable through gender, race, sexuality and class analyses, deepening our understanding of different epistemic positions. The inclusion of disability can transform the university—just as did the critique of gender and the presence of women. I am reminded of Mia Mingus in her blog that disability is heterogeneous. We cannot ignore the fact that oppression and privilege divulge themselves differently among disabled people. This reality can be damaging to cross-disability understanding. As Mingus[10] says,

> to pretend as though those of us who pass as able bodied or "don't look like we're disabled," don't receive a totally different reality than those of us who are undeniably and obviously marked as disabled by everyone they meet, would be ridiculous and does not do justice to what we are up against nor how powerful a system ableism is.

Thus, my attempt is to foreground how the ignorance of disability is replaced by a study of disability as a field of inquiry within which conventional academia can enrich knowledge and experience that can contribute to the understanding of the heterogeneity of disability. My hope is that we rework on the personal and the political. The interdisciplinary character of disability studies will empower the conceptual frameworks and intellectual tools of various disciplines from history to law, literature to sociology as well as enrich these disciplines by questioning their fundamental theoretical and methodological orientations. There will be a day when Disability Studies would be taken up by academia as a moment of pride.

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Chapter 6
Rethinking Monsters: Teaching Disability Studies Through History and the Humanities

Shilpaa Anand

The present juncture is an exciting one where teaching disability studies in India is concerned, given that the Rights of Persons with Disabilities Act, 2016 (Government 2016), India's latest disability law, mandates that all universities promote research in disability studies.[1] While this is an important prospect for teachers and students interested in disability research, it is also an important stocktaking moment. The present chapter, while delineating the teaching of disability in literature departments, responds to the question: How does teaching disability within the humanities contribute to the field of disability studies? Social science disciplines have concerned themselves with the historical absence of disabled people from education, employment, politics and leisure and have become involved in researching the nature, causes and dynamics of such an absence. Literary studies, conversely, have found an overpresence and a hypervisibility of disability, disablement and disabled people in the canon and beyond (Davis 1999; Mitchell 2002; Barker and Murray 2017). Nevertheless, disability's overpresence in literary texts has existed conspicuously as metaphor rather than subject matter; disability has persisted, one can say, as a stylistic device, an allegorical tool even, rather than as material presence (Mitchell 2002; Barker and Murray 2017). With the recent emergence of Literary Disability Studies as a subfield of some worth, the materiality of disability has come to be closely examined by bracketing off the metaphorical representation that overwhelms literary expressions of disability. The bracketed off metaphorical references to disability, in turn, have been theorized as reflective of social responses to disability.

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[1] Section 47, Part 2 of the Rights of Persons with Disabilities Act (2016) states, 'All Universities shall promote teaching and research in disability studies including establishment of study centres for such studies'.

S. Anand (✉)
Department of Humanities and Social Sciences, BITS-Pilani
Hyderabad Campus, Hyderabad 500078, India
e-mail: shilpaa.anand@hyderabad.bits-pilani.ac.in

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Another significant factor in the teaching and theorizing of disability within literary and cultural studies has been in terms of a robust response to quantitative and qualitative disclosures of sociology, political science, economics and anthropology. Given that literary study has methodologically focused on mediation, representation and discourse, it has contributed important insights to social scientific studies of disability that have concentrated on empirical findings within largely positivistic frameworks. Literary approaches have enabled a close examination of the narrative quality of disclosures, rather than the disclosures themselves. So also, the study of what may be grouped as disability texts (life-writing of disabled people, representation of disability experiences, language of disability discourse) has revealed complexities and nuances that determine empirical facts. Undeniably, the narrative turn within the social sciences is evident in disability research carried out by anthropologists, historians and sociologists in the last two decades.

The teaching of disability in English literature and Cultural Studies departments was inaugurated in the United States of America in the 1980s and 1990s as disabled scholars brought into the fold of English Studies academia, concerns and issues that had been raised in sociopolitical platforms in the time prior to and of the passage of the ADA (Americans with Disabilities Act, 1990). Literature and Cultural Studies departments taking up disability studies did not come as a surprise given how intertwined gender studies, queer studies and critical race studies were with the critical study of the English literary canon. English and Cultural Studies departments had become a fountainhead for debates, discussion and research on different social justice matters. With the emergence of postcolonial studies and critical race theory alongside the feminist discourse, Literature with a capital 'L' learnt to reinvent itself continually and has persistently interrogated its canon/s. Literary disability studies only extended this continual rethinking of the discipline by introducing a critical investigations of normality, stability and able-bodiedness.

Two books that consolidated this inaugural moment of disability pedagogy in the United States were Lennard Davis's *Enforcing Normalcy* 1995 and Rosemary Garland-Thomson's *Extraordinary Bodies* in 1997. A significant commitment of these scholars was to 'examine the constructed nature of concepts like "normalcy" and defamiliarize them' (Davis 1999, p. 504). Since the mid-90s, literary disability studies in Anglo-American contexts have been galvanized by the proliferation of book volume series such as the initiative of the University of Michigan Press, 'Corporealities: Discourses of Disability' and journals such as *Journal of Literary and Cultural Disability Studies*. As this sub-field of disability studies comes into its own globally, and particularly in the English-speaking world, the present paper presents a view of what the field has brought to the Indian context.

The postcolonial locale of English literary studies in India has enabled literary disability studies to proceed critically and with caution by identifying insights of disability theory as predominantly Western in nature. While engaging with disability studies' critique of the English literary canon, emphasis has been placed on also distinguishing the Orientalizing nature of these texts. Scholars such as Barker (2011) have critically analysed the use of disability as a trope in postcolonial writing such as that of Salman Rushdie and Bapsi Sidhwa to render perspicuous certain insights about sociocultural contexts and the ways in which they respond to disability metaphorically and materially. Culturally located values that ground disability theorizing in the West have to be distinguished from values attached to disablement in South Asian contexts. Another significant contribution to Indian literary disability studies may be found in the work of Hemachandran Karah's philosophical discernment of 'blind culture' in relation to the life-writing of Ved Mehta, a blind writer of Indian origin. Karah's work on 'blind culture' (2012) explores aspects of blindness and sightedness, not in material terms, but as epistemic and narrative frames in our ways of going about the world. More recently, Someshwar Sati and G. J. V Prasad have edited a volume of essays on disability and translation (2019), following a workshop that brought together translators and academics working in different modern Indian languages to explore and theorize translation of disability language, thought and practice. While these are developments that occurred subsequent to the teaching of the two courses outlined in the rest of this chapter, they, it is hoped, serve to map the continuing interest that teachers and students of English literature have had in adopting disability studies approaches for pedagogy and research.

How can we study the emergence of disability conceptually through literary and historical material? Two graduate-level courses were developed and introduced in response to this question within an English literature department in a public university in Hyderabad that traced the genealogy of disability through representations in literary and archival sources. Basic premises that informed these courses were (a) disability as a conceptual category emerges under certain historico-cultural conditions in European-American west; (b) corporeal differences may be conceptualized in keeping with historico-cultural contexts. Adopting a new historicist paradigm, literary sources were studied as evidence of historical shifts and historiography was examined as culturally contingent. The two courses drew considerably on disability studies theoretically and methodologically. The present paper is a reflection on the coursework readings and how they enabled a study of disability and corporeal difference in the nineteenth-century British/European context on the one hand and in contemporary literature and ethnography on the other. While outlining the course material, this paper elaborates on a few texts that became central in each course and explains why these novels assumed such significant positions.

The first of the two courses was one on nineteenth-century fiction, titled 'Monsters, Freaks and Madwomen' which entailed a re-examination of certain classics of English literature from the perspective of disability studies. The class examined the proliferation of short and long fiction written at that time to trace the multiple ways in which abnormality was constituted as monstrosity, freakery, the colonized other, madness, plague, leprosy, ugliness, racial othering, pauperism, destitution, mania and deafness. Drawing extensively on Lennard Davis's work *Enforcing Normalcy* (1995), the course took an interdisciplinary approach in order to examine how science, religion, medical and psychiatric institutions and industrialization constituted a wide variety of abnormal characters in the fiction of that time. The class studied a series of novels ranging from Mary Shelley's *Frankenstein* to Oscar Wilde's *The Picture of Dorian Gray*. While the focus of the course was primarily on the literary-historical development of three figures—the monster, the freak and the madwoman—our discussions centred on notions of normalcy and how that concept broadened or narrowed through the nineteenth century in different temporal, spatial and circumstantial contexts.

Our primary monster figure was Frankenstein's Monster (Shelley 2008) who emerges in the literary canon as a scientific category and not so much a fantastic one. The concept of monster invoked in this novel is descriptive rather than evaluative. Monstrosity, at that time in European epistemology, was a medical category used to describe any kind of excess in the body, lack of body parts or organs and the displacement of body parts or organs. Frankenstein's monster, we are told, is 'of gigantic stature', has 'superior height' and extraordinarily supple joints. In the course of our classroom discussions, we also reflected on the context-specific emergence of monstrosity as a pre-modern category in the European West, harking back to Aristotle's descriptions of monsters,[2] Calvinistic theology of the elect and the reprobate as well as Montaigne's commentary on monstrousness.[3] Monstrosity, however, was not able to dispense with its moral-religious underpinnings though it earned the modern and secular guise of a medical-scientific category. Michel Foucault's lectures (2004) on the proliferation of monsters and monstrous figures through medieval and early modern France helped us in seeing how the human monster conceptually mutates from a juridico-biological category to a juridico-moral one. In the earlier category, the monster was defined and described in terms of the biological differences and later it is the behaviour that determines what a human monster is. For instance, in the case of the 'hermaphrodite' or a person who was biologically male and female and was regularly categorized as a 'human monster', there is a change in the determinants from the seventeenth to eighteenth century. According to Foucault, the 'hermaphrodite' continues to be categorized as a 'human monster' into the nineteenth century but the concept of monstrosity undergoes certain changes. It is determined by the actions or behaviour of the person at one point and not only by the biological aspects. The extent to which they remained faithful to the sex that they had chosen to belong to determined their monstrousness. And at a later point, the abnormality or monstrosity was determined by the person, who has chosen to be a particular sex, having sexual relations with a person of that same sex.

The inherently moral conceptualization of monstrosity became more apparent as we worked our way through the nineteenth century with Victor Hugo's Quasimodo, R. L. Stevenson's Edward Hyde, Emily Bronte's Heathcliff and Oscar Wilde's Dorian Gray. Hugo and Shelley appear to use the more scientized category of monstrosity in

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[2] In Aristotle's treatise titled 'Of Monsters and Monstrous Births' he speculates whether or not a monster is to be considered a 'beast' and whether monstrous beings have 'reasonable souls' (http://www.egs.edu/library/aristotle/articles/the-works-of-aristotle-the-famous-philosopher-containing-his-complete-masterpiece-and-family-physician-his-experienced-midwife-his-book-of-problems-and-his-remarks-on-physiognomy/part-ibook-i/chapter-vof-monsters-and-monstrous-births-and-the-several-reasons-thereof-according-to-the-opinio/).

[3] Montaigne, Michel de. 'Of a monstrous child'. Trans. Charles Cotton. 1580. *Quotidiana.* Ed. Patrick Madden. 22 Sep 2006. 19 Aug 2015 http://essays.quotidiana.org/montaigne/monstrous_child/.

keeping with Claude Frollo's thirst for non-religious knowledge and Viktor Frankenstein's scientific research, respectively. With Stevenson, Bronte and Wilde, the words 'monstrous' and 'monstrosity' are put to work chiefly as evaluative categories, they work metaphorically, emphasizing or invoking more archaic and moralistic applications of the terms. The term monstrous, through these texts, changes from a word that is used to describe the bodies of human beings to a word that describes actions of human beings, actions that were inappropriate, immoral or illegal. Foucault's genealogy of the concept of monstrosity and its shifts from the biological to the moral were evident in the shifts from Frankenstien's monster and Quasimodo to Mr. Hyde and Dorian Gray. These shifts or mutations seemed to be constituted linguistically if when one observed how Mr. Hyde's and Dorian Gray's behaviour in relation to society is termed 'monstrous' (Wilde and Bristow 2008).

Moving on to the figure of the freak, the class took as its prototype, Hugo's hunchbacked bell-ringer, Quasimodo. And Quasimodo enabled us to study another aspect of the etymology of the word monster which is 'that which is stared at'. The Festival of Fools in Paris, an event described in the novel, where Quasimodo is launched into public recognition as the 'king of fools' presented the class with the opportunity to deliberate on the history of the freak show and the circus sideshow as spaces of entertainment that objectified the body of excesses or the monstrous body as ones that were configured and maintained as 'abnormal' primarily within the visual field. When we considered the history of madness, simultaneously, we found that madness was a category that was construed based on visible behaviour as well; if people displayed behaviour that was not meant to be viewed publicly, they were classified mad.

We traced the Festival of Fools, an event that coincided with a religious festival in fifteenth-century Europe through to the time of P. T. Barnum's circuses and sideshows that had become popular in America in the nineteenth century. We took this opportunity to dwell on two iconic figures who were already subjects of cultural theory and criticism, the Elephant Man and the Hottentot Venus. Joseph Merrick or the Elephant Man's thoughts and experiences were studied in class as part of the discussion on social stigma experienced by a person identified as monstrous or freakish, as evidence of what we now call 'the experience of disablement'. Merrick was aware of why he was being exhibited for public view but relented because it was his only means to an income. He also relented to being the subject of medical examinations. Saartjie Baartman or the Hottentot Venus who has already been theorized from a feminist perspective and from a postcolonial perspective was, in the course, considered from within a disability studies framework of staring. At this point, our class discussion centred on the intersections between feminist theory and disability theory where the woman's body could be regarded as being **othered** on the basis of its being an entity of biological excesses, monstrous, in a sense. We also examined the intersections between postcolonial theory as well as disability theory—the Hottentot Venus is a result of simultaneous **othering** caused by the Orientalizing gaze as well as the normalizing gaze. Orientalism is also based on the characterization of the Oriental body as a body of excesses, monstrousness, in another sense. To return to a description of Quasimodo from the English translation published by Penguin, according to Jehan Frollo, Quasimodo is ‘a rare specimen of Oriental architecture, with a back like a dome, and legs like twisted columns!’. Within disability theory, the objectifying gaze has been linked to the staring that disabled people are subject to in everyday life. While Fiedler (1978) has investigated freakery within a cultural studies framework, Garland-Thompson (1996) has written extensively on the enfreakment of disabled bodies in contemporary urban spaces.

While on the subjects of freakery and staring, the class was introduced to other theories of the social gaze, which include the philosopher, Raymond Geuss’s explication of tacit law of ‘disattendability’ (2001). Guess’s work helped us think about the social production of disability as an involuntary kind of violation of the tacit law of ‘disattendability’. Guess gave us a way of thinking of how Western society practices the tacit principle of civil inattention, or, of not attending to certain actions performed by people and of not, usually, committing certain actions in public presence. According to Guess, absence of body parts or epileptic seizures in a person belongs to that involuntary group of violations of disattendability. His larger focus is on how notions of what is and can be public or private are created by certain tacit practices in the human world and related to the concept of shame. Looking and not looking, worthy of being looked at and not worthy of being looked at, notions of public and private, all these in different combinations constitute and maintain figures of the monster, the freak and the madwoman.

Moving from ocularcentric approaches of defining corporeality to significances attached to the aural and oral, we debated Quasimodo’s deafness. There is a moment in the novel when Quasimodo, the deaf bell-ringer, considers his deafness to be the most debilitating aspect of his personality, thus letting his sensory impairment take primacy over his hunchbacked and facial disfigurement. Using Martha Rose’s work (2003) on the contingency of the concept of disability in Greek antiquity, we were able to reflect on the changing contours of disability over the ages in Europe, as well as the changing contours of specific disabilities across temporal and cultural contexts. For instance, a deaf person within the context of Greek antiquity would have been considered mentally deficient as practices of teaching and learning, in that context, were primarily oral. So, a person who was deaf was not considered under the category of deafness but as belonging to the category of intellectual disability. This conception, we agreed, seemed still to be in place, fifteenth-century notions of deafness, if we were to go by Victor Hugo’s characterization of the middle ages. To quote from the abridged version put out by Bantam Classics, translated by Lowell Bair:

> Quasimodo was born one-eyed, hunchbacked and lame; it was only with great difficulty and great patience that Claude Frollo succeeded in teaching him to speak. But an evil fate pursued the poor foundling. Having become the bellringer of the cathedral at the age of fourteen, a new infirmity came to complete his misfortune: the sound of the bells broke his eardrums and he became deaf. The only door which nature had left wide open between him and the world was suddenly closed forever (Hugo 1981:61).

Or, one could argue that Hugo’s portrayal is closer to the eighteenth century’s conceptualization of deafness as pre-eminently a sensory disability. Lennard Davis, a disability studies scholar, whose work is predominantly focused on studies of the novel in English, in his book *Enforcing Normalcy* (1995) shows us how the eighteenth century was an age that was obsessed with deafness. Deafness was regarded as an impairment that deterred language, as language was identified as predominantly oral–aural in form. The primacy given to deafness as disability opened up intellectual debates centred on questions such as

- Is thought prior to language?
- Can a being be human without language?

The obsession with deafness, in that time, was channelized into ways of making deaf people civil and making deaf people citizens. It was the era of the development of Sign Language and the establishment of deaf schools all over Europe, thus making 'deaf' an educable and therefore manageable category. Davis also points out how reading, as an activity, came to be consolidated, at the same time. The novel emerged as a prominent genre and text began to manifest itself as language, a language that used non-verbal sign. It was also the time when European society discovered textual forms as forms of cultural expression and moved away from the performative arts.

The class proceeded to reflect on how Quasimodo would be configured in the light of contemporary knowledge systems. Quasimodo, today, would probably fit the category, 'person with multiple disabilities', as someone who has hearing impairment, an orthopaedic disability as well as facial disfigurement. In the twentieth century, a little prior to the present, he would most likely have been identified as a person with mental illness, the reason being that the most prominent aspect of his personality was his distress caused by trauma he faced by virtue of his isolated existence in the bell tower of the cathedral. The nineteenth century, the period when the novel was published, most likely dwelt on his hunchbacked, a condition called kyphosis, if we take into account the fact that the English title of Hugo's book emphasizes that aspect of his personality. Eighteenth-century Europe would have primarily identified him as deaf and the seventeenth century may have concentrated on his one-eyedness or his facial disfigurement. This kind of a conjecture brought into sharp focus the relationship between cultural context, knowledge development and corporeality. Using this triad as a basic frame, we were able to take a Saidian view of the European West as a context that consistently produced notions of the body in terms of concepts that are inherently evaluative and peculiar to its epistemic frames.

Ian Hacking's work (1995) helped us analyse specific factors that prioritize a particular corporeal condition at a particular time as well as the factors that contribute to the construction of a category of disability or illness. He describes the fascination with multiple personality disorder at a particular time in the twentieth century which included a process whereby the soul was scientized. Also, the social careers of medical diagnostic categories show that these are what Hacking calls interactive kinds—they are not static or natural kinds, and people classified by them are affected by and interact with the classification. This interaction with the classification, in turn, impacts the discipline or institution that classifies them as such. Madness served as a good illustration here, taking into account the severe backlash faced by psychiatric institutions and authorities on psychiatric diagnoses such as the Diagnostic and Statistical Manual of Mental Disorders, at the hands of psychiatric survivors in Europe and America during the anti-psychiatric movement. Hacking helped to understand how the popularity or fascination a particular condition attracts at one point of time, also fades sooner or later. Multiple personalities vanished from the limelight of public discourse after the world was gripped by the *Sybil* craze for a few decades and this had everything to do with changes in objects of knowledge and shifts in fundamental conceptual frames.

Most of all, the nineteenth-century canon placed before us the pervasiveness of the abnormal–normal dynamic that underlines all notions of corporeality that emerge from the European cultural context. Measures of the body such as height, weight, skin colour, to name only a few are all evaluative and moral categories thus producing the very idea of corporeality in the context of the West as a moralized domain. Normalcy, intrinsically linked to notions of beauty and moral action, produces its other as monstrosity and madness. This left us, at the end of the course, with doubts about the universality of the concept disability, as well as abnormality, forcing us to investigate further whether the abnormal–normal dynamic as a way of knowing the body or as a way of conceptualizing corporeality was peculiar to the context of Europe as a cultural site.

The second course titled *In Different Bodies* (IDF) focused on contemporary fiction while taking an anthropological approach to conceptualizing body/mind and corporeality. Pursuing the contextual understanding of abnormality that was begun in the previous course, this one engaged different notions of corporeality with an emphasis on cultural context. This course also grew out of reflections on the first course that suggested that the study of abnormality and disability also required us to take into account notions of corporeality itself. If abnormality has links to disability within disability studies theorizing in the West then what would a genealogy of disability in different cultural contexts reveal. It seemed appropriate to consider different cultural contexts and the notions of bodies and bodily difference that were in circulation in these contexts. An important aim was to remain alert to processes of transfer of knowledge and concepts that occurred through intercultural encounters such as colonization. This course was keen on engaging with epistemic paradigms and how corporeality as well as embodiment was determined by the framing of culturally specific ways of knowing and engaging with bodies and bodily differences.

The first set of contexts explored were contemporary practices in boxing and wrestling and how professionals in these fields conceptualize their bodies. The specific locations were sites of boxing in the inner cities in the USA and sites of wrestling in small towns in India. Drawing on the works of social anthropologists Loic Wacquant and Joseph Alter, the class studied bodily metaphors and bodily discipline in these sites. Wacquant's ethnography[4] of south-side Chicago in a predominantly Black community of professional boxers showed rigour attached to practising one's body as 'weapon' and 'machine'. Wacquant refers to these metaphors as the corporeal recognition that the boxers had of their occupational praxis. A major way in which the pugilists in this context spoke of their bodies was in terms of 'sacrifice'. Sacrifice, in this context, entailed eating right and giving up women. The latter was

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[4] His book is titled *Body and Soul: Notebooks of an apprentice boxer.*

understood as a way of economizing on emotional energies as well as a way of ceasing and desisting from sexual intercourse (Wacquant 2004). The act of sex was thought of as an activity that made the pugilist weak, that which ‘drains their legs’, ‘takes away their “snap”’, ‘messes their mind’ and ‘makes them soft’. The ethnography unsettled popular understandings of boxing as a violent and wasteful sport. It also underlined how the long involvement of minority ethnic groups constituted the history of professional boxing in the US. The work also revealed how taking care of one’s body formed a major part of the rhetoric with specific focus on one’s arms. The aspect of taking care of one’s looks and body, which in popular discourse had associations with normative femininity, was conceived in this overt articulation as a way of ‘protecting the body’ (Wacquant 2004).

In a similar vein, a selective reading of Joseph Alter’s book, *The Wrestler’s Body: Identity and ideology in North India* brought attention to notions of corporeality prevalent among wrestlers who practise ‘*Kushti*’, a form that combines ‘*mallayudha*’ or wrestling combat and *pahalwani* which is an ideological and ethical practice of the self that is structured in terms of somatic principles. In this case, wrestling is a form of life that includes prescriptions of physical culture, diet, health, ethics and morality. The understanding of the body within the community of wrestlers was one of presentation of the self and as a system of ‘physical culture and health’ (Alter 1992). Wrestling was thought of as a healthy practice but one that also included rituals of restraint in diet and sex. Just as boxing, wrestling was not only conceptualized as a practice of bodily ethics but also involved a strong sense of controlling one’s body by controlling one’s mind and vice versa.

The next aspect we examined was amputation of limbs as well as ageing and the associations they have in different contexts using the novel *Slow Man* (2006) by J. M. Coetzee as well as a short story by Anand titled ‘The Lost Limb’ (2002). While analysing these literary texts we also read Lawrence Cohen’s ethnography on ageing in Benaras (1998) as well V. S. Ramachandran, the neuroscientist’s explication of phantom limbs in amputees (Ramachandran and Blakslee 1998). Coetzee’s novel is about an ageing expat in Australia whose leg is amputated after a road accident. The accident and its result make the protagonist to experience himself for the first time in terms of a family. Paul Rayment, with the loss of his limb, comes face to face with himself as a failed family man. His encounters with his caregiver’s family members make him realize that he wants a son and a wife and that cyclical interdependence of love, conflict and fractured resolution that only a family can bring. We analysed this through Cohen’s notion of the ‘familial body’ (1998). The ageing person was assessed by neighbours and friends by an examination of the voice of the elderly person and whether he or she was ‘hot-brained’ or had a *garam dimag*. If the person was hot-brained and complained about their family then that person’s body demonstrated their presence in a bad family where the children were not taking good care of their elderly. Cohen’s most significant finding was that ageing in his field of study in India was conceptualized in terms of affect and not in terms of cognition as it was in the West. And this resulted in a situation in which the diagnosis of Alzheimer’s was almost absent.

To return to what the study of *Slow Man* brought to the classroom, it would be important to examine the novel in the context of David Mitchell's notion of 'narrative prosthesis'. According to David Mitchell, most often the narrative structure that prostheticizes the disabled character runs thus: the deviance is first presented to the reader; the narrative creates the context for an explanation to be proffered for the deviance; the deviance of the character is brought to the centre of the plot to come; fourth, the rest of the story aims at rehabilitating or restoring the deviance in some way and may often obliterate the difference or deviance 'through a cure, the rescue of the despised object from social censure, the extermination of the deviant as a purification of the social body, or the revaluation of an alternative mode of experience' (20).

In *Slow Man*, the moment when Elizabeth Costello, the writer, is crafting an encounter between the amputee Paul Rayment and the blind Marianna is important to examine closely. Rayment has lost his leg due to an accident and Marianna has lost vision in both eyes because of a tumour. Elizabeth Costello explains to Paul:

> Since her surgery, her extremely delicate surgery, quite unlike the gross butchery of amputation, she has become morbidly scrupulous about cleanliness, about the way she smells. That happens with some blind people. You had better be clean for her too. If I speak crudely, forgive me. Wash yourself well. Wash everywhere. And put away that sad face. Losing a leg is not a tragedy. On the contrary, losing a leg is comic. Losing any part of the body that sticks out is comic. Otherwise we would not have so many jokes on the subject. There was an old man with one leg/Who stood with his hat out to beg. And so forth. (*SM* 99)

Costello's narrative performs multiple roles. She assumes the role of the informed narrator who tells the curious Paul and the curious reader what the difference is between a surgery that is done to remove an eye and one that is performed to amputate a leg. Second, she comments on the persistent presence of characters with amputated legs in literature and dismisses the characterization of that limb loss as a tragedy, thus in one blow excising the tragedy of characters like Ahab[5] and transporting them to the genre of comedy, drawing attention to the emasculating innuendo attached to the loss of a leg. Costello's comments while serving as metafiction may be considered as Coetzee's repeated attempt to critique the very trope of disability representation that his work seems to be participating in. There is little doubt that Paul Rayment may as well be pitied in that typically tragic way by the other characters that populate the novel as well as the readers but their pity is quickly criticized by the narrative that follows.

In another moment in the novel, Paul Rayment chastises Elizabeth Costello for the way she has forced Marianna and him to be sexual partners or romantic partners because of their impairments:

> You treat everyone like a puppet. You make up stories and bully us into playing them out for you. You should open a puppet theatre, or a zoo. There must be plenty of old zoos for

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[5] Ahab, the protagonist in Herman Melville's *Moby Dick*, is considered one of the most tragic characters of all time because of his overarching need to find the whale that had deprived him of his leg. He co-opts a commercial whaling voyage to become a voyage of revenge in search of Moby Dick the whale, which consequently costs the lives of all on board the ship. The loss of Ahab's leg has been severally equated with his loss of manhood and a loss of mental stability.

> sale, not that they have fallen out of fashion. Buy one, and put us in cages with our names on them. *Paul Rayment: canis infelix.*[6] *Marianna Popova: pseudocaeca (migratory).* And so forth. Rows and rows of cages holding the people who have, as you put it, come to you in the course of your career as a liar and fabulator. You could charge admission. You could make a living out of it. Parents could bring their children at weekends to gawp at us and throw peanuts. Easier than writing books that no one reads. (*SM* 117)

And then he says,

> "…what I don't understand is, seeing that I am so dull, so unresponsive to your schemes, why you persist with me. Drop me, I beseech you, let me get on with my life. Write about this blind Marianna of yours instead. She has more potential than I will ever have. I am not a hero, Mrs. Costello. Losing a leg does not qualify one for a dramatic role. Losing a leg is neither tragic nor comic, just unfortunate. (*SM* 117)

The first comment of Paul's interrogates and dismantles the voyeuristic gaze of the writer and the reader by characterizing it as the gaze that is invited to a freak show,[7] of course, Coetzee uses the analogy of the zoo. It is a commentary on numerous writers, part of the canon, who have made a name out of presenting disabled characters as objects of sympathy, repulsion and ridicule, to be examined, pitied, feared and objectified in many ways for the benefit of the author's tragic and comic excellence—Sophocles, Shakespeare, Maugham, Melville, Mary Shelley, Dickens, Hugo, Emily Bronte, Charlotte Bronte, to name only a few.

Paul's last comment on losing a leg being 'just unfortunate' could be read as an allusion to Coetzee's own enduring interest in the experience of disability. *Slow Man*, the novel, clearly presents Paul's loss of leg as an unfortunate occurrence; there is no doubt about it. But it does not shy away from sustaining the writer's or the readers' attention from that experience. We see Paul going through a variety of reflections and everyday experiences that are part and parcel of the life of a person with a disability, where the disability has been acquired through a violent accident. His yearning for a family that is manifested in the way he begins to think about the other Marijana, his caretaker, the disturbing extent to which he wants to be involved in her life as well as the lives of her children just so he can act like he has a family. There is also the sharp and enduring longing for a son that he feels when he interacts with Drago and the way in which he becomes gentle in the presence of Marijana's youngest daughter Ljuba. Besides all of this there is the difficulty of having a fall in the bathroom and not being able to get up, of being in pain from the smarting of the phantom limb and of living through the shame of having urinated on the floor because of not being able to reach the bathroom in time. The narrative brings all of this into sharp focus and does not look away.

While disability activists or those concerned with retrieving positive portrayals of disability, may fault Coetzee for his characterization of disability in *Slow Man* as

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[6] This would translate loosely as 'dog unhappy'.

[7] Freak shows were a common feature of circuses and similar entertainment in the eighteenth and nineteenth centuries and perhaps even earlier in the US and UK where persons with biological oddities were put on display because of their 'abnormal' bodies. The common reactions of the audience included ridicule, awe, disgust, laughter and fear.

reinforcing stereotypes, it would be significant to consider that he presents disability in a context-sensitive manner. The experience of losing a limb is unfortunate in a specific way; it is unfortunate for Paul because of his specific circumstances of being a white male expat who does not have the loving comfort of a family and because he is 60 years old. The narrative that Coetzee provides around disability serves as more than just a prosthetic. The narrative acts as a prosthetic that is self-conscious, reminding us that an important aspect of a prosthetic fitting onto the stump of an arm or a leg is dependent on the level and severity of the experience of the phantom limb. Phantom limb is the experience that an amputee has in the spot where their limb has been severed; the sensation of still having a limb is left behind and this sensation is present as a tingling, an itch and an ache at different times. Coetzee's questioning of the standard tropes of disability representation in his novels is like that tingling that cannot be ignored though a narrative prosthetic has been fitted on the severed limb of the character or the plot. Coetzee's narratives simultaneously critique and expose the fundamentals of the classic genre of tragedy as passed on by generations of writers where the tragic event is often caused by the acquisition of impairment and the experience of disability as causing pity and fear in the audience. Coetzee brings home the fact that literary writing and reading practices have normalized pity and fear as the standard reactions one must have to disabled characters.

This brought us to questions pertaining to the performance of disability in dramatic and filmic forms. Playing a disabled person, across cinematic cultures, in different countries has won actors awards. How would this phenomenon inform our investigation? Staging disability is important because it allows the actor to act like something that he or she is not and something that he or she never dare become. It is the dread of becoming disabled that instils actors, audiences and award adjudicators with the awe that accompanies the performance of blindness, deafness, autism, quadriplegia and mental distress. One could trace this back to Sophocles' tragedy, *Oedipus*, onto Shakespeare's *Richard III*, *King Lear* and *Macbeth* through to the more recent play by Mahesh Dattani, *Tara* and note that disablement has successfully embellished the most theatrical of tragic performances. Aristotle's notion of tragedy as that which causes the audience to feel pity and fear has often been fulfilled through the depiction of disability as fate, as fall from high standing and as vulnerability on stage. What does the portrayal of disability to invoke tragedy on stage and in film enable us to consider? One, we could investigate the sociocultural conceptualization of disability, at least certain disabilities, as leading to tragedy. Two, that disability is often something that is constituted within the visual field (Davis, *EN*). Performing a limp, loss of vision or mental distress is manifested as visible acts that elicit certain responses from onlookers. It causes pity for the character and instils dread of becoming like that character in the onlooker and the audience, leading to catharsis, a cleansing both of the spiritual and the medical or therapeutic variety. With regard to the first case, adopting a disability studies' perspective to study drama, specifically tragedy, has made us critique the very fundamental notions of tragedy and re-evaluate classical ideas about the ontology of tragedy as a literary genre.

We took up the Malayalam writer Anand's translated short story (2002) in which a male amputee in an urban development site remembers the past in the same way as a phantom limb caused itching sensations and pain where the arm was severed. The phantom limb pain in the story serves as a metaphor for unwanted memories that survive and tease the brain. Reading this story alongside Ramachandran's theories of why phantom limb pain occurs and how treatment was discovered for it helped us see how scientific knowledge has generated literary devices and in turn how literary metaphors have adapted themselves into scientific rhetoric and discourse.

As an extension of this formulation of the familial body, we also read two novels, Katherine Dunn's *Geek Love* which is a story about a family of freak show participants, all with genetic anomalies and Firdaus Kanga's fictionalized autobiography *Trying to Grow* (2008). The former novel was read in the context of the freak show or the circus sideshows that were prevalent in nineteenth- and twentieth-century America and helped us to connect back to our study of the Elephant Man in the MFMW course. I must add here that except for three students all others who enrolled for 'In Different Bodies' had also taken MFMW though this was never treated as prerequisite. Firdaus Kanga's narrative offered us the opportunity to think of the idea of the familial body in another way. Kanga, rather Brit, his persona in the novel, has osteogenesis imperfect, what is better known as 'brittle bone syndrome'. As a result, he is of small stature and lightweight so much so that anyone could lift him and carry him around the house. Due to the excessive support he requires for most of his daily life activities, his parents and sister organize their lives around his needs. Their schedules are timed around his requirements and it appears as though his condition is not his alone but theirs as well. What we find in the novel is that the stature that is a result of his impairment makes his family and friends treat Brit as if he were a child, so, lived experience of having brittle bone syndrome was not related to its descriptive name, rather the impairment was conceptualized in terms of its child-likeness.

The novels *Geek Love* and *Trying to Grow* enabled us to examine how disability is adopted for comic effect or how the disability is framed humourously. In Dunn's novel, the parents in the Binewski family design their children to be freaks of different kinds. The situation in the novel is an ironic jibe at how genetic programming works.

We were also able to reflect on the complex issue of care, especially when it comes to caregiving in relation to disabled people who require constant support to perform daily activities. In disabled people's narratives, caregiving has been described as a form of unwanted cloistering or a form of claustrophobic protectionism that curtails informal decision-making power. Though this sentiment is not directly presented in the narrative, the scene in which Brit realizes his status as an individual person, when he looks at his full body in the mirror, is also a moment when his sister has moved away and after his parents have died. There is in a sense a shift that occurs from Brit's conception of himself as a familial body to that of an individual. Another moment in the text that symbolically captures this transition is when the kitchen in the old Colaba apartment is altered and adapted to match his height. Importantly, the moment when Brit appreciates his body for the first time in the mirror is also the time when he is in love and has just had sex with his male partner.

The next set of readings for the course was on 'Descartes, Plato and early Christian history' to comprehend ideas about psyche, soma, body, mind, flesh and so on and consider classical and Christian genealogies of present-day notions of mind and body. The aim here was to comprehend the trajectory of the specific inheritances that concepts like ‘body’ had while also recognizing narratives of embodiment and corporeality that didn’t fit as easily with these notions. We examined differences between the concepts of shame and guilt and how these concepts are related to personhood, selfhood and mind/body elements. In what ways did these notions constitute ideas of body and being? In turn, how did sensory or corporeal aspects compose notions such as guilt and shame? It was instructive to find that notions of guilt were dependent on hearing; the voice from within that one heard which instructed the person to act and speak morally. And shame, it appeared, relied heavily on being seen or on how one’s action was regarded by others in view of a code of ethical action.

The pun implied in the title of this course, ‘indifferent bodies’, was a reference to bodies that are indifferent to concepts such as the body which include a sense of wholeness, completeness and so on. Some of the bodies in these works, such as Brit’s, also seem impervious to the diagnostic labels and descriptive names they go by. The point was to investigate other concepts of corporeality and examine the sociocultural contexts that are native to these conceptualizations. We read a few essays from an anthology of medical anthropology anthology. One was on the Theravada Buddhist conception of human tissue donation which documented how some of these Buddhist beliefs better facilitated post-mortem organ donation which was otherwise a big no-no for other religious contexts (Simpson 2008). As a result, Sri Lanka has become fertile ground for organ transplant. Theravada Buddhism strongly promotes the idea that one becomes spiritually whole by giving away one’s body parts. The ultimate motivation for all forms of giving is the eventual attainment of *nibbāna.* Generosity is aimed at creating merit in the next world for those who give, thereby enabling them to proceed towards higher spiritual challenges. The recipient also stands to benefit spiritually as his or her contentment would form the foundation for an improved society. In all these acts of giving, what is given should not only benefit others but also demonstrate ‘a lack of attachment’ to the self. The notion of ‘self’ operationalized here is entrenched in the action of *giving* rather than in the *possessing* of those body parts; one is not defined by one’s embodiment but by one’s actions.

It would be important to critically engage with methodologies and disciplinary frameworks as we put to work disability studies in schools of humanities and history departments in India. While these disciplines enable teaching of courses like MFMW and IDF they also have the tendency to be restrictive. To take the instance of the work of the Ugandan anthropologist, Oyeronke Oyewumi (1998), she finds that methodological features inherent in the writing of history or in historicizing render what gender is or how the Yoruba world is gendered, the focus of her inquiry, obscure. History genders roles in the Yoruba context when in fact within that conceptualization, gender roles are not determined on the basis of biological features; the relation that we know as ‘wife’ does not necessarily index woman. Taking our cue from Oyewumi’s critique of history, we could nudge further the study of disablement within a genealogical frame so that we may be able to think of disability as a placeholder category than a known object. What these studies within the humanities have found is that we don’t know what our object is. This of course does not mean that there is no disability in the Indian context but that we still haven’t found a way of theorizing or using all the different experiences and concepts that cannot quite adequately be apprehended by the category disability.

A significant aspect of the task of teaching and researching disability studies critically in the humanities is to make explicit the idea that one is not looking for a new object called disability in the primary sources and cultural material one is working with but learning and trying to find **new ways of knowing** embodiments that are already part of our world. The aim is to theorize what is present in these materials in the light of the emergence of a field of study called disability studies.

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Part II
Policy and Institutionalisation

Chapter 7
Service and Knowledge: The Emergence of Disability Studies Extension

Tanmoy Bhattacharya

Abstract One of the issues confronting higher education in India is iniquitous access for different social groups. Among the prominent disparities leading to inequity in higher education participation, disability does not figure in the collective consciousness of various institutions. In this context, I will propose that a clear delineation between the role and function of Enabling Units and Disability Studies Centres must be understood and respected since the genesis of the two ideas, namely, service and knowledge, traditionally follows different routes to achieve a common goal, that of improving the status of persons with disabilities in the society. However, an overlap in the nature of the products of the sectors is unavoidable and in fact not entirely unwelcome if disability studies were to act as the 'theoretical arm' of the disability rights movement. However, this ultimate situation need not obfuscate the difference in the origins of paths taken. Apart from seeking clarity of purpose in policy documents, this chapter importantly raises the question of the contribution of knowledge to service (and vice versa) and proposes the notion of a subfield 'Disability Studies Extension', a thorough understanding of the nature of which is essential for identifying either service or knowledge.

Keywords Disability studies · Equal opportunity · Higher education · Well-being · Oral history

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This is a revised version of a presentation titled 'Service and Knowledge: The Role of Disability in Higher Education' made at the 'Disability Studies in India: Reflections on Future' conference, 6–7 February 2015, held at Jawaharlal Nehru University, New Delhi. Parts of sections 1–3 of the present paper constitute a modified version of my submission to the University Grants Commission, New Delhi, as a convenor of the Expert Committee entitled on 'Review and Revise the Rules, Schemes and Provisions concerning the Disabled Students and Teachers' (July 2012–July 2014). Although there have been some changes since 2015, with a change in the central government, in the relevant policies (especially with the passing of *The Rights of Persons with Disabilities Act, 2016*, which was in making since at least 2012 during the previous Congress government regime), the ground realities have hardly altered—and in fact have become starker due to more elusive policy instruments, making all the arguments presented retain their relevance.

T. Bhattacharya (✉)
Department of Linguistics, University of Delhi, New Delhi, Delhi, India
e-mail: tanmoy1@gmail.com

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Introduction

Discrimination on the basis of caste, ethnicity, race, religion, gender, etc. leads to exclusion at various levels in society. Such exclusionary practices are systematic and directed against both individuals and groups. In our part of the world such stories of social exclusion are encountered daily at both individual, anecdotal and national narrative levels, the extent of oppression, and therefore exclusion, differing only across regions, groups and cultures. Negative attitude and belief against a group/individual leads to prejudice and stereotyping, but discrimination is negative behaviour towards a particular group/individual resulting in denial of rightful services and entitlements. The terms exclusion and discrimination may mean slightly different things but their effects are similar (Thorat and Lee 2006). Five of the most common forms of discrimination the world over are (i) unequal recognition before the law; (ii) unequal education; (iii) unequal employment; (iv) unequal freedom of movement; and (v) lack of transportation (Shapiro 1999). It is hardly surprising therefore to find that persons with disabilities are discriminated against in exactly these areas.

One of the issues confronting higher education (HE) in India, for example, as per University Grants Commission's (UGC) XI Plan (UGC January 2011b),[1] is iniquitous access for different social groups. Among the prominent disparities leading to inequity in higher education participation are rural–urban, interstate, inter-caste, inter-religious group, gender, occupation, and poor–non-poor. It is therefore but expected that even a plan document misses out on disability and thus no mention can be found of the other, obvious dyad of disparity, namely, 'abled–disabled' in line with the marginalised dyads.

The NITI-Aayog was established in January 2015 replacing the Planning Commission by the new government that came to power in 2014. As part of the so-called Sustainable Development Goals, one of the NITI-Aayog goals, Goal 10, is to reduce inequalities within and among countries, which makes gestures towards reducing inequality from the perspective of disability. Though the discourse on the surface has thus changed, there is no report or study to show that there is any change in the ground realities.

As will be pointed out soon, various schemes and provisions that by definition should ideally include disability within their ambit do not do so, leaving persons with disabilities without the benefit of availing such schemes or enjoying the provisions. It will also be pointed out, that this is not by design, going by the history of *accidentally* bypassing the disability agenda world over across a variety of sectors and provisions; in other words, disability simply does not figure in the collective consciousness of even well-meaning group of bodies.

In this paper, I will show that the process of policy formation at the national level is much to blame. More specifically, with reference to policies on disability in higher education, I will propose that a clear delineation between the role and function of two

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[1] However, the XII Plan (duration 2012–2017) did have a detailed mention of disability in chapters on education and social inclusion and had Articles 24.210 to 24.226 devoted solely to disability.

bodies, namely, enabling units and disability studies centres, must be understood and respected, not only to overcome unnecessary overlap of functions, thereby ensuring proper utilisation of funds, but also because the genesis of the two ideas, namely, service and knowledge, though meant to achieve a common goal, that of improving the status of person with disabilities in the society, traditionally follow different routes to that goal.

In keeping with this line of thought, the present paper is strongly guided by the principle that Enabling Units must solely devote to the Services philosophy, to the extent that such services lead to generation of knowledge, especially in the building up of databases, leaving the space for interaction with agencies solely devoted to the Knowledge philosophy to disability studies centres. This proposal is further discussed in detail in section "Service and Knowledge Through Disability Studies Extension".

In the first half of the paper, that is, sections "Strategies to Address Inequity in HE" and "Disability Studies Centres (DSCs)", I suggest that to ensure initiation of a Disability Studies (DS) programme and research in HE in the country, a two-pronged strategy of (i) strengthening the existing UGC schemes/infrastructure and (ii) proposing new schemes is required. As a background to this suggestion, I will take up one of the older plan documents, namely, the 12th Five Year Plan (UGC 2011c), for the purpose of illustration. It will be shown that among the three objectives of access and expansion, equity and inclusion, and quality and excellence outlined as priority areas for increasing access to HE, a consolidation of the existing schemes and proposing of newer ones in the last two of these areas will considerably alter the higher educational possibilities informed by a disability perspective.

Genesis of the Existing Schemes

Inequity in HE

Inequity in HE has been a concern, and UGC and Planning Commission—and by extension, the present NITI-Aayog—have had specific recommendations to improve the situation. For example, among the various recommendations made by the Planning Commission, there were a few that were directed towards improving the quality in HE. Under quality improvement, one of the schemes that was suggested in the X Plan (2002–2007) was the 'Innovative Programmes' which encourages new ideas, courses, etc. in interdisciplinary and emerging fields, that among other things, influences societal growth. Disability studies being clearly an interdisciplinary field of studies—and emerging—it should find a natural home within this scheme. However, the programme was discontinued through a notice dated 27 June 2013 by the UGC.

NITI-Aayog, which replaced the Planning Commission, has provided very little cheer to the disability sector, and in fact, as a result of often ambiguous and unclear framing of objectives, has made evaluating and critiquing the various strands difficult. In addition, if we look at the list of initiatives taken by the NITI-Aayog so far, there is nothing that comes within the purview of disability, except in one of the so-called 'verticals'—social justice and empowerment (SJ&E)—which is a nodal division of the Ministry of Social Justice and Empowerment, Ministries of Tribal Affairs and Minority Affairs.

Within SJ&E, if we look at the achievements reported for the years 2017–18 and 2018–19, the concern for the disability sector is dismal. An analysis of the total achievements for these two periods showed that disability-related proposals figure in only one of the broad sub-areas listed under achievement, namely, SFC and EFC, that is, Standing Finance Committee and Expenditure Finance Committee memorandums to be taken note of by the nodal ministries. For both the periods, a total of 4 EFCs/SFCs each out of a total of 51 and 47 items listed under achievement for each year, respectively, are listed that have anything to do with disability; this makes the percentage a mere 8%. This is a very poor scale by any standard, and especially for a government that has made very loud announcements for various schemes throughout its tenure so far and have even given a new name to the community of disabled people with a lot of fanfare and publicity (Bhattacharya 2016a, 2017).

Strategies to Address Inequity in HE

From the preceding discussion, it becomes clear that the newer ways of policy documentation (where there are in fact very few actual policy 'documents' but very flashy websites with ultramodern terminology, like 'tinkering labs', 'incubation centre' and 'ideation', as in NITI-Aayog) is a clever way of abdicating responsibilities and commitments to the disability sector. For this reason, I will take up for illustration the various other schemes in the past policies where a DS component or essential thrust area could have easily come under their ambit. Like the *Innovative Programme* scheme (see section "Centres for Study of Social Exclusion and Inclusion Policy (CSSEIP)"), there were at least three other UGC schemes that offered this opportunity:

(i) Centres for Study of Social Exclusion and Inclusion Policy (CSSEIP),
(ii) Human rights and
(iii) CPEP.

Each of these will be discussed in turn.

Centres for Study of Social Exclusion and Inclusion Policy (CSSEIP)

This scheme falls within the area of value-based education that was emphasised in the XI Plan (2007–2012) in order to instil values of equity, justice, human rights and social inclusiveness in the learners; it was proposed as part of the XII Plan (2012–2017) guidelines. To support research on the issue of Social Exclusion and inclusion which has theoretical as well as policy importance, the UGC had established teaching-cum-research centres in universities called 'Centres for Study of Social Exclusion and Inclusion Policy'. By March 2011, 35 centres were functioning in 35 universities. During 2010–11, a total grant of Rs. 3.41 crores (34.1 Million) was provided to eight centres.

The motivation behind setting up such centres is the belief that social exclusion encourages inequality and deprivation in society, apart from generating violence, tension and disruption. It is understood that Scheduled Caste (SC), Scheduled Tribe (ST) and religious minorities experience systemic exclusion in all spheres. It was felt that the institutions of higher learning need to address this issue.

It is very instructive to look at the objectives of these centres as mandated by the UGC:

- Conceptualising discrimination, exclusion and inclusion based on caste/ethnicity and/or religion.
- Developing understanding of the nature and dynamics of discrimination and exclusion.
- Contextualising and problematizing discrimination, exclusion and inclusion.
- Developing an understanding of discrimination at an empirical level.
- Formulating policies for protecting the rights of these groups and eradicating the problem of exclusion and discrimination.

It is very clear that each one of these objectives also apply equally strongly to persons with disabilities, sometimes differing in terms of the tools of oppression, but historically the groups are subjected to similar oppression. The realisation that persons with disabilities constitute another such socially excluded and, therefore by definition, an oppressed class, came slowly in the history of ideas and various movements. The sociopolitical upheavals the world over in the late 60s, and early 70s also saw the beginning of a rights-based movement within this sector. If we understand that feminism as a movement is naturally sympathetic to oppressed classes of the society, it is surprising to see that the movement did not consider the problems and issues of women with disabilities for a long time. It is not very surprising then to see disability not included in most of the schemes of the government in spite of this obvious connection. CSSEIP similarly does not include persons with disabilities as a group that should automatically have been a part of such a scheme.

Similarly, if we take an excursion on a current equivalent of this point, yet another 'vertical' of the NITI-Aayog that deals with some aspect of disability is the Human Resources Development (HRD) vertical which is a nodal division of the Ministry of HRD. Among the four areas that come under this vertical's cover is area (c): areas of special focus such as education for girls, Scheduled Castes, Scheduled Tribes, Minorities and also *Children with Special Needs* (italics mine).

It is also crucial to mention in the context of our discussion here (that is of the current updates of the Plan policies) that 'during 2018–19, the HRD vertical actually participated in activities related to 12th Plan schemes'[2]. This makes the comparison of the Plan schemes and their current updates relevant and instructive.

As far as achievements of this vertical are concerned, not surprisingly, there is no mention of any disability-related issues in either of the 2017–18 or 2018–19 reports. Thus, exactly as the analysis in this section shows, in spite of obvious connections to disability (and in this particular case, in spite of literally stating that the HRD vertical covers among other areas the area of children with special needs), concerns of disability are simply bypassed.

In my analysis of the then current situation in my submission in 2012 to the UGC (see introductory note) with respect to a representative sample of the 35 existing centres, set up under the XII Plan, reveals that although 30% of them had a disability-related objective, none of them had any research output, activity (seminar, conferences, workshops and special lectures) or degrees in disability. Only one of them had a research associate specialising in a disability-related field. Thus, although disability falls within the ambit of social exclusion in almost exactly the same lines as other forms of exclusion, disability as a sector/oppressed group is simply forgotten/bypassed in this context of higher education.

In a notice dated 18 October 2017 by the UGC, CSSEIP scheme was extended up to 30 March 2019; it is not clear what the current status of the centres in different universities is.

Human Rights and Value Education (HRVE)

In order to promote human rights teaching and research at all levels of education, UGC prepared a blueprint in 1985, which contained proposals for restructuring of existing syllabi, and the introduction of new courses and/or foundation courses in human rights. Introduction of undergraduate, postgraduate degrees/diplomas and certificate courses, as well as holding seminars, symposia and workshops on Human Rights and Duties Education, was encouraged with the goal of spreading awareness among the teachers, students and public. During 2010–11, 493 proposals from universities and colleges were approved by the Commission on the recommendations of the Expert Committee. An amount of Rs. 7.58 crores (75.8 million) was released to the Universities and Colleges during the year.

This scheme had two components: (i) Human Rights and Values in Education and (ii) Promotion of Ethics and Human Values. These basic objectives of the scheme included, among other things, sensitisation of citizens so that the norms and values of human rights and value in the education programme are realised in addition to encouraging research studies concerning the relationship between human rights and values in education and international humanitarian law. Furthermore, in the XI Plan, there were three components of the Human Rights Education scheme: (i) Human Rights and Duties; (ii) Human Rights and Values; and (iii) Human Rights and Human

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[2] See https://www.niti.gov.in/index.php/verticals/human-resource-development/achievements-in-the-year-2018-19 (accessed August 2019).

Development. Under these, it was believed that the violation of rights could be corrected only when the privileged persons are reminded of their duties towards the marginalised sections, and marginalised sections are gradually empowered through rights education. It is further mentioned that human rights education would extend to such areas as gender equity, caste and community relations, majority–minority conflicts, 'forward–backward' dilemma and North–South power relations.

Clearly, again, human rights education fell just short of legitimately and rightfully including the disability sector. The scheme finds no mention in the XII Plan guidelines although the 60th Annual Report does talk about it without giving any financial details.

Centre for Potential for Excellence in a Particular Area (CPEP)

During XI Plan (2007–2012), the Commission continued with the 12 Centres with Potential for Excellence in various universities approved in 2002 at the end of the IX Plan (1997–2002) with an objective to encourage and facilitate the chosen departments to work together and to be able to jointly launch new innovative academic research programmes. These Centres started functioning during IX Plan under a scheme which was a precursor of CPEP (UGC 2011b). During the XI Plan, a Standing Committee shortlisted 16 more proposals from 12 universities for the final stage of selection. Under this scheme, it is mentioned that 'While there will be no preference on the subject areas to be identified and/or taken up under the Scheme, it is necessary that each one has to be of the inter- and/or multi-disciplinary type and be in the emerging, frontier or cutting edge subject areas of regional, national and/or international importance. It is expected that two or more Departments at the University will be able to jointly launch these programmes'.

By looking at the factor 'Area of specialisation to be developed' for the 12 universities that were granted the programme in 2002, in the Annual Report of UGC 2010–2011 (UGC 2011a: 164), it is clear that disability is not in anybody's mind as disability does not find a mention in any of them. Details of the new proposals approved on 28 February 2011 tell almost a similar story (p. 168). Among various proposed activities, launching *new and innovative* programmes/activities in inter- and/or *multidisciplinary* areas is encouraged that serve as a repository of available *knowledge* in the country in the particular area identified for the University.

Again, it is clear that in this thrust area of Quality and Excellence, a DS programme will easily fit into it by being new, innovative and multidisciplinary that will add to the repository of available knowledge about human condition.

On 29 April 2016, thus during the present government's regime, UGC notified nine new centres under the CPEPA scheme, valid until 2021, therefore clearly implying that the scheme continues to the present day in some manner. However, the same pattern seems to repeat, that is, out of the nine centres, only in one of them, Devi Ahilya Vishwavidyalaya, Indore, the focus area approved comes anywhere near a disability theme, namely, 'Inclusive growth and sustainable development in tribal areas of Indore'. However, this area is exclusively devoted to the growth and development of the tribal population of Indore, especially Malwa and Nimar tribes and therefore has nothing to do with disability in particular.

Disability Studies Centres (DSCs)

Higher Education and Research Bill, 2011 (HERB) drafted by the National Commission for Higher Education and Research (Rajya Sabha Secretariat 2012) and presented to the Parliament for consideration include, among others, the following functions:

- promotion of a curriculum framework with specific reference to *emerging or interdisciplinary* fields of knowledge and
- taking measures to enhance *access and inclusion* in higher education.

Any new scheme proposing establishing a DS programme, therefore, would have clearly followed the mandates of the HERB, whatever turned out to be the final fate of the said Bill.[3] My recommendations to the UGC in 2014 (see introductory note) for setting up DSCs in higher education institutions of the country were based on the following set of objectives, which should be of interest to any such future proposal:

- Disability being located clearly at an interdisciplinary juncture, it is to be studied in its social, political and cultural aspects, highlighting the ‘contexts’ that give rise to exclusion and discrimination.
- Research in disability is to be seen as a contribution and insight into methods in the research itself and therefore must form a crucial core of a DSC.
- Lived experiences (including experience of impairment and the surrounding contexts) as constituting a major thrust area within such a centre.
- DS to act as a repository of knowledge vis-à-vis disability and how best to use that knowledge to bring about a ‘disability-centric’ view of academia in general.

In this respect, as indicated in section “Inequity in HE”, a clear delineation between the role and function of EOCs/EUs and DSCs must be understood and respected.

Genesis of Equal Opportunity Cells (EOCs)

In order to make available general development grant/assistance covering aspects, such as (i) enhancing access, and (ii) ensuring equity as the two top priorities, the UGC recommended both setting up of Equal Opportunity Centres/Cells (EOC) and facilities for persons with disabilities (PwDs) (UGC 2011d). The objectives for EOCs read as ‘To enhance the employability and success of deprived groups by emphasising on learning and creating an opportunity for them in the mainstream’, and for the latter (facilities for PwDs) as ‘To help visually challenged permanent teachers to pursue

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[3] As of 24 September 2014, the then current government withdrew this bill from the Parliament.

Table 7.1 Remedial coaching scheme

Remedial coaching for SC/ST/OBC (non-creamy layer) and minorities
In order to enable students belonging to SC/ST/OBC (Other Backward Classes) (non-creamy layer)/Minority communities, who need remedial coaching to come up to the level necessary for pursuing higher studies efficiently and to reduce their failure and drop-out rate, the UGC will provide financial assistance for conducting special classes outside the regular timetable during the XI Plan

teaching and research with the help of a reader by providing teaching and learning aids'.

The arbitrariness and the overlapping nature of these schemes are quite clear; for example, whereas the objectives of setting up of an EOC may, by definition, include PwDs, on the other hand, facilities for PwDs is changed from a scheme for PwDs to persons with blindness or low-vision teachers only.

The overlap pointed out here is not a stray example; there are several cases of such overlaps that can be observed across various schemes. For example, there were other schemes which do not specifically mention PwDs in their titles, nonetheless include them in their purview (see Table 7.1).

Under the guidelines, this scheme was geared towards improving various skills and knowledge base of students belonging to different groups to bring them at par with other students in pursuing higher education (as part of XII Plan, 2012–2017). However, when talking about the fees, it is stated that disabled students (the term used by the UGC is 'physically challenged students') will be exempted from paying the fee, implying thereby that disabled students are also included in the scheme—perhaps under the heading 'Minorities'.

If this logic is acceptable, then by extension, students with disability should find a place under the other related schemes like the following:

- Coaching for NET/SET for SC/ST/OBC (non-creamy layer) and Minorities.
- Coaching Classes for entry in services for SC/ST/OBC (non-creamy layer) and Minorities.

The former with an eye to help students from disadvantaged groups to clear National Eligibility Test (NET) exams in order to be able to be employed in teaching positions at colleges and universities, and the latter to get jobs in Services A, B and C. However, rather arbitrarily again, students with disabilities are not even mentioned here in the description.

However, in order to run these various coaching classes, some centre is required, and UGC envisaged this as a major motivation for setting up of EOCs. As stated earlier, under the merged schemes, setting up of EOCs in colleges and universities was recommended in the XI Plan, and an order was notified towards this effect. It was mandated that EOCs will be in charge of laying emphasis to the deprived groups for learning and creating space for them to mainstream themselves, which will run specific schemes of coaching for SCs, STs, OBCs (non-creamy layer) and Minorities in order to enhance the employability and success. A one-time grant of Rs. 2,00,000 for establishing an office of the EOC may be provided under the scheme.

Although EOCs were to be set up to oversee implementation of schemes for enhancing employability and success of disadvantaged groups (including PwDs, UGC 2011d: 251), their profile also included overseeing the effective implementation of policies and programmes for disadvantaged groups and to provide guidance and counselling in academic, financial, social and other matters. The cell also takes up programmes of sensitising university/college community on problems faced by these students. In short, the role of EOC as envisaged in the XI Plan was as follows:

- Running Coaching Schemes,
- Implementation of Policies and Programmes,
- Guidance and Counselling (academic, social, financial and Other) and
- Sensitising.

However, the meagre sum of Rs. 2,00,000 one-time grant for setting up an EOC was never deemed enough to conduct so many programmes for a variety of groups, let alone persons with disabilities. The scheme, therefore, remained ineffective to a large extent as far as students with disabilities were concerned.

A Question of Nomenclature

Having looked at the existing schemes and their drawbacks, it can be observed that IX Plan onwards there is scope for some confusion with regards to the reach, function and nomenclature of various schemes for persons with disabilities recommended by the UGC. To see this clearly, consider the possibility that within Higher Education for Persons with Special Needs (HEPSN), there is one specific component which recommends the establishment of Enabling Units (EU) for persons with disabilities in the colleges of the country (see Table 7.2).

The various functions of the EUs listed in the XI Plan document of the UGC overlapped with overt, and sometimes covert, functions/roles of other schemes. In effect, the UGC recommendation makes it possible for a college to set up both an EOC and an EU, in fact, in practice, this situation has led to a certain degree of confusion and the resulting absence of implementation of various provisions in favour of students and teachers with disabilities at colleges and universities. The HEPSN scheme continues to this day, as the then union minister of HRD announced

Table 7.2 Component 1 of HEPSN

Component 1
Establishment of Enabling Units for ‘differently-abled’ persons
In order to develop awareness in the higher education system and also to provide necessary guidance and counselling to differently-abled persons, it is proposed to establish resource units in colleges in the country, which will be called Enabling Units

in a written reply to a Rajya Sabha question on this matter in December 2014 under the present government.

It is suggested that the confusion with respect to nomenclature and overlapping of duties and responsibilities can be avoided if there is one Centre/Unit in the colleges/universities to oversee *all* disability-related services and effective implementation of provisions. It is recommended therefore that only the ‘Enabling Units’ will be responsible for disability-related issues in colleges and universities.

However, an overlap in the nature of the products of the sectors is unavoidable and in fact not entirely unwelcome. This is so because for disability studies to act as the ‘theoretical arm’ of the disability rights movement, an overlap in the nature of the products of the two sectors is necessary. However, this ultimate situation need not obfuscate the difference in the origins of paths taken. This necessary separation has not been understood in any of the previous documents on this issue.

Keeping this in mind, a typical DSC will engage in teaching, research and documentation, and consultancy and advocacy. However, for a countrywide policy to take effect, a proposal for DSCs should be tempered with other schemes which address marginally differing target groups, like a scheme for refresher courses in Social Sciences and Humanities, and some in Sciences (like Basic Sciences, Behavioural Sciences, Health Sciences, Medical/Physical Sciences, ICT Applications, Genetics and Research Methodology) may integrate papers from DS in line with the existing UGC frame for refresher courses.

One of the five components in an Orientation Course run for in-service new teachers laid down by the UGC is to develop awareness for linkages between Society, Environment, Development and Education. However, without an awareness of the interlocking effect of disability in each of these, and the role they play in the life of a person with disability, the knowledge about the linkages remain incomplete; this is so especially in the background of Equality and Human Rights being two of the suggestive topics to be taught under this component.

Similarly, with the recognition of the need to include more students with disabilities in higher education with access to the general curriculum (Humanities, Social Sciences and Sciences), there is need to incorporate more discussion about disabilities in such curricula in order for all to develop an understanding of the meaning and experience of disability. Given that discrimination in many cases arise also from lack of understanding of presence and participation of persons with disabilities in society, and the history of exclusion causing such discrimination, a curriculum infused with disability will go a long way in building a more equal society.

Service and Knowledge Through Disability Studies Extension

Having looked at some of the disability and higher education policies of the government of India, I return to the main theme of the paper, namely, the question of the connection between service and knowledge. This connection will be examined from the point of view of the nature of the ‘traffic’ between the two; in particular, I would

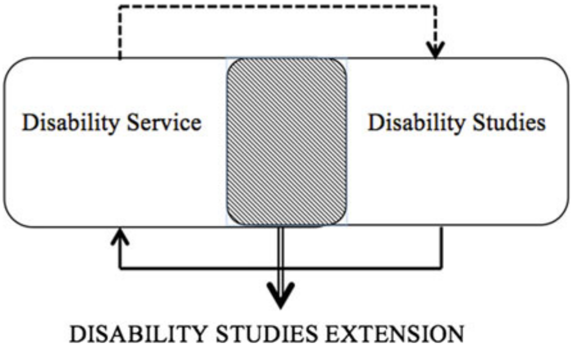

Fig. 7.1 ‘Traffic’ between service and knowledge

like to believe that a knowledge of such a traffic aids in a better understanding of both a disability studies framework and the nature of service provisions.

As was pointed out in the last section, while discussing various overlaps in roles and functions of many agencies informed by disability-related policies, in particular, of EUs (section “A Question of Nomenclature”) and EOCs (section “Genesis of Equal Opportunity Cells (EOCs)”), that although their origins may have been guided by different philosophies (of service and knowledge, respectively), an overlap of their mutual spaces of operation is not entirely unwelcome. Such minimal overlap is desirable because disability rights-based services feed into disability knowledge or DS, and vice versa.

In order to better understand this concept, let us concretise it by way of the diagrammatic representation of the essential idea as in Fig. 7.1.

The arrows in the above figure indicate the traffic between service and knowledge (disability studies); as can be seen, they tell their own stories. The intersection of the two—services and studies—or the shaded area in between indicating Disability Studies Extension (DSE), on the other hand, is literally at the centre of the present proposal; it is through an understanding of DSE that disability studies can be better framed and provisions can be most effectively administered. Coming back to the arrows, it can be seen that the traffic to (rather than from) service is a stronger connection of the two; the other way round is most often a chance happening, for example, in case of an EU or an EOC, with their dominant mandate of service, engageing in disability studies related activities merely due to the presence of team members who believe in the disability studies enterprise.[4] In certain cases, years of experience of dealing with some case studies may help develop insights that inform disability studies (see below for a specific example of dyslexia). However, most often, people engaged in the service sector are seldom interested in disability studies (at least that seems to be the case in India), and as pointed out in Bhattacharya (2013, 2018), in extreme cases, a certain ‘politics of estrangement’ needs to be instituted

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[4] This was the case for the EOC of the University of Delhi set up in 2006, which was one of the first such organisations in the country, where until 2010 five short-term courses that I initiated were run each semester that focused on both skill and knowledge, the latter clearly in the course titled ‘Disability and Human Rights’.

by keeping service-infused activism at abeyance. The direction of traffic is therefore almost unidirectional.

The interaction between service and knowledge, with the accompanying emergence of DSE, gives rise to three possible contexts, which are listed below along with some typical exemplars for each:

(i) Exclusive to each domain:
  - Americans with Disabilities Act (ADA) (disability studies)
  - Assistive Devices (AT) (disability service)

(ii) Common to both (Awareness) and
(iii) Disability prevarications (International Classification of Functioning, Disability and Health (ICF), National Institute for Urban School Improvement (NIUSI), etc.)

The following subsections deal with each of these in order.

Domain Exclusive Experiences

It is not the job of the service sector to define disability or to question who is or is not a disabled person. However, case studies and/or rights-based activism within an institution may contribute towards defining disability, at least from the perspective of classification. For example, dyslexia is a disability which was not recognised as such in the then operative disability act of the country, namely, the Person with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995. At the EOC of the University of Delhi, from 2007 onwards, soon after the cell was set up, we had to deal with students with dyslexia seeking admission and we at the EOC were able to convince the university authorities that such students should be considered for admission to our programmes. Thus, such cases provided us an entry point to the classificational debate initiated by rights-based attempts to include dyslexia as a disability.

However, this is a very organisation-specific example; it was possible at the EOC of the University of Delhi because of the vision that we had brought into the workings of a primarily service-oriented organisation; it was an exception rather than the rule. And since service organisations like EOCs should work within the framework of some legality, it is obvious that in most cases they will work with official definitions, rather than attempt a redefinition.

Thankfully, much later, dyslexia was recognised as a disability in the Rights of Persons with Disabilities Act, 2016 as part of specific learning disabilities.

Americans with Disabilities Act, 1990 (ADA)

On the other hand, the three parts of the ADA encapsulate nuances of an order in the definition of disability that cannot be practically handled by a service sector.

The relevant point about ADA being a disability studies exclusive theme is with respect to Part (C) of the Act. Both Part (B) and (C) deal with reactions of others to an impairment or to a *perceived* impairment; both are considered as a disability and not impairment. This perspective lends an angle to the Act that addresses the discriminatory practices based on the misclassified or mistakenly perceived notions of limitations of individuals with disabilities. The Part (C) of the Act includes the following in its purview:

(i) persons who have impairments that do not substantially limit major life activities but are treated by service providers[5] as constituting substantially limiting impairments,
(ii) persons whose impairments are substantially limiting only as the result of the attitudes of others toward the impairment and
(iii) persons who have no impairments but nonetheless are treated as having substantially limiting impairments.

Part (C) of the ADA achieves something which no other acts do, namely, it acknowledges that the general bias against persons with disability creates as much hindrance as the physical ‘limitations’ that result from actual impairment. This new perspective on the definition of the term disability is designed to protect against stereotypes and other attitudinal barriers in general about disability. Common attitudinal barriers include ‘concerns about productivity, safety, insurance, liability, attendance, cost of accommodation and accessibility, and acceptance by co-workers and customer’ (Equal Employment Opportunity Commission 1995). Part (C) is directed at the employer and not the individual alleging discrimination, thus, the existence of an actual disability/impairment is not important.

As we can see, the concept of perceived disability is an advanced theoretical idea, which in its wake informs the field of disability studies in meaningful ways, consolidating the definition of disability.

Assistive Devices as Transhumanising Ability

The notion of Assistive Devices (ATs) on the other hand exclusively addresses the concerns of disability services. Since the origin of ATs lies firmly in the sphere of rehabilitation sciences, providing these facilities to persons with disabilities carries with it the concept of medicalisation of disability. Disability studies positions itself as a counter to rehabilitation and special education which individualises disability, fashioning a curriculum propagating the idea that disability is an individual’s or family’s problem (Linton 1998). However, according to Campbell (2009), a disabled body poses a challenge to the purification divide as outlined in Latour (1993) between what he calls ‘translation’ and ‘purification’ since such a body in using assistive/adaptive devices challenges the normative category, whereas the project of purification would

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[5] The technical term used in the Act is ‘covered entity’, which includes employer, employment agency, labour organisation or joint labour management committee.

prefer to hold on to the divide between uncontrolled (disabled) and controlled (abled) bodies. On the other hand, a medicalised, rehabilitative, conceptualisation of ATs will logically extend to what Wolbring (2012) terms ‘transhumanisation of ableism’, referring to a state of ability expectation that goes beyond the species-typical body-related activities which may lead to viewing disability-adjusted years (DALY[6]) as years lost not being enhanced.

Although the preceding discussion of ATs, especially, with reference to work by Campbell and Wolbring does provide a possible entry to disability studies related theoretical concerns vis-à-vis the place of ATs in disability studies, given that the notion of ATs has a primarily rehabilitative genesis, the topic may be viewed as falling exclusively within the domain of disability services.

Awareness as a Common Theme

Awareness-raising exercises, on the first impression, seem like a disability service related activity, if not for persons with disabilities themselves, at least for the personnel in charge of dispensing services targeted towards them. For example, while coordinating various activities in the EOC of the University of Delhi, we ran 60 awareness-raising workshops in 2 years during 2010–11. These workshops were conducted sometimes on the premises of the target group or on the premises of the EOC building. Among the various groups in the university, workshops were conducted for a variety of target groups like the engineering department, the security services and the library staff. However, a majority of the workshops were conducted at different affiliated undergraduate colleges of the university.

Awareness is also a theme in disability studies proper. For example, awareness-raising exercises involve dispelling certain prejudices and stereotypes about disability, or more importantly, discrimination that results from such stereotypes. For example, as a result of the Rehabilitation Council of India (RCI) strictly controlling approval of any disability-related courses that run anywhere in the country, such courses have churned out thousands of armies of people trained and qualified in so-called special education. A negative, medicalised attitude is a direct result of the institutionalised ‘special education’ programmes of the country.

For example, the course outline for B.Ed. (Special Education, Hearing Impairment (HI)) has modules such as teaching language, communication and school subject, audiology and aural rehabilitation, listening devices and speech teaching to the HI. Furthermore, in the earlier syllabus for the course, there was one paper that had a 60 hrs credit unit on ‘Facilitating Language, Communication in Children with Hearing Impairment’. However, the words ‘language’ and ‘communication’, contrary to their expectation, suggest oral, aural, oral–aural, auditory–verbal, cued speech, fingerspelling, oralism, total communication, etc. Not surprisingly, only 2 out of those

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[6] Disability-Adjusted Life Years (DALY), years of healthy life lost due to disability, was a concept developed by the World Bank in (1993) and adopted by World Health Organisation (WHO) in the 1996.

60 hrs, that is, 3% of the time is devoted to Sign Language. Among the suggested readings include books on speech (lip) reading, hearing aids, cochlear implants, assistive devices and aural rehabilitation but none on Sign Language (as pointed out in Bhattacharya 2011). In a later update of the syllabus (in 2015), the RCI split this paper into a few units across two new papers, 'Technology and Disability' and 'Intervention and teaching Strategy', however with no update at all in the list of books, which still do not include any book on Sign language.

Similarly, one of the most popular topics of awareness-raising exercises is the language of disability, especially, the usages 'disabled persons' and 'persons with disabilities'. An elaboration of the history behind these two usages, for example, the first usage as a direct result of the historic struggles of the Union of Physically Impaired Against Segregation (UPIAS) in the 1970s in the UK and the resultant initiation of the social model of disability, lands one into the heart of disability studies themes. Furthermore, within the Indian context, as pointed in Bhattacharya (2016b), the relative struggles behind the person-first and disability-first language do not hold much meaning for languages which do not lend themselves to any equivalence of the post-nominal genitive order of words as 'persons with disabilities' and only allow an adjective followed by noun order (therefore the equivalence of 'disabled persons'). Similarly, a discussion about the usage of Deaf/deaf brings us to the core of Deaf Studies issues about the place of sign language in a Deaf person's life.

Disability Prevarications[7]

This constitutes the major area in trying to understand the nature of the Disability Studies Extension (DSE) component; in other words, the creation of a transgression or evasion of disability in theory and practice form the chunk of what is construed as part of DSE. By 'extensions', I do mean areas of research and policymaking that were obtained as a direct result of some of the social and political phenomena of the 1980s. The decade of the 80s saw a change in the economic structure from the universal to the diverse and different, and within social theory, the grand narratives fell out of favour. Consequently, class identity was rejected in favour of a more pluralistic, political and cultural identity. Thus, the new social theory laid emphasis on identity based on factors that lay outside of the class structure. In a famous article, Williams (1992) calls this 'fragmentations', which placed more and more emphasis on subjectivity rather than deterministic structures. This led to the subjective well-being paradigm, which emphasised personal satisfaction and power.

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[7] The English word 'prevarication' is interestingly derived from the Latin *prævāricāri* 'to straddle something' of which the stem itself is derived from *vārus* 'bow-legged'.

Table 7.3 Commonly used functional measure (adapted from Verbrugge and Yang 2002)

Activities of Daily Living (ADL)	Instrumental Activities of Daily Living (IADL)	Physical Limitations (PLIMs)
Bathe, dress, transfer, toilet and eat	Heavy/light housework, shop, meals, money and phone	Walk, bend, stand, steps, lift, reach, grasp and held

Characteristics of a Disability Paradigm

The characteristics of an emerging disability paradigm reflected this change in the social and economic structure of the society. For example, Schalock (2004) lists the following four main characteristics of a newer disability paradigm: (a) the concept of functional limitation, (b) personal well-being, (c) individualised support and (d) personal competence and adaptation. Note that each of these characteristics point towards an individualised conception, in fact, three of the four characteristics contain the word 'personal' or 'individual'. Furthermore, words like 'limitation', 'support' and 'adaptation' indicate negative stereotyping and hint towards a lack or an absence. Similarly, a focus on individuality in terms of individualised assessment of needs, though internationally adopted in the spirit of DSM IV (APA 1994), also leaves open the possibility of a neo-liberalised view of need–support. Although the earlier classification by the American Association on Mental Retardation (AAMR) of classifying MR according to IQ, where 50–55 to 70 being mild to below 20–25 being severe and others falling in between, gave way to their 1992 classification based on intensity of support services, where intermittent, limited, extensive and pervasive are the categories bringing about a shift from intelligence to functioning, the new definitions of MR still had to depend on terms like support in communication, social skills and self-direction. The overt use of certain concepts employed in the three steps in diagnosis where step 1 brought back the IQ scores, step 2 had to rely on physical health and aetiology (among other things) and step 3 variously dealing with health, environment, adaptability and psychological needs, are indicators of the latent semantics of dependency that continue to inform the discourse of 'needing help' or charity. Apart from this, as pointed out earlier, the focus on individual assessment of needs leaves open the possibility for a customisability and therefore amenable to market forces in a free economy.

Furthermore, a codification of functional measures further objectifies disability in terms of a limited set of functions which help conjure a limited individuality of a person with disabilities. This can be examined in Table 7.3.

ICF: The Agentless Body

Similar negative interpretation of disability can be gleaned in the well-known international sources for theories and policies on disability in general, like the World Health Organisation's (WHO) famous formulation called the 'International Classification of Functionality, Disability and Health (ICF)' (WHO 2001), where disability is defined in terms of ‘impairments in body function and structure’, participation ‘restrictions’ and activity ‘limitations’; primarily these are the factors that constitute what the WHO calls ‘Health Condition (disease or disorder)’. It is clear that the outwardly neutral term ‘health condition’ cannot be left to the vagaries of a possible positive interpretation and is forced to be read as either disease or disorder. This is not an isolated instance, as mentioned earlier, this document became the fountainhead for several branches of specialisation that dealt apparently with disability but invariably in terms of codes that essentially retain the medicalised understanding of disability that several disability organisations started to mobilise sentiments against as early as the 1960s.

The following excerpt is a more common view of disability as a disease. In one of the online forums of the United Nations (UN), from 23 November 2009 to 25 January 2010, the WHO moderated a discussion where the topic for Week 8 was ‘Non-Communicable diseases and Women’ – with the subtheme ‘Disability’ had the following opening statement:

> Generally non-communicable diseases (NCD) are those diseases/conditions which are not infectious in nature. These have also sometimes been called ‘Chronic diseases’ although not all chronic diseases are non-communicable. The NCD that will be highlighted for discussion on this forum include cardiovascular conditions, cancers, mental, neurological and substance use (MNS) disorders and associated disabilities.

It was clear that disability, or at least certain disabilities, is/are here clubbed together with disease. Not surprisingly, therefore, quite soon, one of the participants made the following response:

> Hello.
>
> … I got surprised that the discussion about Non-Communicable Diseases and Women is including women with disability as a subject of those Non-Communicable Diseases. Many women and men around the world are fighting against that idea of being considered subjects of the medical environment! I am proud of being a woman, …; but I am also proud of being ‘disabled’ because in my conception, being disabled is another way of being in the world! Not a disease, the problem is when because of being a disabled woman I am discriminated against. …
>
> Regards,
>
> Marita Iglesias.[8]

The three places of experience for human functioning in ICF mentioned above typically focus on the body and its responsibilities towards a functioning, without any cognitive ascription. For example, the first experience is body function and structures which is a body without any agency, whereas the second and third factors, namely, activities and participation, are about the body’s location and performance among other bodies and against things; in short, an objectification of the body. With this, the ICF makes sure that disability is firmly ensconced in the body.

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[8] List members could access the original posting and this reply was available from 12 January 2010 at https://knowledge-gateway.org/womenandhealth/discussions/kwrncssm.

Table 7.4 Core quality of life domains and commonly used indicators (extracted from Schalock and Verdugo 2002)

Core domains of QoL	Commonly used indicators of QoL
Emotional well-being	Contentment, self-concept, lack of stress
Material well-being	Finance, employment, housing
Physical well-being	Health, activities of daily living, leisure
Self-determination	Autonomy/control, goals and values, choices
Social inclusion	Community integration/participation/roles, social support
Rights	Human, legal

Well-Being and Quality of Life

The second characteristics of emerging disability (i.e. personal well-being) (Schalock (2004) section "Characteristics of a Disability Paradigm") is also defined by trends of what Williams (1992) called 'fragmentation' and is reflected in social policies emanating in the 80s, whether it is due to re-emphasis on welfare state in the UK/Europe or the effects of civil rights movement in the US. This new emphasis on subjectivity and identity rather on deterministic structures is also due to what has come to be known as the 'Postmodern Condition' of the post-60s period. Along with the emergence of identity-based politics of the 80s, 'personal well-being' became a factor fuelling the renewed interest in the personal.

The key concepts that in turn determine 'personal well-being' are positive psychology and Quality of Life (QoL). While the former mainly concerns with positive experiences, the latter is related to human potential in many different ways. One way to determine QoL is through core domains and indicators, as in Table 7.4 extracted from Schalock and Verdugo (2002).

Thus, a disabled life is determined by this limited set of universal domains and particular/unique indicators. Apart from this restricted definition of a disabled life, there are other aspects of QoL that establish the entire gamut of such research as confirmed candidates for disability prevarication.

For example, Buntinx and Schalock (2010) consider QoL to be facilitating communication between different clinical disciplines and policymakers so that they can arrive at a correct estimation of individualised support. There are at least two things wrong with this approach. First, this is what represents the modern face of study of disability, rather than disability studies—a distinction made in Schwartz et al. (2006)—where the former sees disabled persons as clients and research objects. This is also an example of alienated research (Stanley 1990) where a disabled person holds the interest of the researcher as long as that person signifies 'enhancement of human functioning and a life of quality' as a result of individualised support. This carries the implication that a disabled life is of lesser quality, needing enhancement, or non-functional, requiring support. Secondly, as pointed out earlier, the notion of individualised support by denying any role of the state leaves the person with disability at the mercy of the market. It is interesting to note that these models almost exclusively focus on intellectual disability (ID), that is because it is much easier to treat persons with ID as a voiceless research mass.

The trend of QoL-based research is to halt the force of international sociopolitical conventions applicable at macro levels by focusing exclusively on individual desire and needs; the efforts to integrate the latter in a systemic fashion which addresses the importance of empowerment for persons with disabilities has not taken root, the veneer of a person-centred approach in this context is only that.

The Oral History Project: Disability as an Artefact

Another 1980s phenomenon that too belongs to DSE is the oral history project. Ferguson (2006) lists 17 ways to 'Infuse Disabilities into Curriculum Across Age Levels' in the National Institute for Urban School Improvement programme in the US, most of which are based on the oral history project which depends upon human memory and the spoken word to bring out people's testimony about their own experiences. For example, one of the activities is to have adults come to class to talk about their lives and history in the local community, including adults with disabilities. As long as this is supposed to impart the acknowledgement on the part of students that disabled persons are part of the society, it serves its purpose. However, a disabled person's life is not going to be like other lives. What happens if the person starts talking about the problems that they face every day of their lives in the community? Will the school be prepared for this? Will they be willing to accept it? Given the general trend of oral history projects often being culturally endorsed tutored accounts, it is likely that discordant voices will be supressed.

Furthermore, the document (Ferguson 2006: 5) also suggests having children do an oral history interview with a family member or friend who has a disability or a family member or friend who has a relative with a disability. As Shopes (2012) notes, interviews within the oral history paradigm often include nothing about the workings of local power even as they constitute the welcome shift towards the understanding of the everyday lives of ordinary people. Thus, 'community-based oral history projects, often seeking to enhance feelings of local identity and pride, tend to sidestep more difficult and controversial aspects of a community's history, as interviewer and narrator collude to present the community's best face' (p. 11).

Another activity asks teachers to 'have students do "accessibility surveys" and maps of neighbourhoods, schools and communities that identify various barriers and accommodations—not just ramps and curb cuts, but also Braille, graphics, visual cues and so on' (Ferguson 2006: 5). Note that these only talk about the objectification of disability, the paraphernalia associated with disability can be considered as instrumentalisation of disability; again, the cognitive ascription of feelings or thoughts is absent, almost as if persons with disabilities are objects themselves with no feelings. Most of the other activities achieve exactly this, create just a disabled body, for example, activities like showing students videos of history of eugenics, having students do 'accessibility surveys' of neighbourhood, discussing stories with characters with disability, having students learn 20 words [sic] of American Sign Language and having students learn the alphabet in Braille. Finally, the guide also talks about taking students to a museum and looking for things about disability. The cycle now seems to be complete—disability has now become a frozen artefact in a museum.

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Chapter 8
Disability Education at Lady Irwin College, University of Delhi

Neerja Sharma

Abstract Lady Irwin College was established in 1932 to impart Home Science education. A conscious step to include the study of disability was taken when in 1970 a 2-year M.Sc. programme in Child Development (CD) was introduced, with one of the courses being 'Exceptional Children'. This course is at present termed Developmental Disabilities while the Department was renamed Human Development and Childhood Studies in 2005. The paper briefly discusses the relationship between disability studies and Home Science education in India and how interest in studying disability emerged at Lady Irwin College. The college has had a nursery school since 1955 which served as a laboratory for understanding childhood. From 1980, the preschool began admitting children who had disabilities, inclusion being the policy and practice. A volume documenting research on disability at the college titled *The Social Ecology of Disability* was also published. Gradually, interest in disability studies and research was picked up by the five other postgraduate departments at the college namely, Fabric and Apparel Science; Food and Nutrition; Resource Management and Design Application; Development Communication and Extension; and Department of Education.

Keywords Disability · Home science · Early childhood · Higher education · Research · Action projects

Lady Irwin College was established in 1932 to impart Home Science education in India. As a constituent women's college of the University of Delhi, it offers both undergraduate and postgraduate degree courses, and it also has a robust doctoral programme. In the university system, the Department of Home Science is placed under the Faculty of Science. The college has six major departments engaged in the study of various aspects of Home Science. These are Human Development and Childhood Studies, Food and Nutrition, Fabric and Apparel Science, Resource Management and Design Application, Development Communication and Extension, and Department of Education. Before we discuss how disability studies became a part of

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N. Sharma (✉)
Department of Human Development & Childhood Studies, Lady Irwin College, University of Delhi, New Delhi 110060, India
e-mail: neerja.lic@gmail.com

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the education at Lady Irwin College, I would like to give a brief backdrop about its growth in the larger Home Science context.

Relationship Between Disability Studies and Home Science Education in India

Child Development has been an integral part of Home Science education in India. The subject includes the study of the child from prenatal life up to the end of adolescence. Over the years, in most universities, Home Science faculties have made a shift to the study of the complete human lifespan, and titled the course Human Development. A few universities have identified their focus to be on specific aspects of human development and indicated that in the title they have adopted. For example, while the faculty at M.S. University of Baroda at Vadodara had named the course Human Development and Family Studies, the Department of Home Science at the University of Delhi preferred the title Human Development and Childhood Studies.

In the study of children as well as adults, there has been a conscious effort to enable students develop an understanding of marginalized groups. These include those living in difficult circumstances as well as those with disabilities and their families. Home Science per se did not prescribe the study of disability in any of its teaching and research areas. For example, in 1984 a report based on a UGC-funded national workshop on Thrust Areas in Home Science Research did not make any mention of research in the area of disability (Lady Irwin College 1984). However, over the last few decades most Home Science institutions have included, as part of Human Development, papers on the study of either only children or both children and adults with disabilities in their curriculum. Some of the well-known institutions that have done so are Faculty of Family and Community Sciences, M.S. University of Baroda, Gujarat; Faculty of Home Science, SNDT Women's University, Mumbai; Avinashilingam Institute of Home Science and Higher Education for Women, Coimbatore, Tamil Nadu; Government Home Science College, Chandigarh; P.G. Department of Home Science, Jaipur, University of Rajasthan; and Lady Irwin College, University of Delhi.

A recent development in the study of disability has been noted at the senior secondary level too. In the 2019 curriculum of Central Board of Secondary Education for class XI, the title of the subject Home Science has been replaced by a new title, i.e. Human Ecology and Family Sciences. The syllabus has an item Children with Special Needs and another one on Clothes for Children with Special Needs. The NCERT textbook for studying this course states five objectives two of which point to an attempt to develop in students sensitivity towards marginalized groups, including persons with disability, (NCERT 2016a, b). These are

- To understand one's role and responsibility as an individual and as a member of one's family, community and society, and

- To develop sensitivity and critical analysis of issues and concerns of equity and diversity.

The class XII syllabus of this subject has a full section on Special Education and Support Services, accompanied with practical work. Thus, the students who study the subject Human Ecology and Family Sciences would enter higher education having gained some knowledge of and sensitivity towards children with disability.

How Interest in Disability Emerged at Lady Irwin College

The epigenesis of the study of disability at Lady Irwin College (LIC) has been organic. Interest in this area grew out of concern for vulnerable sections of society that were stated in the vision document of the college when it was set up. The beginnings of this institution were envisioned by a group of eminent women who were in the vanguard of India's freedom movement. Among them were Sarojini Naidu, Rajkumari Amrit Kaur, Aruna Asaf Ali and Kamaladevi Chattopadhyay (Anandalakshmy 1982). They formed the All India Women's Conference (AIWC) which founded Lady Irwin College, named after Lady Irwin, (wife of then Viceroy, Lord Irwin), who also took a keen interest in setting up the college. The objectives outlined for the college included preparing female students to work towards the goal of serving the home and society with equal resolve so as to remove social and educational disparities that prevented women from reaching their potential. The very first meeting of the AIWC resolved that the college would have an experimental school, a research bureau, rural education and teachers' training (Sharma 2004).

While the college initiated several measures to meet the objectives in order to provide quality education in Home Science, two initiatives that served as precursors to attention towards disability were the setting up of the teachers' training as a 1-year bachelor's degree (B.Ed) course in 1952 and the opening of a preschool on campus. One of the optional courses in the B.Ed. curriculum was 'Education of Backward Children.' Although today this nomenclature sounds grossly inappropriate, it created an interest in the study of children who were 'slow learners' in the classroom. By now, we know that one of the co-occurring conditions of several types of disability in children is their difficulty in learning in a conventional classroom. Later, the title of this paper was modified to a more acceptable one, that is, 'Exceptional Children.'

The preschool, at that time called Lady Irwin College Nursery School, was set up in 1955, and it served as a laboratory for teacher training. Since the admission policy for the preschool was liberal, and no child was assessed for the purpose of admission, any 3-year-old could enter it. In view of this, it can be safely said that children with diverse levels of ability and aptitude must have found a place in the preschool. Thus, respect for diversity was built into the ethos of the school philosophy. Inclusion of children with disability became a special feature of the preschool from as far back as 1980 when most institutions were practising segregated education for the disabled (Sharma 2004).

Later, the preschool was renamed Rajkumari Amrit Kaur Child Study Centre (RAK CSC), and it widened its functioning to include a crèche (6 months onwards) and an early intervention programme called SETU, apart from strengthening its day-care services that it already had. The Centre is monitored by the Human Development and Childhood Studies (HDCS) Department through a lecturer-in-charge since 1970. Among its approximately 100 children today, on an average, 10 children with different disabilities attend it and receive quality-inclusive education. There have been children with autism spectrum disorders, cerebral palsy, intellectual disabilities, visual impairment, hearing impairment and many other types of challenges that place the child in the realm of special needs. In fact, no child is disqualified for admission based on the nature or severity of her/his disability. It is based on the child's developmental readiness to attend an away from home programme.

The RAK CSC programme is self-sustaining and therefore fee-paying. Children from disadvantaged sections could not access it easily. To meet this need of society, the HDCS Department had set up The Enabling Centre in 1988 with funding from the Ministry of Human Resource Development under its scheme of Innovative and Experimental Programmes in Elementary Education. This programme catered to non-school going children (5–15 yrs.), with and without disability, from disadvantaged backgrounds in an inclusive setting. It offered them quality educational experiences for over 16 years, helping many of them take vocational training and find work. Unfortunately, it had to be closed down due to the cessation of grants from the Ministry.

The Study of Disability at Higher Education Levels

This section presents a brief overview of disability-related curricular content and research in the six departments at Lady Irwin College. It does not contain an exhaustive review (as that is beyond the scope of this paper) but provides a glimpse of the interest of the institution in the study of disability and how persons with disability are an inseparable part of its social ecology. Most of the research work is documented in a large number of unpublished masters' dissertations, which are not being mentioned individually in the paper. These are available in the college library. Only a few exemplars are being listed. Doctoral and action research are being given more space. Titles of courses and important elements of the recently revised curricula find mention, as through all these students of the college are sensitized to different aspects of disability.

Interdisciplinary Nature of Work on Disability

While the inclusive preschool at the College, RAK CSC, was the primary source of interest and work in disability, a research grant from the University Grants Commission of India drew in all the departments to research in wider areas of disability. The process was organic and gradual. It was a major milestone in the academic endeavours of Lady Irwin College when it received recognition from the University Grants Commission for supporting research under its Special Assistance Programme. From 1985 to 2012, the college moved from stage 1 of Departmental Research Support (DRS) to stage 2 of Department of Special Assistance (DSA) to finally stage 3, that is, Centre of Academic Excellence (CAS). The grant was received for setting up an 'Extension and Communication Cell' in Home Science. All six departments received impetus to strengthen their research work in specific areas, disability being an important one of them. As a result, many master's and doctoral research studies were undertaken. The 3rd Technical Series publication of LIC titled Social Ecology of Disability (Sharma 2010) collated these papers and it was supported by CAS. Thus, in relation to persons with disability there were contributions about their developmental and educational needs, food and nutrition, clothing and employment in garment industries, about their communication needs, built spaces and physical ecology, as well as measures for prevention of disability.

The Department of HDCS further strengthened its work on disability at the RAK Child Study Centre with SAP support. Apart from its morning programme (9.00 a.m.–12.00 noon), it opened the doors for non-fee-paying special education to out-of-school children with disability from disadvantaged families in the neighbourhood (1.00 p.m.–4.00 p.m.) on the same premises. Called Anubhav, the centre catered to up to 15 children at any given time (3–15 yrs.) from 1985 to 2002, after which the focus of the UGC project changed, and the centre-based approach had to be wound up.

Disability as Social Construction

Home Science institutions across the country do not have a common curriculum. Every department/faculty teaching disability courses develops its own understanding of perspectives on disability; the teachers, it is imagined, discuss the various models in the classroom and guide research. At the Department of Human Development and Childhood Studies, LIC, the students and research scholars are encouraged to subscribe to the social pathology perspective of disability, with emphasis on the human rights approach (Rioux 2009) rather than the medical model of pathology in the individual. The social pathology view, according to Sharma and Sen (2012) is that:

> Disability does not result from the mere fact of the presence of impairment in the person-it results as a consequence of the interaction between the feature of a person's body and features

> of the society (environment) in which the person lives. Therefore, when the environment is supportive and barrier-free, the person is not limited or restricted in performing functions and the impairment does not lead to disability. (p. 282)

For the purpose of this paper, the author subscribes to the perspective that disability is socially constructed.

Maximum volume of curricular content and research related to disability in the college has emanated from the Department of Human Development and Childhood Studies.

Department of Human Development and Childhood Studies (HDCS)

A conscious step to include the study of disability at an advanced level was taken when in 1970 a 2-year M.Sc. degree course in Child Development (C.D.) was introduced which had Exceptional Children as one of its papers. Since 2005, this degree has been renamed Human Development and Childhood Studies as the course now addresses the whole lifespan. The study of disability is undertaken through a semester paper titled Developmental Disabilities. Three other courses that also address disability as part of the course work are 'Early Childhood Care and Education'; 'Diversity, Disadvantage and Equity; and Law,' 'Policy and Programmes for Women and Children.'

In fact, the nomenclature of the course related to disability passed through several progressive modifications, reflecting our readiness to change with times both in titles and content. From 'Exceptional Children,' it became 'The Deviant Child,' then 'The Child with Special Needs,' and today it is 'Developmental Disabilities.' There is a separate course on 'Child and Adolescent Well-being.' The undergraduate students study disability-related courses, and these are 'Children with Disabilities' for the Pass Course group and 'Childhood Disabilities and Social Action' for the Honours group, both with a practical component.

The 'Developmental Disabilities' postgraduate course is accompanied by an 8-hr. practical/week. The M.Sc. students work closely with preschool children with disabilities at RAK CSC. The students observe the children and the educators in their classrooms, learn to undertake intervention activities for their development and visit their homes to understand their social ecology as well as meet the family. In the end, they document the whole process in a case study which is evaluated as part of course work. By now, more than 500 case studies have been prepared in the last 35 years, data from many of which have been published in various research papers. The students who have graduated with a master's degree in CD/HDCS and chosen to work in the area of disability have made a mark in the fields of special education and counselling on account of their strong conceptual grasp and hands-on training.

Masters' and doctoral research is an integral part of the study in all the departments of the college. The emphasis in the HDCS Department research has been to not only investigate cognitive, language, socio-emotional and behavioural features of children with disability but also explore their sociocultural context to understand the prejudice and apathy in society about persons with disabilities. Innovative intervention strategies including those using theatre, dance, music and art have been developed through action research. Three doctoral dissertations, supervised by this writer, have studied various aspects of the lives of children with disabilities in their school contexts. Joshi (2001) explored the meaning of disability in childhood through the perspectives of children categorized as those with disabilities and of others closely associated with them. She also focused on the manner in which the children with disabilities defined, viewed and presented themselves. Madan completed her doctoral study of the processes and challenges in implementing inclusive education of children with disabilities in Delhi schools (Madan 2002). In the end, she proposed guidelines that schools can use to prepare for inclusive education of their students. In a later Ph.D. dissertation, Kaur (2014) explored the social competence of adolescents identified to have a learning disability in their school contexts, with emphasis on the role of peers.

Masters' research on children with disability and families has examined family dynamics, sibling relationships, parents' experiences and grandparents' role. Children's emotions and their peer relationships have also been subjects of study. Some titles are presented below as exemplars of the subjects/areas studied over the years, mentioning in parentheses the year in which these were completed

The Child

1. From inside out: The experience of hearing impairment in adolescent girls (1982),
2. Physical disability and sexuality of adolescent girls (1998),
3. Experience of being a child with learning disability (1999),
4. Fear in children with special needs (2005),
5. Expression of affection in children with special needs (2006),
6. Play and young children with special needs (2006),
7. Friendship patterns of adolescents with disability in school (2009) and
8. Exploring identity of adolescents with a physical disability (2018).

The Family

1. Family dynamics and the deaf child (1976),
2. The autistic child in the Indian family (1991),
3. Growing up with a mentally retarded child: A study of adolescent siblings (1998),
4. Being a sibling of a child with intellectual impairment: Implications for family empowerment(2002),
5. Grandparents' role in the socialization of children with a disability (2004),
6. Mothers of children with disability (2010),

7. Caring for children with disability: Role of fathers (2013) and
8. Patterns of childcare among families with children with disability (2018).

Education and Intervention

1. The integrated education programme for the mentally retarded in the regular classrooms of Delhi schools: An evaluation (1981),
2. Psychosocial profile of blind adolescent girls: Planning educational activities (1986),
3. Materials and methods to teach selected concepts to 4–7 yr.-old mentally retarded children (1987),
4. Drama and stories in the education of visually impaired children (1999),
5. Child-to-child approach in the education of children with special needs (2000),
6. Empowerment of families of children and adults with special needs: Role of non-government and government services (2001),
7. Significance of inclusive education for non-disabled adolescents (2007) and
8. Place of stories in the lives of children with disability (2015).

Department of Fabric and Apparel Science (FAS)

Working with special needs persons has been one of the important areas of research in the Department of Fabric and Apparel Science. The first study in the area of disability was conducted in 1997 (Aggarwal 1997). Since then, numerous studies have been conducted at the masters' level, a summary of which can be found in Bhagat and Mathur (2010) as well as Suri and Sethi (2010).

Many of the studies had undertaken interventions for capacity building of persons with disability for their rehabilitation in garment manufacturing units (GMUs). The garment industry is labour intensive and the manufacturing processes involve repetitive, routine and continuous operations also. Depending upon the characteristics and capabilities of the individuals, suitable tasks/operations in the garment manufacturing process are identified and then the training modules are developed. The subjects are trained individually according to the specific requirements. The training is carried out under the supervision of the researcher with the help of trainers. After training, many subjects have been placed successfully in the garment manufacturing units in Delhi and NCR. These training modules were developed for persons with lower limb disability, hearing and visual impairments, and also for those with intellectual disabilities. The studies were done in collaboration with and support of Delhi-based organizations such as Saburi Disability Division (Balloons), Blind Relief Association, Aanchal School for Special Children, Amar Jyoti School, Kulachi Manovikas Kendra, Radnik Exports, Noida, and AMS Fashions.

More recently, action research at the doctoral level in this area was conducted by Chahal (2013) who developed training modules for the gainful employment of 14 persons with locomotor (5 male), hearing (1 male, 2 female) and visual (4 male, 2 female) disabilities in garment manufacturing units. The researcher developed demand-driven, disability-specific vocational training modules in garment manufacturing processes for the target participants. Inputs and suggestions from various experts were sought. Thus, separate modules for persons with the three disabilities were prepared. Each module was then developed into a detailed reference manual for trainers at GMUs. The results showed that the participants were able to perform a wide variety of jobs. They were more focused than the non-disabled employees while performing tasks and their efficiency level was comparable with that of experienced operators, or even better. Of the 14 trainees, seven were gainfully employed by the GMUs immediately after the completion of the training programme. As a result of the researcher's outreach to various stakeholders through emails, meetings, presentations and paper/article publication, many of them expressed keen interest and willingness to take this initiative forward.

Another area of work, pioneered by the faculty at the Fabric and Apparel Science Department was of developing garments for children with special needs. Through masters' theses, the process of developing special clothing for children with disabilities was documented. A detailed compilation of the studies can be found in Suri and Sethi (2010). Taking this work to the next level Ganguly (2010) turned it into a project, funded by the Department of Science and Technology, Government of India, whereby women from low-income families were trained to develop protective aids and accessories for persons with disability and were helped to make it into an income-generation activity.

In 2019, Chahal, now working as Assistant Professor at FAS Department, participated in a new initiative. She volunteered to work with the National Skill Sector Council (of National Skill Development Corporation) to train women with visual impairment. One of the skill sectors of NDSC was Apparel, Made-ups and Home Furnishings. As part of this skill sector, Chahal selected the course on 'Packer' and aligned it to make it suitable for training women with visual impairment through the National Association for Blind (NAB)—Centre for Women, New Delhi. The course with a duration of 240 hours was presented to NDSC in April 2019, and NAB had initiated the pilot training with the trainees (M. Chahal, personal communication, 9 May 2019).

Department of Food and Nutrition (F and N)

Often it is not realized that the dietary and nutritional needs of children and adults with disabilities may be different from those of typical people. The Department of Food and Nutrition has been engaged in studying children, adults and food service programmes from this perspective. As part of the current undergraduate course on Nutrition: a Life Cycle Approach, items related to feeding problems of children with special needs, and nutrition for the elderly are included. There has been doctoral research on the nutrition profile, dietary pattern and functional ability of elderly men and women (Sabharwal and Sharma 2010). The nutritional profile of young blind children living in residential schools Delhi was studied by Saxena et al. (2010). A study of energy expenditure in young women with spastic hemiplegia was carried out by Siddhu and Goel (2010). There has been active research on assessment of food service systems and development of food management guide for institutions catering to children with special needs (Thomas and Sarin 2010). A significant contribution was made by a doctoral dissertation on the nutritional status of children with disabilities (Seth et al. 2010). The database on the participant children's feeding difficulties and poor nutritional status was used to provide pointers to parents and organizations for planning nutritional intervention strategies.

Department of Resource Management and Design Application (RMDA)

At this department, several studies have been conducted related to disabilities among the elderly and the quality of their lives (Goel and Gupta 2010). An important area being design, a study undertook an assessment of public spaces in Delhi for the physically challenged. The study was conducted to understand the various features that make public spaces favourable for the differently abled in terms of accessibility and usability. Access audit of selected zones of Delhi, viz., Central, North, South, East and West, was carried out to gain an insight into disabled-friendly design features incorporated in all the areas under study (Jain 2009). A barrier-free home design for wheelchair users was studied by Khan (2014) as part of another masters' dissertation.

A third study had surveyed the interior design of regular and special schools. It aimed at gaining insight into the impact of school interiors on children's learning and development (Rizvi 2012). Furniture designs for playschools, which included children with special needs, was also undertaken (Kumar 2013). In a recent revision of its masters' curriculum, as part of the course on Advanced Space Design and Ecology, an item 'Designing spaces for special needs' has been included which addresses persons with disability, apart from others (S. Goel, personal communication, 17 May 2019).

Department of Development Communication and Extension (DCE)

The masters' dissertations in this Department have studied disability in elderly women (Anand and Chopra 2010), and the role of the pulse polio campaign in preventing disability (Anand and Kanwal 2010).

Three significant contributions of the Department through action research are as follows:

(i) The Department undertook a study to assess the effectiveness of selected video Public Service Announcements/Advertisements (PSAs) on health in disseminating messages to hearing-impaired youth and to understand their perception and interpretations regarding these PSAs. The PSAs were being broadcasted on television under the National Rural Health Mission of the Government of India. Four video PSAs on health (TB, Polio, ORS and Contraceptives) were selected for seeking feedback from the hearing impaired youth. It was found that the youth did not understand any message from the four video PSAs shown to them. The information needs of hearing-impaired youth were completely missed by the selected video PSAs. Based on their feedback, the video PSA on polio was modified and repackaged to include subtitles/close-captioning and picture-in-picture with the message in sign language. All the youth found the message in the repackaged video PSA easy to understand and very useful (A. Khanna, personal communication, May 10 2019).

(ii) A Talking Pen, a digital pen, has been developed at the Department that uses the Multimedia Print Reader (MPR) technology allowing people to hear the text while reading along. It is a revolutionary educational technology which enhances the learner's ability to study independently and brings a human face through voice in the learning process. It is especially useful for visually impaired individuals.

MPR technology allows people to hear the text while reading along. The technology uses a digital pen which has an inbuilt speaker. The technology involves printing special codes in a book that are decoded and read aloud by the Talking Pen. This assistive technology allows a readers to use it any time, any place at their convenience. For non-literate, neo-literate and readers with visual impairment, the MPR pen can assist not only the learners but also the volunteer-teachers who are often unable to provide personal attention in a group multilevel teaching–learning situation (A. Khanna, personal communication, May 10 2019).

(iii) The Department of DCE has partnered with Mind Specialists (www.mindspecialists.com—an initiative of RAHAT Charitable Medical Research Trust) and The Richmond Fellowship Society (India), Delhi Branch, to come together to create the C4MH (Communication for Mental Health) Campaign. Both undergraduate and postgraduate students are involved in this activity under the guidance of their professor Aparna Khanna. It has been in progress for 2 years since 2017.

The campaign has been envisioned as a vibrant network of individuals and organizations active in the social, education and health fields that can work together to create a movement and have a lasting impact on the way mental health is looked upon in India. It seeks to address the silence and lack of information around it and create an atmosphere of inclusiveness surrounding mental health issues at the grassroots level.

The campaign uses traditional games like Ludo, Snakes and Ladders, Tambola and Information Cubes that have been specially adapted by the Department of DCE to showcase mental health information for use in generating interest and spreading awareness on mental health in community settings. The games cover topics like myths and misconceptions around mental health, depression, anxiety, schizophrenia, OCD and addictions. The games attract the audience due to their familiarity with them, connection with one's childhood as well as the visual appeal. The audiences that are not literate can also be a part of the game and get information from the visuals used in it, thus making it an inclusive intervention for many. The games help in breaking the hesitation in people's minds regarding mental illnesses and act as a medium to make them comfortable to talk about the issue (A. Khanna, personal communication, May 10 2019).

Department of Education

After a study of the potential of the college regarding disability education, the Rehabilitation Council of India recognized LIC as an institution that could offer a bachelor's degree in special education. In 2007, LIC became the first college at the University of Delhi to offer B.Ed. special education (Mental Retardation). Since then, every year approximately 30 students graduate to be special educators or to join the disability sector in other ways.

Apart from teaching, the Education faculty has guided many doctoral and masters' dissertations, published papers and undertaken projects in disability areas. One example of a doctoral dissertation is related to inclusive education in schools (Lamba and Malaviya 2010). The subject of Specific Learning Disability has been of special interest to Malaviya who has supervised several masters' studies in this area (R. Malaviya, personal communication, May 13 2019). Two projects that Malaviya has been engaged in at LIC are

(i) Disability and inclusion: Perceptions and issues in contemporary India (2015–2016). It was a 15-day course for students with disability from the University of Edinburgh and King's College, London. The objective was to familiarize the participants with issues and challenges of persons with disability in India. The course was sponsored by the University Grants Commission and the University of Delhi under Connect to India project.

(ii) Learning–teaching processes: Using a project approach development of material for teaching of concepts at primary school level for students with disabilities (2016–2017) was undertaken. The project was sponsored by the University of Delhi's Innovative Project Scheme.

Conclusion

With the notification of The Rights of Persons with Disability Act 2016, which replaced the existing Persons with Disability Act 1995, it has become incumbent on all higher education institutions as stakeholders to engage in the study of disability through their students' course work and research. Sensitizing students and encouraging them to conduct research on issues of disability that concern the Indian society, in particular, have long-term positive consequences for the status of persons with disability and their families. Lady Irwin College as a pioneer higher education public institution, under the University of Delhi, has successfully attempted to play a constructive role in this direction. The fact that all its six departments have been able to contribute to the study of disability has a message. An academic does not have to be an 'expert' in the area of disability or special education in order to undertake its study. When one works with an open mind and can accept disability as part of normal human experience, self-learning goes a long way in providing direction to knowing about children and adults with disability.

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Chapter 9
Establishing a Disability Studies Centre in a Law University: Recounting the CDS NALSAR Experience

Amita Dhanda

Abstract The article explores potential of Disability Studies to challenge oppression by reflecting upon the lived experience of running a centre for disability studies in a law university. The article distinguishes between the internal and external challenges faced by the Centre and arrives at the conclusion that whilst disability studies centres could provide sound theoretical support to advocacy and activism of disability activists, they were ill-suited to be front runners in the activism project.

Keywords Disability studies · Centers for disability studies · Disability activism · Law reform

Introduction: Need for Disability Studies

In the post-Foucauldian era, the intimate connection between power and knowledge does not need to be justified, even if the relationship does not guide the praxis of the Academy. Controversies surrounding curriculum development[1] and prescribing, of course, readings (Delhi Historians group 2001) yet again show that research and education are often guided by the concerns and preferences of the dominant majority. Specialized study systems have been created in order to deconstruct mainstream processes and to show how they contribute to the domination of the oppressed. Subaltern (Hung 2008; Onazi 2009; Sharma 2015; LaGreca 2015) and Gender studies (Stefan 1992; Frug 1992; Binion 1997) are obvious examples. Disability Studies are prompted by similar concerns. The non-disabled gaze has viewed disability as deficit and inadequacy; this ableist standpoint has then produced bodies of knowledge which aim at alleviating or at least managing the impairment. Professionals who have acquired special expertise to act on the disabled body and mind are believed to

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[1] Aruna Roy versus Union of India MANU/SC/1519/2002 was a public interest petition filed in the Supreme Court which contended that the national curriculum framework was against the constitution and had been formulated without obtaining approval of the Curriculum Advisory Board.

A. Dhanda (✉)
NALSAR University of Law, Hyderabad, India
e-mail: amitadhanda@gmail.com; amitadhanda@nalsar.ac.in

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possess this knowledge. An inevitable consequence of such expert management is that the experiences and understanding of persons with disabilities are either negated or rendered invisible. Disability studies is an effort to recover the voice of persons with disabilities and to look at the disability experience from the inside (Ghai 2018). Ableism has imperialized the body politic of disability; in order to challenge this dominant understanding, there is a need for disability studies (Kanter 2010; Kroger 2009; Paetzold 2010; Siebers n.d.).

Having acknowledged the need for disability studies, it is logical to next raise concerns around the how and what of these studies? These concerns could be addressed theoretically by describing the literature on the subject and evaluating the practical possibilities of each approach. Another option could be to examine the various operational models and to comment on their relative successes and failures. Instead of choosing any one of those options, I have decided to address these concerns through an experiential case study, i.e. I have chosen to examine in depth and detail the working of one Disability Studies Centre and the Centre I have selected is one in whose establishment, operation and envisioning I have been personally involved. This methodology could be considered deficient on objectivity; it is however hoped, that a first-person evidence-based examination would minimize that deficit and still yield returns of public reflexivity.

Before zeroing in on the organization, which is my case study, I have as a backdrop to that examination, outlined the various possible institutional models and the ideational purposes they could achieve. Subsequently, I elaborate on the institutional design of Centre for Disability Studies, NALSAR, Hyderabad (hereinafter CDS), evaluate its strengths and weaknesses, describe the activities undertaken by CDS and reflect on the lessons learned from the choices made.

Other Institutional Models to Undertake Disability Studies

Since this paper is primarily describing and evaluating a disability studies centre in a law university, in order to distinguish CDS from other Disability Study Centres, this part of the paper examines other sites at which Disability Studies can be undertaken and what the potential and limitations of those institutional models.

Multidisciplinary Centre in a University

Insofar as there is a disability perspective to every discipline, this model of doing disability studies brings together, adherents of various disciplines at one site to explore the disability perspective of their discipline. The evident strength of the strategy is that it allows for the emergence of an overarching perspective on disability. This design by bringing together people from varied disciplines to do disability studies creates an environment of collegiality, which is essential to the growth of any cutting edge scholarship (Tacha 1995; Seigel 2004; Wolff 2012). Even so, since the boundaries of each discipline are being pushed by a limited number of practitioners, this approach could obtain scholastic space, yet have no impact on the parent discipline. Further, the depth at which interrogation of the main discipline is undertaken would depend upon the competence and imagination of the particular person or persons undertaking disability studies.

This disadvantage could be reduced by following the Syracuse University strategy of promoting disability studies—whereby the interdisciplinary content of each discipline is nurtured by admitting students with an interest in disability issues from all disciplines.[2] A multidisciplinary classroom has been found a suitable site to explore the manner in which different disciplines could feed into the development of disability studies.

Disability Studies University

In this model, each discipline could have its own department or centre which undertakes a reconstruction of the discipline from a disability perspective. This design offsets one of the major disadvantages of the previous model. However, the challenge here would be to attract a sufficient number of scholars towards the specialization, both as faculty and as students. Without the numbers, this knowledge production exercise could be a cry in the wilderness. An exclusive university may not be best suited to countermand the isolated existence of disability and to challenge the hegemony of mainstream knowledge. As it stands, this model has been used by the one disability university in the country[3] to reinforce the individual deficits approach of disability. The university conducts courses in special education and rehabilitation to create personnel who can help individual persons with disabilities to cope with their impairments. The structural barriers, be that of the physical environment or normative regimes or social attitudes, which impede the social inclusion of persons with impairments are not on the curricular or organizational agenda of the University. Instead, the University naturalizes the exclusion of persons with disabilities and provides services for the excluded community.

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[2] The website of the Centre admits to the interdisciplinary leanings of the Centre by unequivocally stating that no single academic discipline can place a claim on disability studies. Hence the centre draws on a variety of disciplines to understand the social–cultural and political situation of people with disabilities. https://soe.syr.edu/disability-studies/ last visited on 29 May 2019.

[3] The Jagadguru Rambhadracharya Handicapped University is a private University set up by UP Act No. 32 of 2001 in Chitrakoot, Uttar Pradesh was established to provide higher and professional education to persons with disabilities. http://www.jrhu.com/ last visited 30 May 2019.

Disability Studies Chairs

This strategy could be usefully employed to acknowledge experiential expertise. Eminent persons with disabilities could be invited to occupy these chairs so that the prejudicial doctrine of disciplines could be challenged in real time by lived experience. The strategy has immense potential for sensitization and public deliberation. In order to realize this potential, it is important that these chairs are established in all parts of the country in all kinds of institutions.

Such universal coverage is also required because there is a marked difference in the constitutional and the CRPD approach towards disability. Whilst both the states and the centre are meant to respect the international commitments of the country, the primary reporting obligation resides with the centre. The federal division affected through the lists in the Indian Constitution has placed the responsibility of addressing disability issues on the states. This responsibility has been formulated in welfare terms. Entry 9 of List II requires states to take care of the disabled and the unemployable. In comparison the CRPD speaks of inclusion and suggests strategies for its realization, be it by awareness raising, education and work entitlements and habilitation and rehabilitation policies. There is a need to acknowledge this paradigmatic tension and generate discourse which outlines how the international obligation can be fulfilled in accordance with the Constitution. The chairs could help generate such discourse and the nature of the discourse could be influenced by the managerial design and disciplinary leanings of the parent institution. Chairs in different kinds of learning institutions could generate disability understanding through individual and collaborative activities. The collegial network of all occupants across institutions could guard against an exclusive reliance for the success of the chair on the individual charisma of the particular occupant.

Research Centres Within Single Discipline Universities

This strategy is being mentioned primarily to underscore that disability studies should be undertaken in every kind of educational site. Single discipline universities are established to allow for intensive study of the discipline, and a research centre in such a university has the potential of creating a disability perspective in all the sub-specializations of the parent discipline. Other than this adding and stirring strategy, disability studies could cause some foundational questions to be raised on the parent discipline. Thus, how would social work alter or medicine change if disability studies centres are established in such universities? Would it be possible to wean medicine away from its one-size-fits-all perspective of the human body, stop categorizing it as normal and pathological and study the functioning of the so-called aberrant body on its own terms and not in relation to the allegedly normal body? To find scholars interested in examining the normative underpinnings of a discipline, which activate the processes of exclusion and to obtain empowered space for such scholarship, would be the challenge.

Research Wings of Advocacy Centres

Legal aid clinics and human rights centres engage in advocating for the entitlements of persons with disabilities. The Legal Services Authorities Act, 1986 includes persons with disabilities in the constituency of people entitled to free legal aid. However, both the clinics and the centres are involved in trying to realize, for individual persons with disabilities, those entitlements which are already provided for by legislations, schemes or programs. The establishment of research wings in such advocacy centres would allow for the development of disability centric reasoning, which is being developed to address the lived realities of persons with disabilities. Such research centres could promote the growth of evidence-based disability advocacy provided they are personed by people who understand disability and are committed to pursuing applied instead of pure research. Without such understanding, the research centres may generate academic articulations of little practical utility.

Research and Documentation Wing in Equal Opportunity Centres

Equal opportunity centres have been established in universities in order to enable inclusion of marginalized groups and to ensure that sanctioned entitlements reach the identified beneficiaries.[4] These centres have primarily engaged with service provision without documenting the process. A research and documentation wing could allow for the lived realities of persons with disabilities influencing policymaking. Yet again, without adequately trained personnel who have the capabilities to analyse factual data and glean policy learnings from the lived realities of the primary beneficiaries, the potential of this strategy cannot be realized.

Disability and the Discipline of the Law

Varied schools of jurisprudence highlight the fact that the study of law can be undertaken from several standpoints (Davies 2017). Proponents of the natural law theory seek an inextricable connection between law and morality. A law devoid of morality they hold is no law at all (Fuller 1969, 2019); however, the content of morality has

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[4] The website of the Equal Opportunity Centre of the University of Delhi claims to provide comprehensive services and support to students with disabilities. http://eoc.du.ac.in/web/index.php?page=establishments (last visited 30 May 2019). The Equal Opportunity Centre of Jawaharlal University extends its services to all marginalized communities including scheduled castes, scheduled tribes, minority communities and persons with disabilities. https://www.jnu.ac.in/eoo last visited 30 May 2019.

been variably defined at different junctures of history (Freeman 1994). The subjectivity of this variance bred a social uncertainty which prevented the law from performing its primary role. In order to promote order and predictability, the identification of law was linked to its source (Duxbury 2005). Thus, norms emanating from a recognized legal authority, be it king or parliament, were categorized as law (Bix 2001, 2017). This positivist capture of the legal imagination made the distinction between law and non-law easy to implement. This enforcement advantage was obtained by making the substantive content of legal norms difficult to question. Subsequent schools of thought have demonstrated with some success, the justice inadequacies of positivist law (Coombe 1998). Notwithstanding these critical enquiries on the nature of law, the positivist perception on law continues to dominate (Hart 1967).

Consequently, the law has increasingly become an instrument of state power. Legal validation of a knowledge system extends to that knowledge, the authoritativeness drawn from the force of law. Conversely, the impact of exclusion is redoubled when undertaken through the instrument of law (Naffine 2003, 2009, 2011). Furthermore, since legal norms are backed by sanctions, any process of exclusion cannot be just remedied by social acceptance. Legal disqualifications have to be legally rectified. Thus, for example, if the law lays down that persons with intellectual disability cannot enter into contracts if they do not understand the nature of the transaction or its impact on their interest, then irrespective of the understanding possessed by the particular person with intellectual disability, his or her capacity to contract has been made subject to legal scrutiny (Dhanda 2000). This reality has a special significance for persons with disability as deficit perception has disproportionately influenced legal definitions of disability. Consequently, even when the law says the person cannot contract only if by reason of intellectual disability, he or she cannot perform the specified function; in practice, the disqualification will over include and most persons with intellectual disability would be considered incompetent to contract. Without having the educational or experiential expertise of persons with intellectual disability inducted into the process of interpretation, it would be difficult to establish that the legal presumption of incompetence was discriminatory and its offer of blanket protection is driven by prejudice and not evidence. Social investments in capability development without law reform cannot alter legal understanding; such socially empowered person would continue to be deemed legally incapable. Thus, the legal construction of disability needs to be understood and challenged if the empowerment project of persons with disabilities is to advance. Otherwise, a retrograde law has the potential to derail empowering initiatives on the ground (Dhanda 2006).

Law universities are institutions of higher education that are statutorily authorized to impart legal education. Unlike traditional universities, the research and education activities of a law university only revolve around the discipline of law. Since lawyers are produced by such universities to fulfil the legal personnel requirements of the legal system, the dominant approach of the educational curriculum of these universities is to engage with subsisting law.[5]

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[5] Traditionally, legal education was imparted through law faculties or departments which were a part of general universities. This design was altered in 1986 when the first statute to establish a law

Disability Studies Centres have been proposed to generate knowledge from the perspective of people with disabilities. Such centres in law universities aim to operate as sites of emancipation within conservative territories. Whilst the university concentrates on prevailing law, the centre is engaged with what the law ought to be. There is thus an inherent tension between the operational objectives of the centre and the university.

A tension which is exacerbated by the fact that a large part of the legal course curriculum concentrates on providing information on the laws enacted by legislatures and interpreted by courts and only rarely is this output critiqued.

Thus, for example, a family law course would inform of the legislative requirements for obtaining maintenance, discuss the manner in which courts have interpreted those conditions, but would rarely speak about the injustice of a woman's contribution to a marriage being acknowledged only through measly monthly maintenance, and the inequity of not having a law on matrimonial property on the statute book (Parashar and Dhanda 2008).

In another illustration, the law of contract course would inform students of categories of persons who are not entitled to contract, that is minors or persons of unsound mind, without any deliberation on the impact of such a provision on working children or on persons with disabilities, even when it would be pertinent to ask whether such blanket prohibition of contracts by minors was justified when India has never completely prohibited child labour. After all, if children were being permitted to work, then should they not at the least be able to safely keep the money they earn (Lansdown and UNICEF Innocenti Research Centre 2005)? Persons with mental or intellectual disabilities irrespective of their functional capabilities are forcibly provided protection; conversely, a number of non-disabled persons continue to be considered legally competent to contract even if they lack the judgment to understand the nature of a contract and its impact on their interests. Such non-disabled persons are in need of adult protection but fail to obtain it as they are not seen to need the protection, which is routinely handed out to persons with intellectual and mental disabilities.

Legal disability studies could be engaging in the following activities: documenting the legislative, administrative and judicial initiatives relating to disability; analysing extant laws and policies from a disability perspective and driving change through such analysis; and finally providing voice to the perspective and aspiration of persons with disabilities. The first two initiatives defer to the leadership of the State or the dominant mainstream insofar as the Centre is primarily engaging with the legal output

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university was enacted by the Karnataka legislature. These law schools or law universities were autonomous institutions with all the governance freedom of a university and the power to award degrees. Whilst, the law degree was awarded after graduation in general universities, the national law schools admitted students after they had completed their schooling. The law degree was awarded after 5 years of studying law and non-law subjects. Whilst the integration with law was largely done with a bachelor in arts, some law schools also combined law with a bachelor in the sciences or commerce. There are 23 such law schools in the country today. This case study has been created out of NALSAR University of Law, Hyderabad, the second law school established in the country in 1998.

generated by the State. In the third initiative, however, the reform is driven by the constituency. Listening to the voice of persons with disabilities requires deconstruction and reconstruction of the law from the standpoint of the excluded.

An information strong legal education would authoritatively instruct prospective lawyers on the fact of the law; this written in stone instruction creates a generation of lawyers who resist all change, but especially emancipatory ones, as such change they feel questions the foundational norms of the paradigm in which they were instructed. This antagonism is expressed even when a person is studying at law school; however at that time the person is still acquiring the aforesaid authoritative understanding, a centre for disability studies in a law university can strategically use its presence to sow seeds of doubt. With this scepticism, ambiguity can be introduced in the plain language of the law, which can then be interpreted not in according to the understanding which prevailed when the law was enacted but according to contemporary understanding.

It is in the backdrop of this above-described relationship between disability study centres and law universities that the second half of this paper narrates the establishment and operation of the Centre for Disability Studies, at NALSAR Law University.

This case study on the Centre (hereinafter CDS/Centre) has been divided into two parts. The first part narrates the ideological and logistical challenges faced by the Centre within the University, and the strategic choices that were adopted to constitute the Centre as an empowering space for human rights. In the second part, I narrate the Centre's encounters with the government and civil society and the manner in which these encounters have contributed to my reflections on the role of CDS in advocating for disability rights and developing disability studies.

Centre for Disability Studies NALSAR

The Centre for Disability Studies at NALSAR was established in 2008 as a funding initiative of the administration. Since the University had a professor who could assume the responsibility of head, no further deliberation on the vision or mission was considered necessary. Individual members of the administration primarily had a deficit-based welfarist approach towards disability, but at no point pressed for that perspective to inform the functioning of the Centre. Simultaneously, except for allowing accessibility features to be factored into the University buildings, the disability perspective in no way informed the University. Consequently, what this Centre was to do and with resources from where and with whom were matters which were entirely left to the judgment and imagination of the Head of the Centre.

Nurturing New Paradigm in Old Spaces

CDS was established before the University had enlarged its educational agenda by opting for a credit-based elective system. In those times, the University primarily adopted a conservative approach towards legal education, which when operationalized meant informing students of the various laws which were enacted by Parliament and interpreted by the Courts. The law question was thereby answered in positivist terms. The word of the legal institutions authorized to make law was accorded finality. The law was what they declared it. With such an institutional approach, legal norms were not subjected to a value-based evaluation. In contrast to the University, CDS needed to be driven by reform. As only through the discourse of legal reform could the disqualifying regimes subsisting against persons with disabilities be challenged and empowering legislations enacted. Insofar as the University and the Centre had opposing agendas, CDS had the unenviable task of pushing the case for the new paradigm whilst being housed in the physical and intellectual spaces of the old.

Symbiotic Relationship Between Teaching and Research

CDS NALSAR attempted to meet this challenge by creating a symbiotic relationship between research and teaching. The strategy was devised by drawing from Thomas Kuhn's analysis on paradigm shifts. Kuhn contends that the proponents of an old paradigm cannot be the advocates of the new. For the new paradigm to win adherents, it would need to construct curriculums, produce study materials and thereby create cadres who are trained under the new paradigm (Kuhn 1999). The deficits approach towards disability and the denial of legal capacity to persons with intellectual and psychosocial disability have been unquestioningly incorporated in all mainstream legislations; even disability-specific legislations have been drafted on the substratum of this presumption. In the face of this reality, to mount up a critique from the inside of these laws seemed difficult. I therefore floated a few courses, which helped question some legal presumptions.

One course which had a long innings was a course entitled Comparative Disability Jurisprudence. The course was devised to question the disability-related presumptions of Indian law by comparing them with the knowledge emanating from other disciplines as also from the laws of other countries. These courses were primarily aimed at generating a healthy scepticism towards existing laws—a task which was less difficult when the scrutiny was done from the outside through a new course.

Since stereotypes are reinforced by being presented as truth, I floated another course which showed how prejudice was paraded as truth and consequently denied participation rights to groups on grounds of race, gender, disability and sexual orientation. The course was titled "Pluralizing Inclusion: Equality and Non-Discrimination in a Globalizing World" and aimed to challenge essentialist attributions to any group. The power of prejudicial labelling when undertaken through the law was studied through a course which was entitled “Universalizing Legal Capacity”. In addition to these specialized courses, the exclusion imposed on persons with disabilities was studied in mandatory courses such as Law and Poverty and the close relationship between power and knowledge was examined in “Applied Jurisprudence”. The courses were not evangelical enterprises hence it would be incorrect to claim conversion. What the courses succeeded doing at NALSAR was they sowed a seed of doubt in the mind of the students; consequently, a mechanical mouthing of prejudicial statements on disability started to become politically incorrect.

Except for Law and Poverty (wherein disability was no more than a case study) all the above-mentioned courses were electives, which meant that they would run only if students opted for them. The sensitization potential of the courses was accordingly limited. It was therefore important to draw students towards CDS. A link needed to be forged between teaching and research.

The establishment of CDS and the adoption of CRPD nearly coincided. Since India ratified early, the country was under an obligation to bring its laws in harmony with the Convention. To undertake these law-centric exercises, institutions and individuals with an understanding of the CRPD were in demand; CDS qualified and obtained some important contracts. CDS was selected to draft the initial country report for India, appointed legal consultant to the Committee which was to draft the New Disability Rights Bill and was assigned the task to redraft the National Trust Act. Students were interested in assisting for these contracts but could not get involved without obtaining rigorous training in disability rights. Consequently, the optional courses on Comparative Disability Jurisprudence were fully subscribed and students started to gravitate towards Disability Law and Research.[6] Since the courses were being planned in the backdrop of the CRPD, they were aimed at developing justification for reconstructing extant disability law. India had ratified the CRPD hence the State was obliged to reform existing Disability Law. This reformist concern brought a convergence between the objectives of the Centre and the University. This convergence may have not sufficed to attract students towards Disability Law, if the Centre had not been engaged in doing cutting edge work in Disability Law and Policy. At that initial stage when the Centre had little to offer in monetary rewards, these high-profile policy interventions made a substantial contribution in making CDS a preferred internship and research destination for law students from all parts of the country.

The above consequence could be viewed as fortuitous and hence not replicable. The strategic learning that we acquired was that if a research centre wished to challenge subsisting learning, then it needed to excite the curiosity of the younger generation. A researcher looks for answers if the question is of interest. We needed the younger generation because it was not indoctrinated in the old paradigm and hence more open to conviction. Since discourse creation and advocacy would need to be an integral part of disability writing and research, it seemed apposite to so design the place that persons best suited to perform the task were attracted towards it.

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[6] A number of students went on to specialise in disability studies for their doctoral work.

For the same reason, the Centre inducted a series of fun activities in its schedule. Other than film screenings and discussion, sensitization was undertaken through a range of workshops which taught registrants to campaign and write for disability rights. I have found that any sensitization exercise, especially with students, needs to be subtle and oblique. Consequently, we were teaching campaigning and writing, which was mediated through disability because we were a centre for disability studies. The traction of the idea could be judged from the positive response that all CDS invitations obtained from the students.

The aforesaid initiatives were effective in obtaining followers; the goal of retention needed distinct and more time-consuming strategies. The original plan was to place the responsibility of inducting more adherents on the first set of followers. Subsequent research showed that the nurturance and sustained attention this strategy required was not feasible and additional procedures were required. Subsequently, CDS worked on creating a community of scholars who are willing to engage in an off-site and on-site basis with critical questions of disability rights. Also, whilst the Centre needed core staff to ensure stability and continuity in the conduct of its activities, it also needed a steady stream of visiting scholars, interns and volunteers. Such visitations were needed for two reasons. Effective sensitization required spontaneity and freshness and that is better obtained through itinerant staff and volunteers than paid employees. For the status-quoist culture of the university not to infect the Centre, it was important that the Centre kept steady contact with people who would feed its radical impulses. For such visiting to happen in a structured manner, it was important that the birds of passage found a conducive migratory environment. Learning from its initial heady years, CDS is drawing a strong cultural calendar with carefully built activities which garner visitor enthusiasm and convert it into sustained goodwill.

The above narrative was a description of the initiatives that were taken by CDS to make space for its radical agenda, without coming into conflict with the education programs of the University. These initiatives were implemented voicelessly relying upon the fact that in Indian academic institutions, segregation of domains is practised without question whilst interdisciplinary study had to be advocated for. The open connect between CDS and the University was undertaken administratively. Except for providing extra time to attempt exams to persons with disabilities, the examination rules at NALSAR were uniformly formulated for all. In comparison, disability diversity and reasonable accommodation for inclusion was the ruling ethic of CDS. As the university started to recognize individual preference by ushering a choice-based academic credit system, this compulsion to individuate started to surface in other dimensions of university life such as evaluation, supplementary exams and detention. This demand for individuation was greatly facilitated by extending the principle of a reasonable accommodation to all students, instead of limiting it to students with disabilities (Dhanda 2016, b). Once diversity and vulnerability were universally recognized, the accommodations demanded students with disabilities were sought and provided in more matter of fact terms. The incorporation of the principle of reasonable accommodation into everyday academic administration singularly contributed towards acceptance of disability diversity. More importantly, it demonstrated that disability jurisprudence had the potential to protect the human rights of all persons and need not be restricted to persons with disabilities. This need had to be self-declared and supported with similar evidentiary materials as required from persons with disabilities.

As already mentioned, CDS NALSAR was required to undertake cutting edge disability law work for the country. This external recognition substantially contributed to the recognition of the Centre within the university. This reality came home to us at CDS when the University condemned the Government of India's dilution of the disability law and actively lobbied for the Bill of 2014 to be referred to the Parliamentary Standing Committee. At that point, the University embraced the CDS position as its own and thus the radical politics of the Centre became the politics of the University (Reporter 2014).

This convergence of the politics of the Centre and the University can be described as the complete acceptance of the Centre by the University. The Centre is now acknowledged as the subject expert on disability within the University. All matters, be that of service provision for people with disabilities or analysis of disability policy, are routinely referred to the Centre. How the Centre sees itself after its high-profile forays is a matter I return to after dwelling on the relationship of the Centre with the outside world.

CDS NALSAR in Interaction with the Outside World

As already stated, CDS was to assist in the drafting of the new law on disability rights by the government-appointed committee, which had representation from civil society, some ministries and some state governments. It was also to provide the first country report on the Disability Rights Convention to the Ministry of Social Justice and Empowerment. Before finalization in the spirit of the convention, this report was to be shared with disabled people and their representative organizations; the Central Coordination Committee established by the goverment of India and vetted by the Legal and Treaties Division of the Ministry of External Affairs. CDS was also to propose amendments to the National Trust for Persons with (autism, cerebral palsy, mental retardation and multiple disabilities) Act of 1999. This effort also needed a consultation with the disability sector and civil society as also the Governing Board of the National Trust. The above description was aimed to bring home the highly consultative nature of the procedure and a large number of stakeholders whose opinion had to be obtained before the particular legal artefact could be created. Also, in all pieces of work CDS was in an advisory position but the public domain entry of the work would be in the name of another. When the contract was accepted by CDS, this distinction between producing work in your own name and creating work in advisory capacity was not entirely understood. Consequently, the disputes and dilemmas which could emanate from the distinction were also not anticipated. Since this piece is not about the substantive content of these differences, in what follows I reflect on what we learnt at CDS by doing the law reform exercises and the country report. The question needs to be asked because its answer does not only impact upon the identity and ideology of CDS, but also speaks to the relationships that a technocratic organization like CDS needs to forge with state and civil society.

Law Reform Efforts

The Disabilities Act of 1995 (hereinafter PWDA) guaranteed certain socio-economic entitlements to named impairments. Before the statute was enacted, a number of these entitlements were secured in non-statutory schemes. Statutory endorsement stabilized the realization of these rights even as the process of obtaining them became more formal. In order to avail of these entitlements, the legislation required persons with disabilities to provide authoritative documentation of the extent of their impairments. The quantum of some entitlements could be raised for those persons with disabilities whose impairment percentages were higher than the specified threshold. Insofar as these entitlements were guaranteed by law, the statute made the realization justiciable and both the Supreme Court and the High Courts passed orders which improved the process of implementing the rights. The PWDA did not concern itself with civil-political rights, and questions of autonomy and choice were not addressed. The right to equality and non-discrimination also did not concern the statute.

In comparison to the PWDA, the CRPD acknowledged the tenet of indivisibility and provided for both civil-political and socio-economic rights (Dhanda 2008). Though also relevant for socio-economic rights, the matter of autonomy and choice is integral to the realization of civil-political rights. Whilst PWDA did not address the matter at all, other legislations operated on the presumption that persons with intellectual and mental disabilities lacked the capacity to take their own decisions. Since they lacked the capacity, significant others be it family or friends could be appointed as their substituted decision makers be it as guardians or as trustees. This denial of legal capacity was categorized as prejudice or protection depending upon ideological predilection of a group or individual. The CRPD is an attempt to construct a legal regime where persons with disabilities were required to be treated on an equal basis with others. The ethic of equality required that persons with disabilities are recognized as persons before the law having the capacity to act on all aspects of life on an equal basis with others (Dudley et al. 2012). In the deliberations surrounding the new law, this recognition of legal capacity proved to be most contentious. Whilst the autonomy promoting groups desired that the new law should recognize the legal capacity for all without exception, the protection-oriented groups asked for a saving of guardianship laws considering no systems of support were in place (Dhanda 2017).

CDS as legal consultant suggested a way out of the conundrum by incorporating a transitional provision in the legislation which would set the wheels in motion to reach towards the goal of full legal capacity. Consequently, the statute firstly recognized that all persons with disability were persons before the law and had full legal capacity on an equal basis with others. Since the contention of the absence of support was factually accurate, instead of permanently ensconcing guardianship in the law, the statute made the normative move towards dismantling guardianship laws by laying down that from the time that the statute is enacted all total guardianships would start to function like limited guardianship. This meant that from the best interest regime, the statute made a move towards participative decision-making since the limited guardian could not take any decisions without consulting with the person with disability. During this transitional period, the appropriate governments were required to put in place suitable arrangements of support and then proactively dismantle the arrangements for limited guardianship. An individual person with disability who was in a limited guardianship arrangement could assert the legal capacity acknowledged by the statute to dismantle the arrangement earlier. The provisions only provided for a movement from total to limited guardianship but not the other way around as such a move would be in contradiction of the recognition of legal capacity. Also, the statute was silent on whether a limited guardian could be appointed after the statute came into force. There was no procedure for the appointment of a limited guardian; yet total guardianships could be converted to limited guardianship. This paradoxical situation was a space of deliberate legal ambiguity which was created so that a grey situation is dealt in an individuated manner instead of a general one.

This attempt at trying to address everyone's concerns was not appreciated by that body of opinion which was demanding complete autonomy. They saw it as a regression and a betrayal of the CRPD mandate. The advocates of protection did think that they could live with the aforesaid solution. The position also received an endorsement from disabled people and their organizations as well as parents' associations as the Committee travelled through the length and breadth of the country with the draft legislation.[7]

The Committee presented a unanimous report, but this unanimity did not earn a similar endorsement from the central and state governments. Instead, legislation which diluted all reformative provisions was hurriedly introduced in the upper house of Parliament. Thus, there was no recognition of universal legal capacity but limited and total guardianship were made alternative options. Since the proposed legislation was promising, some affirmative action measures in education and employment even to persons with intellectual, developmental and mental disabilities, a number of impairments which were not included in PWDA felt that these economic entitlements were more important than the esoteric concerns raised by equal legal capacity. However, these concerns of the excluded impairments could not find traction and due to the Bill inviting countrywide protests, it was referred to the Standing Committee in Parliament. The Committee in its report acknowledged the concerns of the stakeholders and asked the government to consult further to resolve the pending concerns. The government received the representations but did not start consultations anew.

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[7] It is pertinent to point out that the legislation was translated into 16 languages of the Union along with being available in Braille and in audio tapes. The consultations caused the legislation to be further nuanced and the final report acknowledged the inputs received from every consultation. The various versions of the Bill have been archived on the website of the Centre and can be accessed at http://www.disabilitystudiesnalsar.org/newlaw.php.

Dilemmas in Law Reform

To elaborate on the first dilemma. CDS as the technical expert informed both the State and Civil Society of the international legal position. It also communicated with the organizations of persons with developmental, intellectual and psychosocial disabilities that there was little chance of their being able to obtain in fact the economic and educational entitlements guaranteed in the new law unless the legal capacity provisions were rectified. The transitory strategy was agreed to in the Ad Hoc Committee but perhaps not understood and hence there were no real takers for it even if its potential as a smart solution to break impasse was recognized in international discussion forums on legal capacity. Are legal advisors in social justice causes similarly situated as advisors in personal or private causes? Did the Centre's duty cease after providing the advice? Can CDS take a political position which is at odds with the disability sector? If yes then what happens to nothing about us without us? Should a division be proposed between advocacy for education and advocacy for action and the Centre situate itself in the first space leaving the second for persons with disabilities and their representative organizations?

The questions arising in the PWDA recurred in the CDS-amended draft on the National Trust Act of 1999 (hereinafter NTA 1999) where CDS reworked the National Trust Act so that the Trust moves from a guardianship-driven regime to a support-enabled one (Glen 2018, 2017). Further to counter the dependent stereotypes which especially attach to persons with intellectual and developmental disabilities, CDS suggested that the NTA should become the statute which makes provision for the support of all impairments and most especially for persons with psychosocial disabilities. The Amendment Statute in acknowledgement of intersectionality and human interdependence also provided for creating alliances between persons with disabilities and other groups disadvantaged by gender and caste. This law reform measure whilst in harmony with the CRPD did not find favour with the Governing Board of the Trust even as the Chairperson Poonam Natrajan saw it as the way to go. The Governing Board was of the view that the Trust had been set up for the most marginal disabilities and in universalizing its objectives, these most marginalized groups could be re-marginalized. Since the draft had been created as part of a consultancy agreement and the Trust was in official communication with the Ministry on the amendment of the NTA, even the discourse potential of the draft was not realized.[8]

This constraint was not felt whilst critiquing the Mental Healthcare Bill of 2013 (hereinafter MHCB) as CDS had not entered into any contractual obligations with any state or non-state entities. Also, though CDS was not an insider to the process, its opinion was taken note of by the Parliamentary Standing Committee on Health. Herein too, as in the PWDA and NTA process the Standing Committee report only agreed with CDS on ancillary matters; its opinion on the impact of MHCB on the

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[8] The various suggestions made by CDS in reworking the National Trust Act have again been archived on the website of the Centre http://www.disabilitystudiesnalsar.org/nt.php.

CRPD recognized rights of legal capacity, liberty, integrity and right to live in the community were ignored.

CDS as a consultant was not able to wield any greater influence with the government, even as it was perceived to be an ally of the government. CDS was thus compelled to ask itself what were the benefits of alliancing with the government when no deference was accorded to its expertise instead it was faced with the loss of integrity and credibility.

The Initial Country Report

This last point can be further sharpened by describing CDS's experience of doing the initial report of the country under Article 35 of the CRPD which has to be submitted to the CRPD Treaty Body. The reporting guidelines issued by the Treaty Body were a comprehensive demand for providing quantitative and qualitative data on each of the CRPD articles. Without prejudice to the detailed guidelines, the Treaty Body also suggested to the state party that the obligation to file compliance report should be used by the State to take stock of the status of disability rights and blueprint for the future. We saw this one guideline the most critical to preparing the report. To that end, it was decided that the status of relevant schemes, programs and services in the country should be documented. In preparing that documentation, the report should not limit itself to government initiatives alone and look at both state and non-state services. Also, report on the ministries who had undertaken initiatives which would impact on persons with disabilities but either did not acknowledge them or acknowledged them in such a way that it would not result in the inclusion of persons with disabilities.

Both these proposals were struck down for different reasons. The inclusion of civil society interventions, it was felt would subsidize the government as it could hide its sins of omission behind the initiatives taken by non-governmental organizations (NGOs). The second objection revolved around the criteria of selection. Since all NGOs could not be included, the ones who were left out could feel discriminated. The last was the objection of bulk. A short report in which even the initiatives of the state governments could not find full mention, NGOs could not be provided space.

The second reporting strategy was suggested to ensure that disability was included in all policies of the Government of India. Thus, if the Ministry of Culture had schemes and programs to encourage all bodies of culture, it was pertinent to point out that disability culture had not been specifically included. Or if there was a sanitation scheme which provided for the building of toilets, then was the fact that a wheelchair-accessible toilet would require a wider door and hence more wood and more money had not been taken into account. Whilst the need to obtain accountability from other ministries was acknowledged, there was an unwillingness to undertake such questioning in a document which was to be internationally submitted. Consequently, this strategy was also dropped. Subsequent drafts resulted in the critical components to be dropped one by one. At first, it was suggested that whilst stocktaking under each article was acceptable, such stocktaking should not smack of fault-finding. Then it was stated that blue printing under each article was excessive and only a concluding chapter could be included. Next, this chapter was also dropped. And finally, all references to court judgments were removed as the need to seek judicial review demonstrated governmental dereliction.[9]

Several efforts were made to persuade the Ministry to view the matter otherwise. It was pointed out that the non-disclosure of facts would result in the Ministry being charged with suppression of facts. The Ministry was agreeable to receive such scathing reports from NGOs in their alternate reports but were unwilling to make any self-reflective admission in the country report. The CDS prepared report was tentatively titled “Poised for Change” to capture the reflective tone of the report. The final report most appositely dropped the title. CDS then insisted that it should be acknowledged for no more than providing relevant materials, since the selection, design and presentation were done by the Ministry itself.

CDS had bid to prepare the country report for the government, in the belief that the officials in the Government of India did not have the time to collect relevant materials and then to process and present them. If an expert body assumes such responsibility, the task of reporting would be fulfilled in both letter and spirit. Whilst in the initial stages CDS got some support from the government on this plan of action, in the progressive years the real politick of international law prevailed over the spirit of human rights. CDS was yet again forced to consider whether an organization, which wished to uphold and advance the substance of International human rights law, could align with any authority who wished to do no more than meeting formal reporting requirements in the allocated 80 pages.

Learnings from the Process

In the introduction, I had opined that disability studies is required to challenge the majoritarian stereotypes on disability. Centres for disability studies are spaces where such knowledge production can happen. Such a centre wherever situated would challenge the dominant paradigm and hence would have to continually wage battles of integrity and identity. This paper was an effort to dwell on the nature of the struggle by recounting in some detail the existential dilemmas faced by CDS NALSAR. These challenges were faced by the Centre both from the inside and the outside.

On the inside, the Centre made its place because it advanced the agenda of the University in form if not in substance. The University established the Centre to showcase the expertise it possessed. The Centre by obtaining a number of high-profile contracts secured its place in the University but became a vulnerable target from the outside. The dilemmas thrown up by that experience and the need to reflect upon them are the reason to undertake this case study of CDS NALSAR.

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[9] The various drafts of the country report can be accessed at http://www.disabilitystudiesnalsar.org/uncrpdreport.php.

The alliances with the government for law reform and international reporting were made with the intention to do innovative law reform and imaginative reporting which would advance the agenda of disability rights. The lived experience of both governmental engagements has been that between a promise and its realization there is a gap. And whilst subject expertise is valued, it is not determinative. Both in law reform and international reporting real politics prevailed. Consequently, whilst the Centre could not remove the resistance to the new, even its effort to smoothen the path for the adoption of the new came to be viewed with suspicion. The learning seems to be that unless a technical Centre can ensure a primacy to its opinion, and a consultation on key components of the final product; it is better to advise the government from the outside instead of entering the system (Young 2001). An unequal alliance jeopardizes the credibility of the junior partner, a risk which a newly born knowledge production entity can ill afford.

The other relational dynamic that the paper speaks is between CDS and disabled people and their organizations. Herein I would hold that even if the Centre disagrees, the determinative voice should remain with the sector with all its ideological messiness. Places like CDS should occupy the space of discourse, education and analysis; however, the final power and autonomy should be with the sector. Reflexive dialogue and pushing of boundaries are required but if disability studies is about recovering the voice of persons with disabilities, then centres for disability studies cannot appropriate that voice in the guise of professional expertise.

Conclusion

The involvement of an academic institution with cutting edge policymaking is not a common occurrence. CDS NALSAR was so engaged. The involvement was at its peak till 2015. This article has especially focused on that period as the developments of those times significantly influenced the subsequent choices of the Centre. More importantly, the choices of those times foreground how lawmaking, research and documentation are far from neutral activities. They call for political choices. These political battles our experience tells us are best waged by the constituency affected by the political choices. Expert bodies like CDS can provide grist to the activist mill but cannot with any credibility or legitimacy press for their ideological positions.

The Rights of Persons with Disabilities Act and the Mental Health Act were enacted in 2016 and 2017, respectively. The statutes are not in harmony with each other especially on questions surrounding legal capacity. There are problems of lack of harmony between the Rights of Persons with Disabilities Act and the Right to Education Act of 2009. These discords would impact upon the gains persons with disabilities can obtain from the law. In line with its new-found wisdom, the Centre has preferred to facilitate conversations in the sector between key players instead of trying to drive the discourse.[10] The Centre has also chosen to foster research in disability studies by creating connections between the seekers and providers of knowledge.[11](Note 2011, 2010; Orsy 2004)

The stepping back by the Centre is not a withdrawal from politics. It is more a recognition of the fact that knowledge institutions cannot do politics in the same way as civil society organizations. The Centre is in the process of reinventing itself so that it does what it can do well. This reflexivity I believe is needed by all institutions who aspire for social justice and inclusion. Public reflection allows for dialogue and generates discourse. This article has been written with the same motivation.

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[10] CDS in collaboration with Astha New Delhi facilitated a workshop on Confronting Conflict Aspiring Accord on the Laws relating to Persons with Disabilities in India in October 2018.

[11] The Centre along with the Department of Humanities and Social Sciences BITS Hyderabad is organising a winter school in December 2019 to foster research in disability.

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Chapter 10
Mapping Disability Studies Programmes in India: A Case of Hyderabad, Telangana

Nilika Mehrotra and Ritika Gulyani

Keywords Disability Studies · Disciplines · Hyderabad

Introduction

The term disability is a highly multidimensional, complex as well as a contested term. Equally varied are the responses to it, which produce not an identical but a variegated picture. One's perception, of an instinctual response to the phenomenon of disability is profoundly shaped by social values and beliefs, which distinguishes between the 'abled' and the 'disabled body'. This categorization lies within the ambit of social, cultural, economic and historical matrices.

In India as well as in much of South Asia, disability is seen largely as a product of cultural impediments such as beliefs and stereotypes as well as structural barriers like poverty, lack of development, illiteracy, unemployment and caste, class and gender asymmetry. The meaning of disability in India is embedded in this basic struggle for survival and cultural understanding (Mehrotra 2013: 98). With nearly 2.1% of the Indian population being classified as disabled and with more than two-third of them living in rural areas, it is no surprise that disability is recognized as one of the important axis of marginality and inequality in India. Despite its recognition world over as a social barrier, restriction or discrimination, social sciences have yet to wake to its academic potential. However, owing to recent assertions by disability rights groups, international and national debates on governance and policy formulations have made disability visible (Mehrotra 2013).

N. Mehrotra (✉) · R. Gulyani
Centre for the Study of Social Systems, Jawaharlal Nehru University, New Delhi, India
e-mail: nilikam@gmail.com

R. Gulyani
e-mail: gulyani.ritika15@gmail.com

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Over the last few years, the usage of the term ‘disability studies’ has become popularized within the academic writings especially those which relate to the issues of people with disabilities. While it is not possible to pinpoint an exact date for when disability studies was established, yet the organization that is entirely dedicated to this area, The Society for Disability Studies, began in 1982. However, prior to this also there have been instances of either individuals or entire programmes that create a base for establishing different ways of looking at the experiences of disability. In a way, disability studies could be looked at as the academic aspect of the disability rights movement (Ferguson and Nusbaum 2012).

The understanding of disability studies has evolved and this is visible through more and more disability studies programmes coming up. Disability studies centres and/or centres that are promoting disability studies are usually seen to emerge in the metropolitan centres like Delhi, Mumbai and Hyderabad, and a few other places in the south of India. These places have the establishment of multiple sites of engagements, which makes it easier for not just engaging with Disability Studies academically, but also in the creation of the networks which helps build and promote and spread the understandings garnered from one centre of learning to the other. Frequent talks on issues pertaining to disability, organization of seminars and workshops have helped the disability scholars be a part of the Disability Studies community.

The current chapter is drawn from a research study[1] undertaken to understand the growth and structures of the disability studies in India within the major higher educational institutions. The study was conducted in three major sites of the country and attempted to trace the making of the centres which imparted disability studies courses, to look at the way these programmes have evolved and to also look at how the disability rights movement and the civil society have continued to have an impact on their workings. Owing to the cultural diversity in the country, the ways in which the Disability Studies programmes in the various parts of India have shaped up are also different. The presence of the disability rights movements in the region and the main players involved in it has also affected the way Disability Studies centres have developed in these fields. In an attempt to understand what and how these changes are, it becomes important to understand the history and beginnings of Disability Studies as well as the emergence of Disability Rights Movement in India.

Disability Studies in Humanities and Social Sciences

Socio/political theories of disability can be divided into two distinct but linked traditions; the American and the British. The former draws heavily on functionalism and deviance theory, and explains the ‘social construction’ of the problem of disability as an outcome of the evolution of contemporary society. The latter is rooted in the materialist analysis of history associated with Marx (1970) and maintains that disability and dependence are the ‘social creation’ of industrial capitalism (see Oliver 1990).

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[1] The authors wish to acknowledge the support of UPOE-II, JNU in funding the research study.

Both approaches, however, have been criticised for overlooking the role of culture by a 'second generation' of British writers concerned primarily with the experience, rather than the production, of both impairment and disability (Barnes 1997).

The interest in Disability Studies began in the UK in 1972 with the proclamation by the Union of Physically Impaired Against Segregation (UPIAS) and in 1982 in the US with the founding of the Society for Disability Studies (SDS). But it was only in the late 1990s that education researchers have started to pay attention to it closely. A special interest group named 'Disability Studies in Education' was formed by the American Educational Research Association (AERA) in 1999, which was a beginning in the movement for educational research, theory and practice. The interest group defined disability studies as

> Disability Studies is an emerging interdisciplinary field of scholarship that critically examines issues related to the dynamic interplays between disability and various aspects of culture and society. Disability Studies unites critical inquiry and political advocacy by utilizing scholarly approaches from the humanities, humanistic/post-humanistic social sciences, and the arts. When specifically applied to educational issues, it promotes the importance of infusing analyses and interpretations of disability throughout all forms of educational research, teacher education, and graduate studies in education (DSE: 1).

The initial efforts of the group were aimed at encouraging researchers to become interested in disability studies as well as come up with alternative ways to think about it critically. Beginning in 1999, Disability Studies in the US has included a number of peer-reviewed journals, regular conferences, regular meetings, book series on disability studies, as well as the introduction of Disability Studies at various universities and institutions (Gabel 2005: 1–2).

Till the 1990s, the understanding of disability was usually confined to it being allied to rehabilitation, medicine, special education needs, psychological needs and social work. However, in the latter phase, disability studies in Britain had a major shift where it started being associated with disciplines like social policy, sociology and education. The coming up of the social model was a very important milestone within Disability Studies as the concerns of the disabled could no longer be brushed aside on the basis of it being the concerns of minorities (Barnes et al. 1999: 213). The social model followed the model of UPIAS (1976) to adopt their distinction between impairment and disability. Social model can first be found in the writings of Oliver (1990). It was this social model that was built on Britain's Open University course (Brechin et al. 1981) and Campling's (1981) influential collection by disabled women and the emergence of international journals such as *Disability and Society.* Social model scholars turned attention away from a preoccupation with people's impairments to a focus on the causes of exclusion through social, economic, political, cultural, relational and psychological barriers (Goodley 2011: 11).

Influenced by the American Black civil rights and the queer politics demands for raised social status, and a number of key writers (Zola 1982; Hahn 1988a, b; Rioux and Bach 1994; Longman and Umansky 2001) and disabled people's organizations in the USA (including American Coalition of Citizens with Disabilities, Not Dead Yet), asserted a positive minority identity, (McRuer 2002: 223–224) which was an identity forged under an American 'ethic of individuality and achievement' (Davis

2002: 11). This model, for Davis (2002) and Gabel (2006), was a clear challenge to *ableism,* which is the social biases against people whose bodies function differently from those bodies considered to be 'normal' and beliefs and practices resulting from and interacting with these biases to serve discrimination (Wendell 1996). The People First language of 'people with disabilities' was coined to recognize humanity before the label (Linton 1998b; Gabel and Peters 2004). For Gabel (2006), while the social model boasted neo-Marxist leanings, which addressed socio structural barriers, the minority model took a more eclectic approach to the sociocultural formations of disability. By illuminating the common marginalized experiences of disabled people, African, Native and Hispanic American groups, the minority model addresses the importance of race and ethnicity in North American politics and the emergence of new activism from minority bodies, behaviours and abilities (Goodley 2011: 12)

A distinguishing feature of North American—including Canadian—disability studies has been its interdisciplinary dispersion across the social sciences and humanities. Writers such as Davis (1995, 1997, 2002, 2006); Garland-Thomson (1996, 1997, 2002, 2005); Wendell (1996); Mitchell and Snyder (1997, 2006); Linton (1998a, b); Kittay (1999a, b, 2001, 2006); Albrecht et al. (2001); Longman and Umansky (2001); Snyder and Mitchell (2001, 2006); Tremain (2001, 2002, 2005); McRuer (2002, 2003, 2006); Michalko (2002, 2008) and Titchkosky (2003, 2008), brought to bear cultural and literary analyses. Their work has been keen to connect analyses of disability studies with transformative ideas from feminism, queer and critical race studies. Humanities scholars came to the study of disability with this critical lens already honed to put forward a *cultural model of* disability (Goodley 2011: 14).

Disability Rights Movements in India

The emergence of Disability Studies within the ambit of India as a separate field of academic enquiry emerged post the disability rights movements in India, which also goes on to reflect a change in the conceptual framework of how disability was perceived within India and how disability rights were articulated. In the present times, Disability Studies is a part of certain syllabi such as those of medical sciences, engineering psychology, special education, social work, sociology, among others (Karna 2001). Though it is a start, the discipline needs to emerge as a fully fledged discourse in its own right. The creation of a disability studies in India owes much to its beginnings to the disability rights movement in India.

The disability rights movements in India emerged to help do away with the structural and attitudinal barriers present in the society against persons with disabilities and help empower them (Malhotra 2001). Various social movements have helped shape and influence the disability movements in the West, such as the women's movement and the environmental movements. The environmental movement as well as the women's movement emphasized life with dignity as well as a dignified livelihood in the developing countries. The ideas that gave rise to the origin of these movements were seen emerging the post Second World War society in the West, and resulted in the coming up of civil rights movements, the anti-racist movements and the women's movements. In the 1960s and 1970s, the questions of gender and race as well as of power hierarchies started to occupy important positions, which further influenced the social movements all over the world. The disability rights movement, like the other movements of its time, was the coming together of many groups and individuals which gave it a cross-disability identity. The aim of the international movement on disability was to shift the focus from the impairment of the body and medical constructions to that of a society where the social and cultural arrangements were oppressing the disabled person. In other words, the intention was to move away from the medical model of disability to social one.

Within India, the disability rights movement was influenced by the women's movements, the Dalit movements and quite recently the LGBTQIA+ movement. In the late 1970s and 1980s, a number of Non-Govermental Organizations started to lay emphasis on issues relating to development and women's groups on issues pertaining to violence against women. Post this; quite a few universities started to setup courses and programmes pertaining to Women's studies and Development studies (Mehrotra 2011). In the Indian context, the onset and progression of the women's movement unfortunately marginalized women with disabilities (Ghai 2002). In the 1980s, the concern of the Dalits became prominent and took the course of political mobilization, forcing one to question caste, as one had gender in the past (Mehrotra 2011). In the recent years, Anita Ghai has tried to look at the concept of disability from an academic point of view in which she looks at not just at the disability rights movement but also how women took part in it (Ghai 2002). The work of Asha Hans and Annie Patri also looked at various disability rights and feminist movements from the point of disabled women, which provides a theoretical analysis of women with disabilities in the society as well as provides understandings of disability from various viewpoints (Hans and Patri 2003).

The Disability rights thus emerged in the 1990s, where before that period, lot of the disabled population were divided owing to differences of caste, class, race and region. But with other social movements gaining importance, the DRM also managed to unite and find common grounds, viz, disability as a common denominator for mobilization. In the South Asian context, especially in India, disability was still regarded as a consequence of various cosmological beliefs like *karma* as well as a direct outcome of illiteracy, poverty, caste, class, etc. It is still being couched in charity model where disabled persons are perceived as beneficiaries of welfare. The understanding of disability continues to be embedded in the models that talk about prevention and rehabilitation. As a result of mobilisations around disability issues, Persons with Disabilities Act was passed in 1995 giving much momentum to discussions around disability issues as well as state action (Mehrotra 2013).

The Persons with Disability Act (1995) was the first-ever law for persons with disabilities in the country. Disability activists as well as government bodies recognized the need to understand the disability dynamics in the country. Research and writings on disability issues started to come out mainly in the decades to follow.

In 2007, Indian government also ratified the United Nations Convention on the Rights of Person with Disabilities (UNCRPD) which sought to give a broad categorization of the term ‘person with disabilities’ while also guaranteeing human rights to them, while also laying down the standards according to which all the member countries were expected to treat their disabled population. It, however, took India close to a decade to pass the new bill on disability. This was finally made possible in 2016, when the Rights of Persons with Disabilities (RPwD) Act was passed. The new bill also was a result of a constant and long struggle by a number of various organizations and individuals, who have tirelessly campaigned for it. The new bill has increased the number of disabilities it recognizes form 7 to 21 which is a welcome change as it includes a much a larger group of people within its preview who had been shunned so far. In relation to Disability Studies Centres specifically, it mandates on all the universities to encourage teaching and research within their ambit as well as to establish centres for undertaking such studies. However, one is yet to see the extent to which this will be implemented and to what degree of success.

As is well established, the roots of Disability Studies lie in the disability rights movement to a great extent. Therefore, the students’ movement led by the blind activists in some way can be regarded as the emergence of the perspective which gradually prepared the ground for Disability Studies over a period of time.

Disability Studies in India

The understanding of disability is usually confined to a disadvantage or a deficiency in the physical or mental spheres which does not allow for activities that are considered ‘normal’ in nature. Mostly, these physical and/or psychological conditions have their origins in the medical understandings, which also seem to be the dominant mode of understanding them. As a result, disability is seen as a deviation away from the norm and it was to contest these very understandings that disability studies emerged (Reddy 2011).

The semantics of the word ‘disability’, Linton (2006) maintains being used in disability studies is different from the term disability itself. For her, the prefix ‘dis’ in just the term signifies a separation and it separates ability and its absence. A person who is disabled lacks ability. On the other hand, in the context of disability studies, the word represents not the biological condition but a negation of what ability is defined as by the society, and so it represents a social arrangement instead of a biological one.

It is this due to this understanding in the western countries that there has emerged a shift from the earlier perspectives of purely medical perspectives and have moved on to social and political issues. Within the Indian scenario, work on disability studies for a long time was still majorly based on the medical perspectives and there was a dearth of literature that looked at it from the interdisciplinary point of view (Rajeshwari and Saxena 2014). According to Chander (2008) with an exception of a few works, most of the literature in the Indian context falls within the medical perspective.

In the western context, disability rights movement and disability studies became intricately linked. The very idea underlying disability studies was to bring about a change pertaining to the way the society thought about persons with disabilities and empower them in such a way that the disability and the disabled person get separated from the prejudices attached to the disability (Karna 2001). Within India, Disability Studies has been recognized as an academic discipline by Ministry of Human Resource and Development (MHRD), though progress still has to be made regarding a model curriculum (Kumar 2009). Scholars also believe that DS has an emancipatory and critical perspective and DS and DRM need to feed into each other.

Status of Education Within India

Education in India is provided by the public sector as well as the private sector, with control and funding coming from three levels: central, state and local. Though education in India is largely the responsibility of the state government, the central government has also made various provisions so as to address the inconsistency within the different state laws. From 1990, different ministries and departments have launched various schemes which were meant for the different groups of children (Singal 2008). In 2002, by the 86th Amendment Act to the Indian constitution, free and compulsory education to all children from the ages of six to fourteen years was guaranteed as a fundamental right. This was the *Sarva Shiksha Abiyan (Education for All),* a programme of the Indian government for the achievement of the Universalization of Elementary Education (Ministry of Human Resource Development, Government of India).

For students with disabilities, the government of India has a 'Scheme of National Scholarship for Students with Disabilities' whose main purpose it is to guarantee that the students with disabilities have a fair access to higher and technical education by means of reserving 3% seats in educational institutions. The object of this scheme is to also provide financial assistance to allow students with disabilities for pursuing higher and technical education as well as supporting them in acquiring special aids and appliances for their respective studies. The presence of enabling units in the university setup play a very important role in this as it provides an open space for the students with disabilities to be able to voice their opinions and problems. These Enabling Units are usually composed of the senior faculty of the department and act as anchor points for these students to have a barrier-free and accessible environment at the colleges and universities.

Within the academia, disability issues have for a long time been caught up in subjects which are primarily medical in nature, like rehabilitation studies, psychology, social work and to some extent, education. In the mainstream social science disciplines like those of history, economics, political science and sociology/anthropology, there has been a virtual neglect and dearth of interest in disability issues. Of late, though, the disability perspectives are gradually emerging and challenging the very premises of the social science understanding of social life which centre around the supposedly ‘normal’ or ‘able’ bodies. The concept of disability questions the assumptions and conventional notions which construe persons as able or disabled and uncovers the knowledge and power politics inhering in these discourses.

There is a general suspicion of research which disapproves the claims of exclusion, deprivation and discrimination (Mehrotra 2004; Staples 2007) and as a result, only a few scholars have adopted a disability studies perspective within India. Economists have mainly shown interest in the measurement of disability and the related number of disabled in the country. There is vigorous debate among the social scientists on the measurement of disability and the definition of disability itself and its implications for GDP and the overall question of development especially with reference to the employment situation, costs of care and constraints on the families (Erb and Harris-White 2002).

Political scientists and lawyers have now started to engage with questions of citizenship, rights and entitlements with reference to the state and civil society while educationists are beginning to explore links between disability and education not only in schools but also in institutions of higher education. Some anthropologists have come up with real-life ethnographic studies of Persons With Disabilities within their families, communities and institutions, which throw light on the heterogeneous nature of impairments, diversity of social structures and of the nature of exclusion and inclusion, and the agency of people, thereby providing a correction to rhetoric and contributing to policy issues (Staples 2007; Lang 2001; Mehrotra 2006, 2008; Mehrotra and Vaidya 2008; Addlakha 2008). There is an urgent need for researchers to recognize disability as an important marker of social inequality (Mehrotra 2013). Disability studies around the globe situate disability as a reality to be deconstructed and demolished through political and intellectual activity (Stone 1999).

There is spurt of recent literature pointing out to the intersectional gendered dimensions of disability in the Indian context (Ghosh 2016; Vaidya and Aneja 2016; Vaidya 2016; Addlakha 2013; Nayar 2018; Mehrotra 2013). This literature points to the disabling and oppressive conditions existing for women who bear multiple burdens of gender, class, caste and disability. Sexuality has emerged as an important area of concern. The gendered nature of care work as an issue of disabled women both as caregivers and those in need of care have acquired recognition (Mehrotra 2013).

However, recently, these have been many moves which indicate that the question of disability is moving away from medical concerns and entering the arena of social sciences. However, consensus in the community of disabled scholars seems to be for the establishment of disability studies which is taught by disabled scholars. While disability studies in the USA and UK have been dominated by researchers who themselves have an impairment and often combines political activism and research, in other countries, it has been more closely linked to the welfare state from evaluations of social reforms than to radical disability movements (Söder 2009: 70). How disability has been understood and studied, and the purposes of such studies have typically been intended to serve, are deeply bound up with specific national political and welfare traditions. Like in some European countries, disability studies in India also get funding and legitimacy from the state. Disability studies in India are trying to make space through critical engagement in interdisciplinary perspectives. A large number of universities and Research Institutions (see Mehrotra 2017) have begun efforts at institutionalization but they are facing number of challenges.

In the past few years, the realm of disability studies has grown beyond the applied fields of medicine, social work and rehabilitation in order to become a vibrant new field of inquiry within the critical genre of identity studies. Recently, interesting works on Architecture and universal design in relation to disability are emerging. Architecture as a design discipline has a strong underlying social commitment and the potential to facilitate social inclusion by addressing needs of all sections of the society. Such a thought usually remains vague and a generalized idea, and is rarely taught in the schools of architecture and minimally practised by professional architects. Barriers in architecture continue to hinder People With Disabilities (PWDs) basic access and activities. Additionally, architecture does not yet have a body of work around disability equivalent to that exploring other disadvantaged identities such as gender, poverty or race. Universal design, on the other hand, refers to the design of products, systems and environments, which are usable by people with the widest range of abilities without the need for adaption or specialized design within the widest possible range of situations. They broaden the understanding of accessibility to apply to the design of products and services, and the way people (of all ages and abilities) interact with them. Thus, the focus is not on age or disability alone but on inclusivity at a social level which meets its objective without stigma. Medical professionals, such as Dr. Satendra Singh Delhi, are also working for interfacing medical and social through engagements in medical humanities. He is one of the few people who are actively involved in advocating for the rights of disabled people while being from a medical field. He has been very active in filling RTIs and PILs regarding the accessibility of physical spaces, of websites, of polling booths, as well as regarding discrimination arising within areas of employment within government as well as private sectors. He also runs an online medical humanities journal, RHME (Research and Humanities in Medical Education) which is an open platform where patients as well as doctors can share their feelings and it explores the role of literature, cinema, art in our lives (Satendra Singh, interview in 2015).

As mentioned above, in India, the effort to institutionalize disability studies is underway and a number of centres have been setup to look into this need. This paper is based on a research study undertaken in 2015 titled ‘Disability Studies in India: Issues in Institutionalization’, (supported by UPOE-II JNU) which sought to look at the growth and institutionalization of disability studies within India and to locate the interdisciplinary perspectives involved in the setting up of these centres within India. Additionally, it also sought to locate the trends that emerge from within the different disability studies centres housed within the various educational institutions. Three major locations were chosen for this project, namely, Mumbai, Hyderabad and Delhi and fieldwork was conducted at TISS (Tata Institute of Social Sciences), NALSAR (National Academy of Legal Studies and Research), University of Hyderabad, EFLU (English and Foreign Language University), MANUU (Maulana Azaad National Urdu University), University of Delhi, Jawaharlal Nehru University and IGNOU (Indira Gandhi National Open University).

Setting Up of Disability Studies Centres in India: A Case Study of Hyderabad

The idea was to look at how Disability Studies is getting institutionalized in different university locales. The presence of Disability Studies so far has been in the rehabilitation settings, which is changing as we move with more western concepts and practices. In particular, the chapter explores the emergence of these practices in Hyderabad and the various educational setting within it. Four locations (NALSAR, UoH, MANNU and EFLU) have been looked at and visited within Hyderabad. Of these four, it was only NALSAR which had an established Centre for Disability Studies, while the others have a few scholars involved who are trying to weave in disability studies within their respective disciplines, such as literature, language and sociology. Interestingly, from within the different departments, the responses as to how disability discourses were taking place were very diverse. An interesting aspect of disability studies within the city was that it was not just contained in a single place but also that it was not restricted to one discipline.

The factors behind the choice of this city are multifold and include the institutional make up of the city but also the overall political environment of the city. The emergence of the city as a metropolitan hub has brought it into significance and helped in establishing it as a hotbed of political activities. In the last five decades, a lot of political action, such as the women's movements or the Dalit movements has seen its effect here. The presence of a charged political environment with protests and activism has given a progressive nature to the city. In addition, the presence of prominent institutes of learning which are working towards the goal of promoting disability studies is an added advantage. Finally, the legal environment in the city adds to the efforts of the disability activists.

As is reflected in Amita Dhanda's paper in the present volume, she points out how disability studies can be undertaken in multiple ways within the institutional setup A multidisciplinary centre may be setup, which brings together all the various disciplines in order to explore disability from their point of view. While this helps achieve an overarching perspective on disability, it also may not have any impact ultimately on the parent discipline which is offering it and thus be reduced to just the person who is teaching it or the people being taught. Further, a setting up of a single Disability Studies University could be taken up, which while will make sure that DS is at the core of things, but might run into trouble when it comes to the people taking up the specialized courses offered. Additionally, universities could setup specific chairs within the centres which would be occupied by eminent personalities and the discipline could be challenged in real time by the lived experiences of these personalities. Research centres within a single discipline university could be setup as that single discipline will have the potential for a intensive study. Alternatively, advocacy centres could have research wings established for disability studies which would allow for a disability advocacy based on lived experiences. Finally, research and documentation wings in the various equal opportunities centres could be setup which could help analysis of data and policy.

Engaging Disability Within Law

National Academy of Legal Studies Research (NALSAR) University has been an important site of research due to the presence of Centre on Disability Studies headed by Professor Amita Dhanda. Prof. Dhanda's doctoral thesis critically appraised the laws relating to the mentally ill in India and was the first effort in the country to evaluate the human rights conformity of mental health laws.

The beginning of the Centre, as Professor Dhanda put it is that:

> The university decided to set up various centres along with the Disability Studies Centre which came along with the Centre for Legal Philosophy and Justice Education. The reason behind setting up of the centre was nothing to do with me but it was a governing council decision. It is just that if they could have an expert amidst them, they could have a sort of a justification in setting up the centre. (Dhanda, March 2015).

A level of interdisciplinarity could be seen in NALSAR if one looks at the fact that Professor Dhanda headed both the centres of Legal Philosophy as well as Disability Studies. The logic as she states lies on the idea that a teacher of Legal Theory is also a specialist in Disability Studies.

Apart from a seminar course in 'Comparative Disability' offered every alternate semester the disability component is addressed in most of the compulsory courses taught. The centre is based on the belief that an elective course on disability may attract only the very interested students in the area, whereas a compulsory knowing of the disability issues enhances the understanding of the same. So within the compulsory courses of 'Legal Theory,' 'Law and Polity', 'Administrative Law', disability studies remained as a prominent and important area.

Role of the Centre Beyond NALSAR

Since the Disability sector is experiencing a lot of flux, the centre has a strong opinion that disability scholars should precede towards more research-based work along with advocacy and intervention. There have been stands taken against the Disability Legislation when it got totally mutilated from the original draft that the centre had made. Prior to this, the centre has worked on the National Trust Fund before working on the draft on Rights of PWDs. The committee appointed for the latter was a mix of civil society and people from the key departments of the government of India. The centre got involved in the case of the draft on Rights of PWDs when the committee required legal advisors and also academicians to capture the lived experiences of the PWDs and blend it with lawmaking. However, the difference that came in was between the belief systems of lawyers and academicians. The former seemed to constrain their advice to what has been already done in the field of law. But the latter decided to take the route of analogical reasoning. The legal advisors hesitated to make a law which might have never figured in anywhere but in need of people with disabilities, while the academicians opined that the Indian Disability Law can be brought in harmony with the international law of UNCRPD.

The middle-level document in 2012 that was made by law was largely influenced by the efforts of the centre but the one in 2014 has largely been changed. Though an idealistic stand by the centre, it is a stand that it maintains and it believes that without ideals one cannot practice and a change is not possible within the existing practices that prejudice disability. It considers that the law itself has been the perpetrator of that prejudice and unless a huge critique is not developed within law the prejudice gets reproduced. It was owing to this thinking that when the subsequent drafts of the bill started coming, the centre distanced itself from the bill. The bill has now been passed and is the new Rights of Persons with Disabilities Act 2016.

Dialogues with the Civil Society and the NGOs and Within NALSAR

There have been engagements of the centre with the civil society and NGOs by providing a space for legal expertise they need for the work they do as well as for individuals needing an opinion on a stand or entitlement they deserve. Though the centre has come under controversies like a large number of parent organizations have had problems with the centre in context of inclusion of the intellectual disabilities, the conversations on the area haven’t diminished.

NALSAR is also a sensitized university wherein there is a prominence of the Disability Rights Movement which empowers the students with disability to not get singled out whether it is about to raise an issue, or claiming an entitlement. The presence of the centre encourages the understanding of disability through the inclusion of disability activists, all over the world within the curriculum by bringing in perspectives from the ground.

Voicing the Understanding of Disability Through Literature

Another ethnographic case was gathered from the English department of Maulana Azad National Urdu University. Due to the presence of Dr. Shilpaa Anand, a disability studies expert within the English department, the university has been able to incorporate disability as an area of enquiry.

Any work done related to the field of disability is often perceived as a ‘service’ to society. Such a perception has been viewed critically by Dr. Anand as it prejudices the disabled as somebody who is in need of service. To come out of this perception it was required to look back at history in order to document the beginning of such an understanding. As a department of literature, attempts are made by looking at literary instances of disability as well as historical responses to disability through the centuries to see how disability is treated and represented. There are many religious texts that project the presence of Disability. However, within the domain of literature the presence of disability has been prominent making escape hard. Like Dalit Studies, Race Studies and Women’s Studies, the understanding of Disability Studies have originated from literature as it informs a strong background of marginalization. In the context of marginalization disability is incorporated through the two courses that are taught in the department. One is the ‘Nineteenth Century Fiction’ course which was based on scholarly works of people who have written essays on the presence of disabled characters in the nineteenth century. Since the course looks at British fiction as well as other European fiction, the characters of the ‘Monster the Freak’ and the ‘Mad Woman’ were traced as there are a lot of representations on that. For example, Frankenstein as a character is actually a body which is put together from body parts of dead bodies. The trauma that the monster experience is similar to that of disablement. So the social ostracizing as to how a monster looks comes through very strongly through the novel. Apart from stigmatization this course of literature has been able to look at a different form of inclusion in the medieval period there were lots of occupations that were assigned to the ‘fool’ or ‘the mad man’ or the other disabled characters. Another course called ‘Indifferent Bodies’, was an attempt to look at contemporary fiction from different parts of the world to see if notions of disability are universal or are there complications in the very way they are conceptualised.

A very similar attempt was also being made in Jawaharlal Nehru University at Delhi by late Dr. Navneet Sethi. Dr. Sethi was a wheelchair user and had her specialization in the area of American literature. It was in 2008 that she began to float a course that covered disability and its representation among the American literature, the works of authors with disability and also of those authors who came from certain other discriminating and disabling backgrounds, such as those of race or colour. This course was open to all students of the university, not just ones from her centre and also was held in classrooms that were easily accessible to students with disabilities. Within the class also, she would try and make reasonable accommodations for everyone present.

Other than the courses at Maulana Azad National University, there have been research scholars who have been incorporating the understanding of disability through their works. Such an example arises in a particular work on ‘Partition Fiction and Disability’, wherein the attempt was made to see disability as a metaphor in terms of the fractures that the nation experienced.

Along with the academia there has been an attempt of a movement in the campus to bring in disability rights in the forefront. An equal opportunities cell is in the process which has decided to bring about a section for what they aim to call ‘Differently Abled’. Meetings of the core members are held which includes many disabled persons—faculty, students and non-teaching. There are also talks, by NGOs giving a general overview of the different nuances of disability. However, the presence of the disabled people especially visually impaired in spite of the 3% reservation is fairly lesser than at HCU or EFLU. It is also because it gets jeopardized many of the times because of the smaller numbers. Although there is a lack of existing consciousness at present among the people over disability issues it is in the process of becoming more and more visible.

Debates of Disability Through an Aesthetic Approach

English and Foreign Languages University [EFLU] was viewed as another site of exploration wherein representations of disability was analysed through:

> The aesthetic approach—an approach that invokes students' responses to certain objects and ideas of aesthetic value. The students at EFLU were introduced to the artistic creations of Otto Dix and Paul McCarthy that represented disability in some form. Seventy-five undergraduate students were directed to write down their responses in 500 words on the selected paintings. Most of the students responded in the form of appreciation without even mentioning about representation of disability in the artistic creations. For them, it was ART, and hence, it could only represent beauty and hidden layers of meaning. The students were of the opinion that the artist has been very complex in representing her/his ideas and the style as many noted, is of contemporary art or of a surrealist imagination. However, when the students were told that this form of art is called disability aesthetics that foregrounds the so-called "abnormality" and subverts the assumptions about an ideal human body, the students started developing an interest towards understanding issues concerning disability (Amith Kumar, interview 2015).

The view here is that teaching disability through aesthetic methods familiarizes students with issues concerning disability in a non-theoretical and uncomplicated manner. It is believed to be beneficial to explain the cultural constructions of 'normality' and 'abnormality' by way of demonstrating the same in art. The understanding of disability also becomes stronger as it is understood to provide a counter-discourse on the ongoing stigmatization. As a faculty of Comparative Literature and Indian Studies (EFLU), as well as a disability studies scholar, Dr. Amith Kumar (interview in 2015) believes that DS is mistakenly considered to be the domain of just activists as they claim to provide rehabilitation. But as in the Indian scenario, this area of research is in its infant stage it is extremely important to institutionalize disability studies which are possible through the introduction of an aesthetic approach through nonpartisan and apolitical vantage points.

The institute also believes that the way humanities try to impart the ideas of disability is very different than that of the social science perspective.

'The very act of living with a disability is a performance. This is one theory which we are trying to expand in the Indian notion. For example, I am a person with extreme low vision and my colleague Rajshekhar is gifted with no vision. The very act of us walking into our office makes us attract a crowd which keeps staring at us and as a result a constant performance goes on. Most of the people with CP and also those who use sign language to communicate is actually a performance, a gesture. In the view of humanities the act of living with a disability is a performance and as Shakespeare would put it the world is a spectator' (Amith Kumar, interview in 2015).

In EFLU there are ongoing discussions over introducing a course on Disability Studies. Some of the faculty does incorporate disability within their courses like in terms of 'Disability Poetics' to see how a disabled is presented. The primary idea is to see if and how disability is presented in English Contemporary Literature in India.

The Cell for the Disabled has been established in EFLU in 2012, by Dr. Amith Kumar and Dr. Rajashekhar to provide a space to students with disabilities to ensure comfort as well as individual growth. The Disability Cell of the University has made pioneering efforts to use the latest technology in order to help disabled students overcome all limitations. The Cell uses software such as Jaws screen-reading software and Kurzweil scanning software for use by blind students; Magic Magnifying Software for low vision students and Duxbury Braille Software which converts texts to Braille. It is a prominent symbol of the University's continuous support for its disabled students that a disabled student was able to get elected as the President of the Student Union.

This also encourages the prominent presence of scholars with disability as well as research in the areas of disability. Some of research interests are: 'Disability in Maharashtra', 'Disability as a Tangible Aspect in Literature' etc.

The accessibility of the buildings is taken under special consideration, as the coordination comes from a lived experience perspective. Though as a city, Hyderabad is strongly considered to be not accessible in terms of keeping disability in mind as compared to other cities especially Delhi. Delhi is an epicenter for disability movements, while Mumbai more of a service-oriented space for the disabled.

The NGOs in Hyderabad as Dr. Amith Kumar, puts it do not aim to make people with disabilities aware of their rights but focus more on distributing services. These NGOs were setup around a decade ago and the perspectives of the founders do not complement with the transitions of the disability studies perspectives. This makes collaboration of the NGOs difficult for the disability movement within the campus due to the clash of perspectives.

Disability Studies Within Social Sciences

Within the Centre of Sociology in the Hyderabad Central University, the notion of normality and abnormality is looked at keeping in view disability. Emphasis is laid through the papers taught by a disability studies scholar, Dr. Raghav Reddy. These papers are, 'Survey Research and Basic Statistics' to the first semester students of Sociology, an optional titled 'Sociology of Organizations'. His research areas of interest include 'Science Technology Studies' with special focus on sociological studies on technology transfer and disability interventions. He has supervised a number of projects and research studies around disability issues. Centre for Exclusion and Centre for Regional Studies also supervise scholars looking at the area of disability. Though within the Sociology centre there has been a thought of introducing an optional course on disability studies but the debate is over who is more suitable to teach it—a scholar on disability studies or a disabled scholar interested in disability studies. In January, 2018, Annavarm a blind faculty member organised a national seminar on Disability Rights.

There is a general consensus of the students and faculty that disability movement within the campus is not very strong. Due to the absence of a Disability Studies programme in the university, there is very low academic participation in terms of disability-related seminars or conferences. Also, funds and grants in terms of disability studies research are not very accessible other than the UGC.

Conclusion

Disability Studies is still in a very nascent stage in India, with very few institutions actually establishing a dedicated centre for it. However, the lack of centres at present is made up with the involvement of various academicians and activists in their own capacity, across the country. The reach of disability studies in India is very interdisciplinary as can be seen from the variety of disciplines that are engaging within the forwarding of this study. DS has clearly moved beyond the tradional disciplines and it has informed the teaching of research in subjects where disability remained invisble for a long time.

The emergence of a Disability Studies Centre more than often has its roots within the Disability Rights Movement, but it is a mutually constitutive process, whereby even the DRM is unable to sustain itself unless it is backed by an ongoing constant research and engagement on the topic. So, the DRM and DS both occupy almost parallel roles, where one cannot take precedence over the other, but rather, both have to work in perfect tandem with each other.

In the Indian context, the DRM emerged in the early 80s and 90s and it is around that time itself that Disability Studies in India, being influenced by the western timeline of thinking also started taking shape. It is important to understand that it is not practice and activism alone that pushes that movement ahead, but rather, Disability Studies is a vital part of this movement, which is constantly giving it support from the backstage, and is also modifying the way activism is put forward so that it is able to create a wider impact, to the concerned authorities (Chander 2011).

Most of the disability studies interventions till date have been either an individual and/or collective effort on the part of a few scholars who wished to inform the notions and understandings of disability within their own disciplines. The government is yet to recognize disability studies as an important tool for change beyond policy formulation. The efforts undertaken by the scholars in Hyderabad clearly show that gradual and constant engagement in the discipline does yield awareness among others regarding the subject and bringing about physical change in infrastructure also forces people to question the notions of disability, policy implications and try and engage in understanding its nuances. The presence of a strong network also helps in the establishment and the furthering and expansion of the disability studies and its critical potentials. A strong core of disability scholars and the presence of activists and academicians working within the field of disability and promoting it within the institutions makes the disability studies programmes easier to take a stronghold within the area, the city and subsequently the state.

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Chapter 11
Disability Social Work Education: Emerging Trajectory in India

Srilatha Juvva

Abstract In India, social work professionals have been learning to work with persons with disabilities while on the job. While social work education provides the foundation for social work practice, it did not adequately equip professionals with skills and competence to work in the disability sector. Hence the Tata Institute of Social Sciences has pioneered in offering a Masters' programme in Social Work in Disability Studies and Action. The aim of the programme is to create a cadre of human service professionals to work in the field of disability with specific skills and competence. This paper traces the development of a teaching programme in Disability Social Work in India, the antecedents and the trajectory of the programme since its inception in 2008. It focuses on the background research that led to the formation of the curriculum; the initial conceptualization of the programme; revisiting the curriculum to respond to student needs and demands of the field as well as the emerging social work education in the country. The paper concludes with tracing the emerging trajectory for Disability Social Work in India.

Keywords Social work · Education · Fieldwork · Field engagement · Curriculum · Learning enhancement activities

One of the largest minority groups in India, who have suffered long years of neglect, deprivation, segregation and exclusion are persons with disabilities. However, the last three decades of the twentieth century have been momentous for people with disability worldwide, as it witnessed international and national initiatives for reforms in legislation and policies for affirmative action to improve the quality of lives of persons with disability. To begin with, 1981 was declared as the UN International Year for the Disabled, followed by the declaration of the years 1982–1991 as the Decade of the Disabled and the years 1993–2002 as the Asia Pacific Decade of the Disabled. International Instruments like the Charter of Human Rights, Convention of the Rights of Children, and Declaration of Rights of Persons with Disabilities have promoted a shift in ideals, ethics and values; the United Nations Convention on the Rights of Persons with Disabilities and the Incheon Strategy Action Plan have

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S. Juvva (✉)
Centre for Disability Studies and Action, Tata Institute of Social Sciences, Mumbai, India
e-mail: juvvas@tiss.edu

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added impetus for actively drawing attention to issues and concerns of persons with disability. These in turn have changed paradigms from providing charity and welfare to persons with disability to protecting their rights and promoting their empowerment.

Contextual Background in the Disability Sector

In India too, the last two decades of the twentieth century have seen tremendous changes in the philosophy and provision of services for persons with disability. The definite movement away from the concepts of custody, care and treatment towards prevention, education, rehabilitation and inclusion has reinforced the interest and commitment in field of disability. This has progressed to the availability of both governmental and non-governmental rehabilitation services, and comprehensive legislations in the field of disability. The current focus amongst professionals in the field of disability is on the rights of disabled persons, equalization of opportunities and their inclusion in all aspects of societal living. It has, therefore, recognized that people with disabilities are human beings with all the economic, emotional, physical, intellectual, spiritual, social and political needs that other people have. Roulstone (2012) has discussed the dissonance between the growth of the disability sector and the tardy response of Social Work education. This is despite the reality that social workers work with persons with disability.

Though India has come a long way, we still have much to do to ensure an inclusive, barrier-free and rights-based society for persons with disabilities. Disabled persons are still oppressed and marginalized. Sometimes they are denied the opportunity for full citizenship and participation and from living a reasonable quality of life. This is due to the society's persistent stereotypical and prejudiced perception of them as inferior, incapable, inadequate and a burden on the family resources and society. While social protection measures are available on paper, their translation in the form of services is rather limited.

Influence of Emerging Perspectives and Models

Prior to the advent of the social model, disability literature and professionals in the field of disability have primarily focused on the medical and technical aspects of rehabilitation. Most disabled people in a developing country like India, if they have been exposed to any services at all, have experienced only a medical/institutional/individual model of rehabilitation, which views the human body as flexible and alterable and the social environment as fixed and unalterable. It, therefore, treats disabled people as patients to be cured or cared for, whether in institutions or 'in the community'. This individual/medical model of rehabilitation has been the only model used by some rehabilitation professionals for approaching disability. This model does not provide a holistic perspective as it focuses on the individual without placing him/her in a social and environmental context which has resulted in the creation of dependency and patronizing relationships.

The social model of disability on the other hand, views disability as socially constructed and finds explanations for disablement within the context of a person's life, rather than within individuals themselves. Rehabilitation conducted within a comprehensive social framework is about the removal of barriers at the individual level and also the removal of physical and attitudinal barriers in society at large. Rehabilitation, therefore, includes not only engaging with persons with disabilities, but also emphasizes the need for engaging with the community and other systems of society for creating more enabling environments so that their complete integration into the mainstream of society is possible. This entails that the structures that oppress and discriminate be challenged rather than focus on individual challenges alone (Oliver 1990).

The change in philosophy and rapid growth of rehabilitation services for persons with disabilities in India has also ushered in the acceptance that comprehensive rehabilitation requires the efforts of a multidisciplinary professional team. The team typically comprises the physical rehabilitation expert, physiotherapist, occupational therapist, audiology and speech therapist, disability social worker, rehabilitation psychologist, disability counsellor, orthotics/prosthetics expert, to name a few. In this new and expanding field, the Government including the Rehabilitation Council of India (RCI—an autonomous central organization under the Ministry of Social Justice and Empowerment) and non-governmental organizations working on disability are increasingly recognizing the need for trained disability social workers who can provide comprehensive counselling and other rehabilitation services at the individual, familial and community levels.

The social model of disability urges scholars to contest the complacency of 'services' provided within the realm of social work and challenge the 'status quo' response of the legal structures that makes contentions an arduous task (Roulstone 2012: Morgan 2012). Such a stance positions disability social work in a threshold space where one needs to adopt a proactive, critical and reflexive attitude that facilitates praxis, rather than follow the run-of-the-mill methods of intervention. Dupré (2012) encourages social workers to gain a critical understanding of disability culture and thereafter inculcate culturally (in the context of disability) competent social work practice. Using Shalock's (2004) taxonomy of well-being, Simpson (2012) urges social work profession to explore the structural and community perspectives of well-being for critically reflexive and engaged practices.

Disability Social Work

Historically, the social work profession has been engaged with initiating and providing services that are driven by a definite philosophical grounding, guided by theoretical conceptualizations, with competence in practice skills and within the required ethical recommendations, in all spheres of working with people who are marginalized and vulnerable. The mandate of the profession is to respond to situations where there is oppression, inequality, and discrimination and to 'be' the voice of the people, so as to 'give them the power to be'. This then calls for social workers to keep abreast with law and policies and analyse them using 'critical reflexive engagement' (p. 144) as it applies to a particular group, in this case the disability sector (Roulstone 2012). The professional nature of social work, therefore, calls for training and practicum that grounds the trainee in embodying the core values of justice, dignity, inherent worth and self-determination of a human being.

The Tata Institute of Social Sciences (TISS) has been a pioneer in social work education and practice and has over the years responded to the needs of the poor, the marginalized and disadvantaged in society. The social work profession has had long experience in the area of total individual, family, community and policy intervention. It also has a body of knowledge and skills important for helping individuals at all life cycle stages as well as families, groups and communities overcome barriers in their environments and actively participate in their own empowerment.

Trained social workers today are working with people with disability in a wide variety of settings including hospitals, preschools, inclusive schools, special schools for children with disabilities, institutions, child guidance clinics, family welfare agencies, urban and rural communities, and vocational training centres. In fact, they are key members of multidisciplinary rehabilitation teams in all of these settings. However, they view persons with disability as 'client group' without using a critical lens to understand disability and diversity in this sector. The focus on the individual model (Morgan 2012) renders all attempts to work in the disability sector ineffective. On the one hand, while social workers have always responded to the needs of this group and have worked in the field of disability rehabilitation, they have learnt their job in this field by trial and error and have largely been using the medical/individual model of rehabilitation. On the other hand, the Bachelor's and Master's degree programmes in social work have so far not paid adequate attention to equipping social work students with relevant and specialized knowledge, critical perspectives, attitudes and skills in working with people with disability using the social model and the rights-based frameworks. While schools of social work have disability-related field placements for their students, this has not been supported with the required knowledge, skill and attitude inputs in the classroom, except perhaps for one subject on disability.

As a team member, whatever the rehabilitation setting, it is the social worker who acts as a liaison between disabled individuals and other members of the rehabilitation team on the one hand, and between the disabled individual and his/her family and community on the other. The social worker is in a better position than others involved in the rehabilitation process to work with socioeconomic, political, cultural or familial environments that pose a barrier to the optimal use of services by persons with disability. These structural barriers are often untouched by other rehabilitation professionals. In addition, the social worker also has the necessary skills to participate actively at the community level and work in partnership with persons with disability and the NGO sector for campaigning for changes in public policies and legislative reforms, for developing local services and for advocacy for social justice for persons with disability.

Antecedents to the Masters' Programme in Disability Studies and Action

The Tata Institute of Social Sciences (TISS) is an institution of excellence in higher education that continually responds to changing social realities through the development and application of knowledge, towards creating a people-centred, ecologically sustainable and just society that promotes and protects dignity, equality, social justice and human rights for all. In pursuance of its vision and guiding principles, the Tata Institute of Social Sciences organizes teaching programmes to facilitate the development of competent and committed professionals for practice, research and teaching; undertakes research; develops and disseminates knowledge; and reaches out to the larger community through extension, at the local, national, regional and international levels (https://tiss.edu/about-tiss/overview/ accessed on 25 May 2019). In this backdrop, the institute created space to respond to needs of the disability sector. Drawing upon the vast experience of the faculty and the need to address gaps, the Master's programme on Disability Studies and Action was initiated.

The members of the faculty in TISS have been engaged in research, including evaluation research for various organizations in the disability sector. During the course of research, it was imperative to offer workshops and training programmes for various stakeholders of these organizations too. The beginning of such an association laid the seed for the need to develop teaching/training programmes in disability. Mackelprang (2010) emphasizes the need to go beyond offering one course to train social workers to be disability social workers, including those with disability; and provide perspectives, skills and terminology with cultural competence in such training programmes.

At TISS, we were offering an optional course on 'Social work intervention with the disabled and their families' for the Master's programme in Social Work, since 1986. This course focused on the life span approach of families having a child/person with disability. It aimed to understand and work with families using holistic interventions. Having offered this course, there was a need to equip disability social workers with skills of undertaking rehabilitation counselling. In response to this, the erstwhile Department of Family and Child Welfare (FCW) initiated a Certificate Course in Rehabilitation Counselling since 1994. The course aimed at providing skills training to social workers in the disability sector in areas related to counselling and community-based rehabilitation and direct intervention with people with different disabilities. The inputs in this Certificate Course include information related to disability and the contexts of persons with disability; policies and programmes (international and national) related to disabilities; direct interventions with vulnerable groups and families of persons with disability; and management of rehabilitation programmes. Courses related to interventions with specific types of disability were optional. Fieldwork formed a third of the entire curriculum. Students were placed with different organizations based on their choice of sector and issue they wished to work on.

The pedagogy included classroom teaching, field visits, discussions and use of audiovisual documentaries. The feedback from the trainees of the Certificate Course as well as demands from the field has led to the development of a Master's programme in Disability Rehabilitation Social Work to meet the needs of an expanding field. This was further strengthened through the experiences that members of the faculty gained while providing Consultancy services to various organizations, and serving on National Standing Committees of various National Institutes in the disability sector since.

In collaboration with Ali Yavar Jung National Institute of Speech and Hearing Disabilities, the members of the faculty organized, in 2005, a two-day national consultation workshop on 'Enhancing Inputs on Disability issues in Social Work Education' for social work teachers from Departments of social work from different Universities. The output of the workshop was a model course outline for teaching Disability in the Social Work curriculum. A 30-hour course was formed and the participating universities/departments of social work adopted this curriculum. The teachers were also free to adapt this curriculum to meet the needs of their university/students.

The Rehabilitation Council of India (RCI), an autonomous organization under the Ministry of Social Justice and Empowerment, has mandated that all social workers who are working in the field of disability rehabilitation undergo certification in Rehabilitation Social Work or acquire a credited degree in Disability Social Work. RCI recognizes Rehabilitation Social Workers as one of the professionals in the field of disability rehabilitation. Given this mandate, there is a need for the social work profession to create a cadre of professional social workers, with competency in empowering people with disability and all stakeholders. By offering a graduate degree programme, social workers would receive the appropriate status, remuneration and recognition within the professional community in this field.

The Centre for Disability Studies and Action (CDSA): In 2006, as a part of the restructuring process at TISS, a Centre for Disability Studies and Action was formed within the School of Social Work. This Centre is the first of its kind in a University setup. The members of the Faculty in the Centre have had long experience in the field of disability, in terms of research, teaching and capacity building, as mentioned above. The mission of the Centre is to work with and through people with disabilities and stakeholders with human rights, strengths and related perspectives, using social discourse, anti-oppressive and empowerment-based partnership practice. It aims to develop a cadre of personnel with specialized competency in working with people with disability and all stakeholders through building an anti-oppressive, empowerment-based partnership practice. This has laid the foundation for the Masters' Programme in Social Work in Disability Studies and Action, offered by the Centre. The Centre, in 2007, has been awarded the Departmental Research Support I, under the University Grants Commission (UGC)—Special Assistance Programme to design and offer the Masters' programme. This support from the UGC also encouraged our pursuit of the Masters' programme on Social Work in Disability Studies and Action.

Trajectory of the Programme

Background Preparation: The curriculum for this programme was developed using a three-pronged strategy:

1. *Initial Framework of the Curriculum*: The initial curriculum framework was discussed and developed by three members of the faculty, and this process began in 2005. We identified the broad knowledge, skill and attitude components that are required for professional training in the field of Disability Social Work. Within the broad umbrella of Social Work and the TISS Masters' curriculum, we identified the overarching theoretical perspectives and ideology that underpin the programme. Talvelkar and Juvva (2009) elaborate the perspectives that constitute the curriculum at the meso-and macro-level. They are offered as Foundation Courses, which is compulsory for all postgraduate students of the Institute, and as programme specific courses that equip the students with the critical lens with which to locate knowledge and practice. It also provides the epistemological and ontological understanding and location of the student in the programme. Based on the experience of offering a Certificate Course in Rehabilitation Counselling, we brainstormed about the courses that would form the core of the programme. The practice wisdom that guided us encouraged us to stretch and incorporate critical contemporary perspectives, having learnt from feminist teachings.

   Identifying the requisite internal aspects of the teaching–learning environment is an important process element of curriculum development, as is the scope the curriculum offers for field connection. Fawcett opines that a "…*disregard of theoretical perspectives, and reluctance to make links between theory and practice and practice and theory, have made and continue to make social work vulnerable, both as a profession and as a discipline*" (Fawcett 1998: 264). The current context of disability makes the task of curriculum development a challenging one requiring knowledge frameworks of varied perspectives rooted in diverse and plural theoretical lenses that will be delineated in the next section.
2. *Conducting a curriculum need assessment study* to understand the needs of social workers regarding inputs for specialized training while working in the field, with organizations providing services related to disability. A questionnaire consisting of about six open-ended questions was sent to about 50 NGOs working in the field of disability across the country. Responses were received from about 20 NGOs providing feedback on areas related to attitude, skills and knowledge aspects of the curriculum. Much of the feedback pertained to the curriculum that was envisaged. This reiterated and reinforced the focus that underpinned the curriculum that was developed. However, suggestions regarding specific roles that

social workers should prepare for helped us to fortify our curriculum with respect to community-based rehabilitation, expertise in training and capacity building, fund raising and proposal development, unexplored issues such as older adults and disability, deaf blindness, adventitious disability, and so on. This feedback added value to the curriculum. Further, it underscored the need for such specialized training for social workers in the disability sector and the suitability of both the programme and the curriculum.

3. The formulated curriculum was sent to about 50 *experts* from the field of disability, ranging from rehabilitation professionals, psychologists and social workers who worked in the disability as well as inclusive sectors, for feedback. The comments received indicated about 40% of the experts were of the opinion that the curriculum was very well framed and would be able to effectively meet the human power requirements for trained disability social workers. Additional feedback received from 20% experts included the need for focus on prevention, multiple disabilities, vocational training and the psychology of disability. These suggestions were incorporated in the final curriculum, particularly inputs on multiple disabilities, psychological perspectives and prevention. Vocational training is touched upon in two courses; however, it needs greater focus and attention in the curriculum with a broader focus on livelihood.

Based on the above three strategies, the curriculum was framed and presented to the General Body of the School. The school offered a few suggestions that were incorporated and the curriculum was approved by the Academic Council of the TISS and programme is being offered since 2008. Hallahan (2010) advocates the need to use a broad lens (such as that of Bourdieu) to capture both the individual identity and the disability identity within the contexts of power and culture. It is the responsibility of social work education and educators to develop teaching and learning approaches that go beyond the introduction of different aspects of the curriculum and that offer students a chance to fully explore the innate perceptions that they hold about the professional domains as well as different groups of people they would work with. Reflective teaching and learning approaches to facilitate student's exploration of 'meanings' they place on particular issues within a critically reflective environment is the need of the day (Redmond et al. 2008). The curriculum aimed towards fostering such a teaching–learning environment.

Principles of the Curriculum

The non-negotiable key principles underpinning curriculum development for higher education in disability studies and action have been drawn from both the social work as well as the rights-based approach towards disability. They include the following:

1. Respect for the dignity of persons with disabilities, including integrity, empowerment, confidentiality, autonomy, individuality and self-esteem
2. Individualization, meaning that persons with disabilities are individuals first, and must be considered, assessed and accommodated individually

3. Rights of persons with disabilities to inclusion and full participation.

This entails that there is appropriate and reasonable accommodation and modification of the physical, infrastructural and attitudinal environment before launching such a programme. The first attempt at such a modification was undertaken when the Certificate Course in Rehabilitation Counselling was offered. At that time, there were rudimentary attempts to provide at least one accessible hostel room and washroom for students with disabilities. With the initiation of the Master's programme, the students of the programme undertook access audits and advocated for making the campus accessible and this crystallized into a field action project of the Centre.

Individualisation necessitates the use of person first language. While we concur with 'disability' pride, we encourage the use of person first language specifically in a University setup, so as to imbue respect for the person than the disability. The moot point behind this emphasis is to stimulate change by speaking in a manner that rewires our thinking. This re-wiring enables us to express our thinking and bring about congruence in our speech and actions. This is the essence of the Speech Act theory proposed by J. L. Austin in 1955 and further expounded by Searle in 1969 and 1979 (http://jwood.faculty.unlv.edu//unlv/Articles/SearleWhatIsASpeechAct.pdf accessed on 25 June 2019). In keeping with this argument, when inclusion is used as a strategy to narrow the gap between what is said and how it is transacted, and it is embedded in the curriculum, it has the potential to challenge dominant hegemonic discourses of ableism and the medial model (Thompson 2012).

Initial Conceptualization of the Programme

The programme was initially conceived to be offered in the Specialization mode. However, further to the suggestions given by colleagues in the School of Social Work, the curriculum included teaching of core social work methods courses in the process format. However, it was later offered as a separate Masters' programme in Disability Studies and Action. The feedback enabled us to tighten the teaching of various courses. Social work was taught in a process format that included methods of social work, besides courses on team work, discovering self, spiritually sensitive disability social work, and ethics and values in social work. These were taught as separate courses with discrete modules. This format incorporated the suggestions obtained from various sources and was offered for a period of 3 years. Bean and Hedgpeth (2014) highlight the significance of social work students to 'attend to their own needs before they begin their careers as social workers' (p. 58). The authors opine that social work education with a focus on disabilities impacts the students' perceptions of persons with disabilities in a respectful manner.

Theoretical Inputs: The theoretical frameworks underpinning the curriculum are drawn from 'feminism, structural perspective, modernism, social constructionism, post-structuralism (that focuses on the subjective meanings of knowledge, power, language and meaning—micro-practices), and postmodernism (with its emphasis on contextual knowledge and exploration of paradoxes) and at the same time linking them to practice' (Talvelkar and Juvva 2009). It has been greatly influenced by the discipline of Disability Studies. This allowed for praxis in the curriculum that enables a student to critically engage with disability, gain reflexivity that challenges the norms (as in dominant medical discourses) and initiate action that is pro-people and value based. The social model of disability provides the context for 'macro-social analysis which reflects a structural or modernist orientation, whereas the exploration of difference and diversity can be seen to be a feature of postmodernist and poststructuralist perspectives' (Fawcett 1998: 273).

Theories or psychological foundation of learning are derived from the broader orientation related to vision and process of learning like humanistic, social reconstructionistic or academic orientation (Hirst 1974). While developing an M. A. course in Disability Studies and Action, a conscious decision was taken to have an academic orientation (rather than humanistic or social re-constructionistic) as this was going to be the first such course in a University setup requiring strengthening and contextualizing of knowledge related to disability. Knowledge has scientific temperament and is not based on ignorance, mere opinions or guesses; but is based on how well it can explain and justify phenomena (Hirst 1974). The curriculum of a subject should be determined by the most fundamental understanding that can be achieved of the underlying principles that give structure to a discipline (King and Brownell 1966: 90–91). Such learning permits generalizations, makes knowledge relevant even in contexts other than that in which it is learned and facilitates memory by allowing the learner to relate what would otherwise be easily forgotten, unconnected facts (Talvelkar and Juvva 2009). Morgan (2012) proposes that most students of social work enter the programme with current ideological stands. This needs to be deconstructed. She says that the social model of disability and theorizing in disability studies 'unsettles' the students and challenges them to go beyond the 'helping' stance that the profession aims to do. The theoretical framework encourages students to critically analyse the concept of help and work in partnerships.

The primary structural elements that an academic orientation to curriculum development offers provide the basis on which the courses are designed—problems or concerns, key concepts, principles and modes of enquiry (McNeil 1985). Other than these structural elements, certain process elements were also given weightage while developing a curriculum with a belief that the process of inquiry itself is a form of knowledge to be acquired—such as fieldwork, self-awareness workshops, spiritual social work in relation to the programme on Disability Studies and Action.

In terms of problems, concerns and key concepts, the learners of the postgraduate course on disability must understand the unique difficulties experienced by the people with disabilities in the areas of privileges, power and access to resources including coping resources, and the stereotyping tendencies of much of society including social workers and other helping professionals. Moreover, within groups of disability, there are groups which are more vulnerable to marginalization, discrimination and exploitation, as a result of their poverty, gender, age, caste, class and ethnic background. Learners (social workers) need to strive to address issues in terms of their needs and unique concerns. The principles, modes of enquiry and the process elements of the curriculum development aim at professional development for partnership practice. It also requires an exploration of one's beliefs, views and feelings, since all these may impinge and influence the professional relationship working with individuals, groups and communities.

Social work courses included besides the methods of social work include quantitative and qualitative research which sharpens the skills of the students to undertake relevant research so as to address and respond to immediate challenges. Core Disability Social Work courses include a course that provides an overview to key perspectives related to disability such as models of disability, strengths perspective, anti-discriminatory and anti-oppressive perspectives, empowerment and advocacy perspectives; systems perspectives related to ecological and systems theories; feminist, human rights and capabilities perspectives and conceptualization of stigma. While arguing for adopting newer forms of practice (underpinned by partnership, emancipatory and anti-oppressive rights-based approaches) Meekosha and Dowse (2007: 117) underscore the importance of using classical social work methods of working with individuals and groups, counselling and therapy. Oliver and Sapey (1999) illustrate the importance of using group work in the context of building agency through self-help groups and advocacy.

The course on persons with disability and their rehabilitation contexts include information and inputs related to types, causes and interventions with regard to various types of disability, prevention and rehabilitation, enabling and disabling environments and its impact, and psychology of disability. Human Rights, Policy and Law provide an understanding of the existing legal and policy frameworks in the international and national level so as to develop a critical lens to champion the rights of persons with disabilities. The course on advocacy aims at critically engaging the person with disability and other stakeholder groups towards partnership and for self-advocacy (Meekosha and Dowse 2007). The course on disability counselling discusses advance social work practice with individuals, groups and communities. Family Centred Interventions with Families of Children and Adults with Disabilities offer scope to learn how to work with families across the lifespan. The course on gender dimensions of disability equips the students with a lens to undertake a gender analysis to understand disability from the perspectives of femininity and masculinity to explore and critically analyse the issues that people with disability across various genders face and arrive at appropriate interventions. The course on Management of Rehabilitation Programmes for Persons with Disabilities uses the management lens to design, implement and evaluate programmes for persons with disabilities in the not for profit and corporate sectors.

The curriculum mandated that students undertook a compulsory research project that culminated in a dissertation and a practicum related to community intervention in the rural context. The practicum aimed at exposing the students to the various perspectives in understanding rurality and disability in the Indian context; and to enhance knowledge of local self-governance and welfare schemes that aid disability interventions in the rural context. Through these learnings, the students are expected to design and implement activities in the field using various skills of intervention. This allows for praxis to be able to reflect on one's own rural field practicum and life experiences and develop connections with theory. They also are encouraged to explore micro-level and macro-level issues within sociocultural context, and form linkage while examining the opportunities for a range of interventions, and to foster change.

During the first 3 years of developing and transacting the curriculum, the teachers were learning while on their feet, as a prototype curriculum was not available in India. Student feedback about the programme was sought every year and their suggestions were considered as valuable inputs to strengthen the programme. Based on this feedback, minor additions to the curriculum were made during these 3 years. They include theoretical perspectives related to coping, social support and including psychoeducation as form of working with individuals and groups, including masculinity perspectives in gender and disability. In 2011, an internal review of the entire programme, course-wise, was undertaken and it was found that some courses could be strengthened. Inclusion of the above-mentioned topics added strength to the courses. The feedback about the field study trip and Rural Practicum was positive and it continued to add value to the programme and it was decided to keep it the way it was designed, both in terms of curricular logic and content. These are the hallmarks of the course, as they allow for praxis in student learning.

Fieldwork: Fieldwork is integral to social work training. It constitutes one-third of the entire curriculum and is one of the strengths of the professional training. It allows students to ‘dirty their hands’ while learning and in the process apply theory to practice. This calls for students to introspect, draw upon their inner source, and identify what systems to shift to produce results. This calls for practice with integrity and professionalism. Fieldwork consists of a range of activities. The initial preparatory activities include making visits to organizations in diverse settings, learning about them and observing the roles that a social worker plays in these diverse settings. Alongside laboratory exercises in the form of simulations and experiential learning that prepares the student for plunging into the field and this exposure is a critical aspect of learning.

The importance of practical training for student social workers in the disability sector has been highlighted by Leutar and Markovic (2011). Hence, the students are placed with a human service agency, after adequate matching between agency requirement and student choice. The students are expected to learn about the agency and it’s functioning, the diverse people they work with and provide interventions commensurate with their learning in the classroom. In doing so, they are able to apply the methods of social work, namely, working with individuals, groups, communities and research, besides learning basic skills in counselling. They are expected to mobilize resources, network with other organizations and raise funds for the agency, while engaging in documentation work for them. In the second year, they are expected to be posted in core disability settings so that they not only gain skills and practice in the disability setting, but also to be able to initiate programmes with a disability focus in inclusive settings too. Currently, inclusive settings are also explored for student placement as the demand to initiate programmes related to disability and addressing need for convergence is on the increase. Fieldwork may be offered in the form of concurrent fieldwork (2 days per week) and block, where they attend fieldwork continuously for about 5 weeks.

At fieldwork, sometimes social work students have to contend with rough and challenging turfs pertaining to professional ethics and demands and organizational expectations (Morgan 2012). The curriculum prepares them to navigate these challenges, keeping in mind the danger of a possibility that 'we can probably now announce the death of social work at least in relation to its involvement in the lives of disabled people' (Oliver 2004: 25). Students of this programme have to employ diverse skills and techniques to not only contend with these challenges, but also make themselves relevant as human service professionals with a critical empowerment perspective in this sector. The recursiveness and intersection of theory, ethics and practice is crucial for disability social workers.

Field-Based Engagement: A unique feature of this course is the *field study trip*, where the students are immersed in a rural setup and anchored by an organization that practices community-based rehabilitation through its various programmes for diverse types of disabilities. The students are taught community-based rehabilitation in the field, by both the teachers and the staff who work in the organization. They have an opportunity to visit various community sites and interact with people who are stakeholders of community-based rehabilitation, across the CBR matrix of the World Health Organisation. Lectures in the field and site visits add value to their learning and this practice continues till date. This has been a rewarding experience and an important precursor to the rural practicum.

The *rural practicum* is a 3-week intense engagement with people in the rural areas. This was initially located in the beginning part of the final semester, when the students have been exposed to significant inputs on disability and related contexts, so that they can work independently in identifying issues, designing programmes and interventions and implementing them in the rural area. However, because of curricular alignments, it is currently located at the end of the third semester, when substantive inputs have already been given. They are typically associated with a local NGO who anchors them and provides them with support. The 3-week immersion offers the scope for students to plunge into activities, including undertaking a participatory rural appraisal using the rights-based approach, that are largely outputs. In some instances, they use these outputs to prepare ground and strategy for state change, namely, outcomes that can lead to long-term sustainable impact. Working with local communities using the CBR matrix enables the students to undertake the first step towards providing knowledge about disabilities particularly with NGOs who do not have a disability focus in their work. Through this knowledge and building strategies for convergence for government schemes, the students draw out a sustainability plan and create spaces for such NGOs to initiate work in the disability sector. Encouraging both persons with disabilities and the NGOs in making available information about disability and government policies is the first step towards empowerment (van Pletzen et al. 2014).

Learning Enhancement activities are another important area of praxis. They include diverse activities, namely, access audits, Challenging Challenges (one–two-day simulation activity to give participants an experiential understanding about disability), Mumbai Local, Film festival on Disability, and a student-organized academic event called Sameeksha. These are non-credited, non-graded activities that the students initiate every year. The students have conducted access audits of the two campuses of Mumbai, and the rural Tuljapur campus. The findings of these access audits were shared with the management and TISS had applied for and received a grant from the UGC to initiate changes in its infrastructure. However, there is more to be done with regard to accessibility and this is work in progress.

The students have, over the past 8 years, conducted experiential simulations exercises, namely, Challenging Challenges, to sensitize and create awareness about disability on campus and in our field action projects. This includes sensitization exercises to experience blindness, deafness, learning difficulties and so on, that provokes us to think and challenge the dominant hegemonic discourses and argue for the social model of understanding disability without negating the import of the medical model. In recent couple of years, the students have developed an exercise on listening to multiple conflicting but compelling audio stimuli to simulate hallucinations on the lines of the simulation developed by Skoy et al. (2016). This simulation intends to develop empathy for persons living with mental illness too, amongst the participants of this programme. In 2012, a railway project in the Mumbai local trains was initiated, so that commuters can be sensitized to issues and concerns of persons with disability and they can partner in championing the disability rights discourse. Based on the experiences of exclusion and discrimination of a colleague in Mumbai local trains, the students undertook sensitization activities at train stations and platforms for commuters about disability and the need to respect the needs of persons with disabilities.

The student's annual festival, namely, Sameeksha has been a platform where the students have been able to showcase their talent and design and implement relevant academic discourses. Disability as one of the topic of discourses was initiated by the students and they invite expert speakers and scholars from the field of disability to address students and share current developments in the disability sector, related to ability discourse, subaltern perspectives, accessibility, and so on. These activities have also enthused students of other programmes to evince interest in disabilities. For example, a course in the School of Media and Cultural Studies had designed an assignment to develop short films on disabilities.

The above activities and experiences have emphasized the need to continually respond to lack of knowledge about disability in the general population. Social workers bridge the gap between lack of information and knowledge in order to providing opportunities to access this knowledge. It is a mandatory requirement of the profession to be ethically responsible to addressing the concerns of oppressed groups (Schormans 2010). The masters' programme aims to address this through diverse activities, both curricular and extracurricular.

Restructuring in the School of Social Work: In 2012, when the curriculum of the entire school was restructured, it was decided that all the programmes in the School of Social Work will have common School level courses and specific domain-related courses will be taught by domain experts. Further student feedback revealed that we teach the methods of social work discretely rather than following the process approach. Hence the programme underwent a shift in terms of offering the methods courses in a discrete manner, dropping a couple of courses to fit in with the other programmes of the school and also decreasing the total number of credits to bring in parity with other programmes. Some minor changes were incorporated in the specialization courses that were being offered. However, the fieldwork and research components remained the same. The learning enhancement activities continued and programme was sought largely by candidates who had a special interest in the field of disabilities. Therefore, this course catered to those candidates who had an inclination in a niche area of work.

Another comprehensive review of the programme was undertaken in 2015. A self-reporting questionnaire, with 10 open-ended questions, was sent out to the alumni via email and there was a response rate of 40%. The alumni identified the courses they found currently useful in their work life and the courses that need modification. They suggested including tools for project planning (including logical framework analysis), monitoring and evaluation, and NGO management, besides strengthening the contemporary disability discourse. The students requested for workshops on sign language, braille, mobility training, and spiritually sensitive social work practice and so on, so that students would be able to access all forms of communication. They also requested additional inputs on mental health, political economy, poverty, masculinity, political participation and disability, marriage counselling, sexuality counselling, greater emphasis on simulation in classroom and role of technology in disability. These were subsequently added to the curriculum. Overlaps were addressed, and gaps were plugged in the curriculum to the extent possible, given the expertise of the teachers. Based on feedback regularly sought from the students, efforts are made to keep the curriculum abreast.

Research Support: The Centre for Disability Studies and Action has received support from the Special Assistance Programme of the University Grants Commission for two 5-year terms. An emerging discipline such as Disability Social Work benefits from receiving such grants. These grants have been helpful to incubate learning enhancement activities that pave way for new areas of work, such as the access audits, challenging challenges programmes, sensitization programmes in communities with various stakeholders at the grassroots levels, etc. They have also assisted in organizing network meetings with government and non-government service providers to respond to various needs such as consultation meetings for responding to draft bills of the recent legislations that have been given assent in the country.

After graduation, the trained social workers have been able to find job options, both in the disability sector as well in inclusive sectors. The greatest advantage of jobs in an inclusive setup includes permeating the sector with a disability agenda, thus ensuring that nobody is left behind and making everyone count. This has become the uniqueness of the programme. In the recent past, with the development of the Right to Persons with Disabilities Act, state departments hired recent graduates. The NGO sector continues to hire the largest contingent of disability social workers. Corporates, through the Corporate Social Responsibility initiatives have also recruited Disability Social Workers. Start-up companies that are an amalgam of technology and social issues are recent entrants to the recruitment scenario. The versatility of the profession has made it possible for young graduates to be absorbed in diverse types and sectors of employment.

Emerging Trajectory

The programme on Disability Social Work (alternatively known as Social Work in Disability Studies and Action in TISS) is relevant and imperative in postgraduate Social Work education. This not only helps to plug the gap in training and services, it also aims to build scholarship in a contemporary field that calls for action at all levels—knowledge/theory generation; identifying and developing pertinent practice models and techniques that are culturally relevant in areas of living, learning and work; informing and influencing policy building and practice; advocacy and networking amongst the diverse disability sectors and fortifying research in the disability sector. This Masters' programme equips professionals to work at individual, group, family, community, programme and policy levels including building strategic alliances. The strength of the programme lies in training in the above aspects that contributes to a cadre of dedicated professionals with appropriate mentoring, training and skills that fosters dignity and agency in persons with disability to realize their potential. While acknowledging the significant contribution of the programme in the disability sector, we also wish to state that the inherent and diverse complexities of the field of disability are not fully addressed through this programme. The diverse perspectives gained enable disability social workers to challenge existing norms and seek to establish a level playing field for all people, including persons with disabilities.

Given that the UGC mandates the creation of a Centre for Disability Studies in all Universities, this programme is a forerunner in terms of learning and sharing of experiences. The experience of offering the current programme has not only contributed to building human service professionals for the complex and diverse disability sector, but has also contributed to strengthening research and generating practice based on relevant conceptual understanding that are context-specific and therefore robust. This experience has percolated to exploring areas of research, such as focused areas including sports and disability, gender nonconforming identities and disability, accessibility and disability and so on that could be a harbinger for change in the disability sector. This also paves way for creating courses that address the needs of the field mentioned above. Over the past couple of years, the RCI has shared our curriculum with other universities with a proposal to encourage up more schools of social work to offer such a Masters' programme.

There is huge scope for transdisciplinary collaborations in knowledge generation, meaningful research and in policy practice that transforms the lives of people with and without disability. We envisage the scope for expanding the focus of specialized disability centres that create and strengthen knowledge and skills; for example deaf studies, developmental disabilities, multiple disabilities and disability research. Creating teaching programmes both in distance and contact mode are also options that we might want to consider for the future growth of scholarship in the disability sector. The university setup has a specialized focus in training and teaching. However, we recognize there is an urgent need to respond the competing challenges of the disability sector by encouraging partnerships and alliances with all people at diverse levels, so that we can make the sustainable development goals a reality, at least in higher education.

It would be interesting if the aspect of student feedback could be added to the paper briefly. The reasons for starting the course has been explained in detail along with the theoretical basis. A brief section on student experiences if available on the relevance of the course in the field would strengthen the argument of the paper regarding the need for more such programmes.

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Part III
Academia—Activism Interface: Enabling Practices

Chapter 12

Resisting Dominant Construction of Blindness and the Genesis of Disability Studies in the University of Delhi: A Historical Context

Jagdish Chander

Just like Gender Studies, Queer Studies and several other emerging areas of studies, particularly the ones related to marginalized sections of society, Disability Studies is also one of the emerging areas of studies in a few parts of the world. It has its roots in activism. It continues to remain a highly marginalized area of study in the academic discourses in most universities in the world and the University of Delhi is no exception to it. But recently, there has been a ray of hope for the creation of a fertile ground for its emergence due to notable developments since 1970s.

Lately, there has also been an emergence of groups of scholars in the field of Disability Studies in India as well as those based abroad and working on disability-related matters while adhering to Disability Studies perspective. While their presence is quite negligible and is at its nascent stage, this small group of scholars of Disability Studies based in India and abroad, coupled with disability rights activists, is gradually leading to the creation of the ground for the introduction of Disability Studies in a few academic institutions in the country including the University of Delhi, hereafter referred as 'University'. Hence, despite the fact that Disability Studies as an area of academic inquiry in the academic institutions in India continues to be invisible and almost nonexistent, there are discernable signs of its gradual introduction in certain academic institutions arising out of disability rights activism and emerging indigenous scholarship.

This chapter engages in a historical analysis of the developments which have been creating a fertile ground for the emergence of Disability Studies over a period of time in the University. It begins with a discussion of the disability rights activism which has been going on in the University with the struggle launched by the blind activists for their rights since 1970s, that challenges the dominant construction of blindness. The chapter concludes with a critical analysis of the recent developments

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J. Chander (✉)
Department of Political Science, Hindu College, University of Delhi, Delhi, India
e-mail: jagdish100@gmail.com

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leading to the emergence of Disability Studies as an area of academic inquiry and the increasing interest of the young scholars in the field of Disability Studies in this University. Since the study of the issues of the marginalized sections of society has generally its roots in activism, it is pertinent to examine the developments related to the disability rights activism in the University which have been preparing the ground for the emergence of Disability Studies over a period of time.

Resistance to Dominant Construction of Blindness

The disability-specific rights movement in India began with the self-advocacy movement of the blind activists in 1970 in India. This movement also known as the movement of the organized Blind, began at the national level with the founding of the National Federation of the Blind Graduates in Delhi in 1970 (Chander 2011 pp. 141–145). The word Graduates was later dropped in 1972 which gave rise to the National Federation of the Blind (NFB) (ibid). It is worth emphasizing that the two leading figures, who were intensely involved in NFB in the initial stage of its growth during the early 1970s were faculty members in the University; Dr. Ved Prakash Varma and Dr. Sant Lal Thareja. Professor Varma is a leading philosopher, who has immensely contributed to the discipline of philosophy through his writings in Hindi. He was the first blind faculty member in the University who, from the beginning of his career, engaged in academic discussions on blindness in addition to his core area of research. Varma contributed several articles in Braille Monitor, the monthly magazine published by the National Federation of the Blind of USA during the late 1960s and the early 1970s. Subsequently, he wrote the biography of Louis Braille, the inventor of Braille in Hindi. He continued to be quite active in the All India Confederation of the Blind (AICB), a split away group of the NFB and remained the editor of *Braille Bharti* (a Braille magazine published by the AICB), for almost two decades during 1980s and 1990s. He recently brought out his autobiography in Hindi. It is titled *Jivan: EkYatra* (life: a journey) in which he has dwelt upon his experiences as a blind faculty member who struggled as a member of the first generation of the blind academics in the post-independence era in India and who explored and challenged the construction of blindness (Varma 2012).

Dr. Theraja, unfortunately, died very young in 1973, but he was able to leave a mark as a great activist and as the only other blind faculty member in the University in addition to Dr. Varma in early 1970s (Chander 2011). He got his employment as a result of the identifiably first demonstration carried out by the blind activists in front of Vigyan Bhawan (one of the important Central Government buildings in Delhi) in 1969.[1] Theraja was well known for his highly radical approach towards advocacy

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[1] J. L. Kaul personal interview, February, 14, 2005. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights.*

and remained quite active in advocating the rights of the blind people through his involvement in the NFB till his death.

Both Varma and Thareja have been known for holding a perspective that challenged the dominant construction of blindness during the early era of the 1970s. In addition to Varma and Thareja's presence as blind scholars and activists, the decade of the 1970s also witnessed the beginning of the students' movement by the blind activists in the University. This movement was based on the disability rights perspective which challenged the construction of blindness in the University based on the belief that the blind are, in fact, incapable of pursuing higher education and are by no means to be employed as faculty members. It is, therefore, pertinent to discuss the origin and the agenda of this movement and its resistance to the dominant construction of blindness.

Soon after the NFB started functioning in Delhi, discontentment arose as the college students became frustrated with the mild methods of advocacy adopted by the first generation of leadership at a time when the socialist movements were gaining momentum in various parts of North India (Limaye 1984; Mohan 1984). They blamed the leadership (comprising the first generation of blind activists, who founded the movement) for its inability to help them obtain the required support in the pursuit of their education. This highly conscious and active group of college students realized that the leadership of the NFB was in the hands of the well-settled middle-class blind individuals who did not give adequate attention to the interests of the high school and the college students. So, in reaction to the mild forms of advocacy adopted this group of students formed small independent organizations to address their interests. As a result, beginning in the early 1970s, a few small organizations were founded in Delhi to represent the interests of the college students or those who were aspiring to be admitted to certain college programmes. These and the future students later became a part of the second generation of the educated blind activists, who had challenged the authority of the first generation after the first formal split in the National Federation of the Blind in 1978. They also challenged the prevalent construction of blindness and demanded equal access to higher education.

Two of these organizations, both formed in the 1970s, were the Akhil Bhartiya Netrahin Vidyarthi Parishad (ABNVP) and the Blind Persons Association (BPA). The BPA was established in 1975. The ABNVP, on the other hand, had been in existence since April, 1972, but it could not be registered and was later disbanded and most of its members founded a new organization called the National Students Organization of the Blind (NSOB). A third organization, the National Blind Youth Association (NBYA) was established in 1974. While the BPA comprised the young members of the NFB and worked in close collaboration with it, the other organization had no link with the NFB and worked independently. It is pertinent to make a brief analysis of the role of the ABNVP at least in demanding the equality of opportunity for blind students in the pursuit of their higher education in Delhi and challenging the construction of blindness.

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p. 117. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

The ABNVP was the first advocacy organization formed by the blind students in Delhi. The Organization was established to promote the interests of the group of prospective high-school graduates of *Andh Maha Vidyalay* (School for the blind), the oldest special residential school in Delhi located in Central Delhi in the vicinity of Connaught Place (Chander 2008).

It was quite common during the early 1970s that the blind students were denied admission in colleges even if they had the required qualifications.[2] Based on the past experiences, the students of AndhMahaVidayalay (School for the blind), who took high school exams in the spring of 1972, feared that even if they performed well in the exams, they would be denied admission into colleges. They, therefore, realized that they needed to raise their issue of admission to colleges before the high-level government authorities. For this purpose, they decided to establish an organization and that is how the ABNVP was formed in April 1972.[3]

As informed by Dr. Bharat Prasad Yadav, who was also then a student in AndhMahaVidayalay and subsequently played a significant role as a youth leader: 'on 21st May in 1972, three students of *Andh Maha Vidyalay*, who had appeared for class 12th that year, went on hunger strike in front of the residence of Indira Gandhi [the then Prime Minister of India]. They demanded that they should get admission in colleges and a decent amount of scholarship to pursue our education .... It was all done under the banner of the ABNVP'.[4] Thus, soon after the establishment of the ABNVP, these students launched a movement demanding admissions for the qualified blind students in the colleges and an increase in the amount of scholarships.

As pointed out by Yadav, 'Mrs. Indira Gandhi met us in the last week of May and she too said that 40 rupees of annual scholarship for college students were very less. So, addressing our request, she immediately ordered to increase this amount to 150 rupees a year. Dr. Shanti Narayan was the dean of the colleges in Delhi University those days. Indira Gandhi called him as well as the vice chancellor of Delhi University for a meeting at her residence. She told them that it is very unfortunate that the blind people want to study and you don't give them admission to colleges. She warned them that if we were not given admission in the colleges, then the grant to The Delhi University through the University Grants Commission [the Central Government body which disburses the grants to the higher educational government institutions in India]

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[2] R. M. Vyas personal communication, February 3, 2006. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 158. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[3] R. M. Vyas personal communication, February 3, 2006 (A). Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 159. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[4] B. P. Yadav personal interview, April 17, 2005. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 159. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

may be withdrawn. So, upon her instruction, all of us were granted admissions in the colleges in that year and were provided accommodation free of charge'.[5]

Another significant achievement of ABNVP was that the activists used it as a forum to oppose a paragraph in a high-school textbook prescribed by the National Council of Educational Research and Training (NCERT) in which the author argued that the blind people should not get married because they are likely to have blind children—'There was a book written by V. D. Ramchandran in which it was clearly written that blind people should not marry because if they get married, then their children will be born blind too. We started raising our voice under the banner of ABNVP. Finally, a meeting was scheduled with minister of social welfare, Sri Arvind Kumar. We explained our objection to him. We said that they should organize at least one marriage for one of us and if our child is born blind, then we will accept the statement of Sri V. D. Ramachandaran; and in case his statement is proved wrong, then they should remove this book from the school curriculum. He finally called a meeting with the secretary of the Department of Education and asked him to look into our complaint. After that, the author's widow came and started crying and pleaded not to remove the book from the curriculum as the royalty from that book was the only means of her living. The Minister once again called us for the meeting. He explained the gravity of the situation and asked for our suggestions. We suggested that keeping in mind the problem of both [the objection raised by blind activists and the concern of the widow of the author], what best can be done is that this particular paragraph should be removed from the chapter. Finally, a formal letter was given to us explaining that such and such paragraph from the book has been removed …. It was our opposition that she gave us an apology letter and such statement was removed from the book. It was a time when such achievements were not easy as it was very difficult to get such a response from the authorities'.[6]

Due to some internal disputes and in the absence of proper infrastructure, which would have helped any organization to get institutionalized, the ABNVP could not last long and its dissolution paved the way for the rise of the NSOB in the fall of 1974.[7] Many people who were members of the ABNVP joined the NSOB. As a result, its focus remained on the same issues relating to the problems of the blind students studying in colleges.

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[5] B. P. Yadav personal interview, April 17, 2005 (A). Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 160. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[6] B. P. Yadav personal interview, April 17, 2005 (B). Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 162. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[7] R. K. Sarin personal interview, January 30, 2005. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 163. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

By the 1990s, a group of educated blind individuals became eligible for teaching posts in the university. The NSOB now engaged itself in a number of activities to demand the appointment of the qualified blind to the teaching positions in the University. It was basically the result of the efforts of the NSOB that the Academic Council of Delhi University passed a landmark resolution in 1994 to reserve 3% of college teaching positions for the disabled.[8] This happened, significantly, a year before the Persons with Disabilities (PWD) Act (1995) was enacted to mandate the reservation of 3% jobs in all Central Government Services.

As elaborated later in this paper, even though the PWD Act of 1995 was enacted, it was not implemented till the administration was pressurized to do so. One of the most strategic methods of advocacy to get the law implemented has been to approach the courts and demand that they issue directives to the administration to implement the provisions of a particular law. The blind students, most of whom happened to be doctoral students, had to file a suit in the High Court of Delhi in order to get the provisions for the 3% reservation in teaching positions implemented at the University. The suit was filed in 1996 and the high court gave its judgment in 2001 asking the University administration to implement the provisions of the PWD Act by filling the teaching positions with eligible disabled candidates (Pushkar Singh Kushwaha and others Vs. University of Delhi 2001). It is notable that though this suit was not technically filed by the NSOB, the chief petitioner, Pushkar Singh Kushwaha, happened to be the unchallenged leader of this organization. However, the NSOB has predominantly been silent and dormant with the exception of occasional advocacy activities relating to issues concerning accommodation and appointments for the blind candidates in teaching positions in the University.

Some of the members of the NFB, who constituted a group of college students during the mid-1970s, were growing increasingly dissatisfied with its leadership in Delhi. They felt that the leadership of the Federation was inadequate to address their interests. As a result, they decided to form an organization which would solely focus on the interests of the college students, their issues of accommodation and other matters to facilitate the pursuit of their education. That is how the BPA was formed by some of the members of the Delhi Branch of the NFB in 1974 as recounted by Ram Avtar Sharma, a leading figure and founding member of the BPA.[9]

It is notable that the blind people were not even allowed to take certain exams for civil service jobs. There was a provision in the eligibility tests for the Indian Civil Services conducted by the Union Public Services Commission (the recruitment agency for Central Government civil services) that the exams needed to be written

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[8] P. S. Kushwaha personal communication, February 6, 2006. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 163. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[9] R. A. Sharma personal interview, June 27, 2005. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 164. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

in the handwriting of the same person who was taking the exams.[10] This meant that no one was allowed to use amanuensis for writing these exams. As a result, the prospective blind examinees could not sit for the exams, as they had to depend on the amanuensis to write for them. The BPA mobilized the educated blind and got a handful of them to push the leadership of the NFB to file a suit in Delhi High Court to challenge the Union Public Service Commission. Finally, the Delhi High Court instructed the Union Public Service Commission to allow qualified blind job seekers to take these exams, which are held annually, and to ensure the necessary accommodations, such as extra time to complete the exams and the permission to seek the help of an amanuensis to write for them (Pandey and Advani 1995, p. 104).

In addition to these smaller organizations primarily representing the interests of the blind students in Delhi, the National Blind Youth Association (NBYA) also emerged in opposition to the NFB as a discontented group of young blind people, most of whom were still college students. Unlike the ABNVP (which did not last long), the BPA and the NSOB which were active from time to time and often kept the scope of their activities quite limited, the NBYA grew in size and shape and continues to be an alternative forum for representing the voice of the blind people in the capital city even today. Most of the members of the NBYA, from the time of its foundation, were the students of AndhMahaVidyalaya and were involved with the ABNVP and even the NSOB to some extent.

The NBYA was established in 1974 after the dissolution of the ABNVP. Bharat Prasad Yadav, who was the founding and long-term prominent leader of the NBYA, was himself a college student at the time of its formation. Yadav later earned his doctorate from The University and has recently brought out a book highlighting the contribution of Louis Braille and the importance of Braille.

The activists, who formed the NBYA, initially intended to launch a struggle for the rights of the blind students pursuing higher education in the University. Therefore, to start with, they focused on ensuring a support system required in the pursuit of their higher education. This included equipment such as tape recorders and tapes for taping books, provisions for human readers to read out books loud, transcription of books in Braille and amanuensis to write their exams.[11]

By the late 1970s, the members of the NBYA began negotiating with the authorities with respect to a range of issues including concessions in the college hostel fee, establishing a Braille and Recorded Books Library at the University of Delhi, admission in the Bachelor of Education [B.Ed] programme and in organizing sports weeks for the blind youth. So, an attempt was made to address almost all the issues

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[10] N. R. Nishad personal interview, July 3, 2005. Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 166. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

[11] B. P. Yadav personal interview, April 17, 2005 (C). Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 96. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

related to the student community.[12] Their efforts bore results. A separate section known as the Braille Library was established for the blind readers inside the Central Reference Library of the University and admissions were allowed for the blind in the B.Ed courses in the University along with concession in the hostel fee.

As is well established, the roots of Disability Studies lie in the disability rights movement to a great extent. Therefore, the students' movement led by the blind activists in some way can be regarded as the emergence of the perspective which gradually prepared the ground for Disability Studies over a period of time. Some of the key points in the construction of blindness that were challenged by the blind activists, who were engaged in the movement for the rights of the blind people in Delhi during 1970s, can be summarized as follows:

One of the dominant perceptions in the Indian society of the 1970s towards the blind as, a group was that the blind are not capable of pursuing education in the mainstream education system. Consequently, though they were able to pursue education up to the high-school level in special schools, they were not in a position to pursue higher education at the college and university levels. Hence, the doors to a college education were closed for them. This circumstantial urgency and the need to debunk prevailing myths, the blind students of AndhMahaVidyalay got together to fight for their rights to higher education in 1972 through first the ABNVP and later some other organizations like the NSOB, the BPA and the NBYA. They had to be constantly engaged in challenging this myth and asserting for their equal rights to higher education first by admissions in the colleges and later by demanding the required support system. It was in continuation of this struggle that the blind activists under the banner of the NBYA demanded admission in the B.Ed course in the University challenging the myth that the blind were incapable of working as school teachers. Another myth that the blind are not suited for the Civil Services was, likewise, challenged and demand went up that the Civil Services should be opened up for the blind candidates. The NSOB also advocated for University positions challenging another prevalent myth, and on another front, achieved radical breakthroughs by questioning social myths attached with the blind on marriage related issues as mentioned in the textbooks.

Intellectual Movement Challenging the Myth of Blindness in the University of Delhi During 1980s and 1990s

During the 1980s, the national level movement was carried out by the NFB and the NBYA. While the prominent leader of the NFB, Santosh Rungta was the law graduate of the University of Delhi, Dr. Bharat Prasad Yadav, the prominent leader

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[12] B. P. Yadav personal interview, April 17, 2005 (D). Cited in Chander, J. (2011). *Movement of the Organized Blind in India: From Passive Recipients of Services to Active Advocates of Their Rights*, p. 169. Cultural Foundations of Education—Dissertations, Paper 50. Syracuse University, Syracuse, New York. Retrieved on August 5, 2015 from: http://surface.syr.edu/cfe_etd/50.

and then president of the NBYA was still a doctoral student for the most part of that decade in this University. Most of the executive board members of both these organizations were either the students or the graduates of the University. While the major strength of this movement was derived from the students of residential schools for the blind in Delhi, a good number of them also came from the Government Hostel for the college-going blind students located in the vicinity of the main campus of the University of Delhi. Almost all of the residents of this Hostel were the students of the University. Hence, while there was no sustained advocacy movement led by the blind activists in this University barring a few during the 1980s, the students of this University were still very much involved in the national level movement carried out from Delhi. They were thus a part of a process of challenge to the prevalent construction of blindness. Before moving to the recent developments leading to the contribution to the emergence of Disability Studies in the University, it is worth emphasizing the importance of *Mubahisa*, a study circle, which had existed for more than a decade since mid 1980s.

Muhabisa, which means discussion and a study circle in Urdu, was started in the University in 1986 by Dr. Govindi Joshi, a faculty member in the Department of Political Science at Ramjas College, University of Delhi. It was formed following the death of Abhay Kumar, a blind student who was then a student of Dr. Joshi at Ramjas College. Abhay was a resident of *Andh Maha Vidyalaya*, a residential school for the blind in Delhi also served as a hostel for its alumni. It was alleged that the death of Abhay took place due to the negligence of the school authorities. Dr. Joshi, who was quite sensitive towards the issues of the blind students in her college, felt the strong need to have a forum for constant interaction with them in the University so that she and the other faculty members of the University could be aware of the issues concerning the blind in the University. Hence, *Mubahisa* was established as a result of the initiative of Dr. Joshi and it comprised primarily the blind students studying in various colleges of the University. Since Dr. Joshi was keen to promote inclusion of the blind students, she strongly encouraged the sighted students and the faculty members to be a part of it. So, some of her sighted faculty colleagues, a few of her sighted students and some of their sighted friends joined *Mubahisa* from time to time. But for the most part, it comprised the blind students and Dr. Joshi.

The routine activity of *Mubahisa* was a weekly meeting at which Dr. Joshi or some other sighted faculty member or student used to read out an article from some newspaper or magazine on important social or political issues. The presentation comprised the front page headings of the newspapers during that week followed by a discussion. Occasionally, issues concerning disability were also taken up for group discussions in the weekly meetings. In addition to these meetings, a few other activities were also organized by *Mubahisa* from time to time, which included lectures on various issues including disability. Three of such activities which deserve special mention were: the bringing out of a souvenir, the organization of Louis Braille Memorial Lecture Series and installation of Louis Braille statue in the campus of the University.

Mubahisa organized an annual function around the time of Louis Braille's birth anniversary on the 4th of January. This anniversary programme included various activities like the publication of a souvenir which contained the original contribution of the blind students and some faculty members. Most of the articles or poems included in this souvenir aimed at challenging the construction of blindness. For example, an article included in the souvenir published during the year 1989 was titled '*netrahinta abhishap nahi, ek chunauti hai*' ("Blindness is not a curse, rather it is a challenge") (Panwar 1989). It was authored by Dayal Panwar, who was then a student majoring in Sanskrit at St. Stephens College in the University. The article vehemently challenged the dominant construction of blindness that looked at blindness as a curse arising out of bad karma in the past lives.

As mentioned earlier, *Mubahisa* also organized lectures on various issues including disability from time to time. The most important of these was the Louis Braille Memorial Lecture Series organized to commemorate the birth anniversary of Louis Braille. This lecture series, which was organized for about 5 years, comprised lectures delivered by leading professionals and scholars in the field of disability. Lal Advani, who pioneered the establishment of services for the empowerment of the disabled in India (Chander and Baquer 2005) and Justice Krishna Iyer, a retired judge of Supreme Court, who also authored a book on disability and law (Krishna Iyer 1978) were some of the prominent speakers. Most of the lectures delivered under this series aimed at challenging the established social view of disability.

Before summing up the discussion relating to the contribution of *Mubahisa* in challenging the prevalent construction of blindness, it is worth emphasizing that *Mubahisa* members also succeeded in getting the statue of Louis Braille installed in the Center of Faculty of Arts, the old building where most of the social sciences as well as languages and literature departments were housed before the new building for social sciences was constructed during the later part of the decade of 2010. The installation of Louis Braille statue was the result of a long drawn out sustained lobby carried out by the members of *Mubahisa* under the leadership of Joshi to highlight the role of Louis Braille in the promotion of education of blind in the world. Joshi and other *Mubahisa* members argued that if the University could install the statues of Swami Vivekanand and Ravindranath Tagore and even Jawaharlal Nehru to highlight their contribution to the promotion of education, why should the contribution of Louis Braille not be recognized in promoting the education of such a large section of society comprising blind people. This argument which remained neglected and rejected by the University officials for half a decade, finally came to be accepted by the then vice chancellor of the University, Professor, Upendar Baxi in 1990 when he conceded the demand for the installation of the statue. Professor Baxi is considered to be a progressive legal scholar who had also co-authored a book on law and disability with Professor Amita Dhanda, a well known leading scholar of Disability Studies (Dhanda and Baxi 1990).

In the era of globalization, owing to changing nature of the campus culture in the University it has lately become difficult for study circles, which may not be directly related to curriculum, to survive. It was not easy to sustain *Mubahisa* too primarily due to the lack of students' involvement in the late 1990s. However, the decline of *Mubahisa* over years gave birth to another organization called *Sambhavana*, which means 'possibility'. Several students who were involved in *Mubahisa* got involved with *Sambhavana* when they got hired as faculty members in the University. Dr. Joshi, who established and ran *Mubahisa* for over a decade and half, strongly encouraged the establishment of *Sambhavana* and continued to be associated with it despite her retirement from her job. Most of the members of *Sambhavana*, now, are blind faculty members, while a few others happen to be physically impaired.

It is notable that its long-term president, Nikhil Kumar Jain, who was groomed into activism as a member of *Mubahisa*, has been quite active in the Delhi University teachers' trade union movement and has also served as a member of Academic Council in the University from 2012 to 2014. In the year 2014, *Sambhawana* also supported Lokesh Gupta (one of its physically impaired members) in the contest for the elections of Academic Council. While Lokesh Gupta could not win the elections, the fact that there is a continuous presence of disabled faculty members in the public discourse relating to trade union activities, explains the fact that disability is making its presence increasingly felt in the public discourses in the University.

While *Sambhawana* is primarily an advocacy organization which deals with the concerns of the disabled faculty members, it occasionally organizes lectures and discussions on disability-related issues. Being primarily an advocacy organization comprising blind and a few physically impaired faculty members, *Sambhavana* adheres to the disability rights perspective and the lectures and discussions organized by it aim at challenging the construction of disability in the Indian society.

Emerging Disability Research and Evolution of Services for Disabled Students

Conventionally, disability has been an area of inquiry by the faculty members of the University in subjects like Social Work (Batra 1981; Kitchlu 1991) and Psychology (Sen 1988). Lately, however, there has been a gradual acceptance of the developing Disability Studies perspective as an area of research in various other disciplines like Political Science (Chander 2008, 2011, 2012, 2014, 2019), Linguistics (Bhattacharya 2014) and History (Gupta 2017).

This can be attributed primarily to the following five factors:

I. growing research and available literature in line with the perspective on Disability Studies in India and abroad;
II. increasing interest of some of the faculty members in the University to engage in research on disability with a Disability Studies perspective;
III. presence of a sizeable number of disabled students pursuing postgraduate studies, who are interested in research on disability;
IV. availability of institutions like the enabling units or the Equal Opportunity cell which serve as forums for the disabled students, scholars and faculty members to engage in discussion on disability issues;
V. recent recruitment drive to hire disabled faculty members.

There has been immense contribution by several scholars and writers in the West to Disability Studies. They are too many to be mentioned here, but some of the important names include: (Barnes 1992; Biklen 2005; Danforeth 2009; Kanter 2003, 2007; Davis 2002, 2008; Linton 1998, 2005; Michalko 1998, 1999, 2002) while there are some who are disabled scholars as well (Oliver 1990, 1996; Shakespare 2014). This has been strongly enriching the literature on Disability Studies although it is grounded primarily in the western context. The discipline of Disability Studies is also getting crystallized through several academic programmes, journals and academic bodies. There are universities in the world, particularly in United States and the UK where graduate level Disability Studies programmes have been introduced. Some of these Universities are Syracuse University, University of Illinois at Chicago in the United States, the York University and the Winn peck University in Canada and the Leads University in UK. Likewise, there are several journals that focus on Disability Studies: e.g. *the Disability Studies Quarterly* and *Society and Disability.* In addition, establishment of academic bodies like the Society for Disability Studies (Society for Disability Studies 2015) and the Canadian Disability Studies Association (Canadian Disability Studies Association 2015), etc., serve as forums for academic discussions and interaction among Disability Studies scholars. Apart from these systematic and organized efforts to promote the discipline of Disability Studies in the Western context, a few scholars have also been working on the discipline of Disability Studies in the Indian context. They include both Indian scholars based in India (Bhattacharya 2014; Hemachandran 2012; Dhanda 2000; Ghai 2003, 2015; Ghosh 2010, 2016; Mehrotra 2013), those settled abroad (Chaudhry 2011; Rao and Kalyanpur 2014; Singal 2010) and a few western scholars (Friedner 2015; Miles 2013).

Lately, The University of Delhi has witnessed the presence of some of the faculty members who may be teaching conventional subjects, but have been increasingly getting interested in conducting and advising research on disability in the University. Some of them include historian, Vikas Gupta from the Department of History; Political scientist, Jagdish Chander from Hindu College, linguist Tanmoy Bhattacharya from the Department of Linguistics and psychologist Anita Ghai, who taught at Jesus and Marry College for more than three decades before joining Ambedkar University of Delhi as a Professor of Disability Studies in 2015. These scholars have been conducting research and also directing young scholars.

Inspired and encouraged by these faculty members, a group of young scholars has evolved out of a group of disabled doctoral and M.Phil students that is increasingly taking interest in conducting research on disability with a Disability Studies perspective. To name a few, some of these young scholars, who also happen to be disabled themselves include Kapil Sapra, who earned his Ph.D. in Political Science in 2018, Neha Sinha, who earned her M.Phil from Department of Sociology in 2014, Mahendra Dhakar, who completed his M.Phil from the Department of History in 2013, etc. At the same time, Ramnath Singh and Jaya Mishra are enrolled in the Department of Political Science as Ph.D. scholars in the Department of Political Science in 2020 at the time of publication of this book.

As mentioned in an earlier section, a separate section inside the main library, the Central Reference Library of the University has been designated since the 1970s to provide reading services and Braille books to the blind students. This section, known as the Braille Library has come about as a result of the advocacy carried out by the NBYA. During the last 10 years, however, the services for the disabled students have been expanded leading to a more conducive atmosphere for research in the field.

A special cell known as the Equal Opportunity Cell (EOC) was established in the premises of the Central Reference Library next to the Braille Library. The EOC has been assigned the task of providing services to the disabled students and encourage the establishment to provide separate units known as the Enabling Units in each college of the University. The Enabling Units are being setup in several colleges of the University through a UGC funded scheme to provide services to the disabled students inside colleges.

While the EOC and the Enabling Units are primarily expected to provide services to the disabled students in the pursuit of education, they both have been occasionally serving as forums for academic discussions on disability. Some of the colleges which include Miranda House, Guru Govind Singh College of Commerce and Dyal Singh College have occasionally held seminars on disability-related issues through their Enabling Units during the decade of 2010. Likewise, Department of English organized an international conference on disability and literature in March 2018 through an intense involvement of EOC of the University ('Interrogating Disability Studies: literature, culture, performance' 2018).

The initiative to setup the EOC was made by some scholars in the university, who were sensitive to disability issues. Some of them also took keen interest in exploring the field of disability academically. At the initial stage, the Equal Opportunity Cell was led by a highly academically oriented faculty who was keen to promote research on disability. Hence, a certificate course on Human Rights and Disability was started in the year 2008–09, which was identifiably the first course of this kind in India. It ran successfully for 3 years. At the same time, the EOC also organized a national Seminar on disability in March 2011, which was one of the first of its kind (web reference). The EOC collaborated and substantially funded the Lal Advani Memorial Lectures organized by the 'Indian Association for Education and Rehabilitation,' a Delhi based non-governmental organization. This Lecture is organized to acknowledge the contribution of Shri Lal Advani, who as mentioned earlier, had pioneered the services for the empowerment of the disabled in India, and the two lectures organized in collaboration with the EOC were delivered by two leading scholars working on disability issues in India; namely, Maya Thomas and Professor Amita Dhanda. Ms. Thomas has been considered to be an expert on Community-Based Rehablitation and she has been editing a journal on this subject. On the other hand, Professor Dhanda is a renowned scholar of Disability Studies, who specializes in law and disability in the Indian context.

The first comprehensive Disability Rights Law known as the PWD Act enacted in 1995 provided for 3% reservation for the disabled in all categories of jobs. Sporadic advocacy activities were carried out by the blind activists from time to time and finally, a lawsuit was filed which resulted into a judicial pronouncement (Pushkar Singh and Ors. Vs. University of Delhi and Ors. 2001) mandating the implementation of this provision in teaching posts in the University. As a result of the decision of the court in this case and a few other cases including the one filed by *Sambhavana*, the University was compelled to recruit a sizable number of disabled postgraduates as faculty members. Some of these young professors have been keen on conducting research on disability through a Disability Studies perspective. In addition to conducting research on disability, this group of young faculty members has also been active in organizing lectures, conferences and study circles. As a result, an atmosphere has been created in different quarters of the University which is conducive for academic discussions on disability. Now, even the trade union organizations and the administration are gradually beginning to accept disability as a social–political issue, which deserves the attention of scholars irrespective of disability.

Conclusion

While the predominant strength of the movement of the organized blind was derived from the residential schools for the blind, the leadership basically came from the students and the graduates of the University. This in some way, contributed to the creation of an environment in which the construction of blindness was initially challenged and now construction of disability is being broadly challenged. The University has been quite slow in responding to the need to introduce new areas of study. It is still ranked very low in the hierarchy of academic institutions in the world. It is, therefore, not surprising that the University has not been proactive or responsive to the demand for the introduction of Disability Studies as an emerging field of study. However, with the increasing presence of disabled students and faculty members and growing interest of some of them to engage into academic inquiry with a Disability Studies perspective, there is now a possibility of introduction of Disability Studies in the domains of social sciences in The University in the due course of time.

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Chapter 13
Emancipating the Lives of Persons with Disabilities: Potential for Contributions by Disability Studies

Deepa Sonpal and Vanmala Hiranandani

Abstract Majority of persons with disabilities are disenfranchised and experience profound exclusion globally as well as in India. Persons with disabilities are barred from obtaining basic services for a decent living. Underestimation on the prevalence rate is a major factor contributing to marginalization coupled with persons with disabilities having no voice or say in the policies that affect their lives. If persons with disabilities are to truly emancipate, then evidence based research that clearly states the "real need" from the perspective of the disabled is the call of the hour to build a collective voice and seek justice and assert rights. Such emancipatory research is based on the premise that the agenda must be set by persons with disabilities with the disabled being at the helm of such studies. Drawing from the authors first hand experiences, this chapter exemplifies how a collaborative approach between persons with disabilities, civil society organizations and academia could generate meaningful outcomes leading to setting the future directions or course of action to be taken. The concept of emancipatory research is particularly in line with the new Law on the Rights of Persons with Disabilities 2016, and therefore the coming decades are an opportune time to undertake emancipatory research to study the implementation of the new law and its impact.

Keywords Disabled persons's organizations · Emanicipation · Disabiliy Studies · Development strategies

Introduction

Most persons with disabilities are barred from leading a dignified life, being profoundly secluded within the home or the walls of institutions. Persons with disabilities are majorly disenfranchised (WHO and World Bank 2011; World Bank 2019) and

D. Sonpal (✉)
UNNATI Organisation for Development Education, Ahemdabad, India
e-mail: deepasonpal@gmail.com

V. Hiranandani
Global Nutrition and Health, University College Copenhagen, Copenhagen, Denmark
e-mail: vahi@kp.dk

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have poor access to basic services of health, education and social protection around the globe as well as in India (ILO 2014). This nexus of socio-economic and cultural factors contributes to poor estimation of the prevalence of disability in India thus adversely impacting their collective strength of demanding and advocating for their rights. The World Report on Disability (WHO and World Bank 2011) claims that about 15% of the global population comprise of persons with disabilities, with about 80% residing in developing countries like India. Ironically the Census of India 2001 states that there are only 2.13% persons with disabilities in the country with a marginal increase of 2.21% in the 2011 Census. This underestimation in the prevalence rate is a result of multiple factors alluded to the above has its basis in the power struggle (Gill 2007; Hiranandani and Sonpal 2010). Hence, disability studies must question the nature of subjugation experienced by persons with different types of disabilities within the given socio-cultural context. Disability studies must incorporate the voices of persons with disabilities in shaping disability theories, approaches and influence policies and the agenda for action just as women's studies, ethnic and race studies and queer studies (Addlakha 2013). It should focus on critically analyzing the reasons for oppression of persons with disabilities, including women with disabilities and in eliminating barriers limiting the participation of persons with disabilities. Drawing insights from the individual's lived realities and experiences of persons with different types of disabilities in different socio-cultural context, disability studies should learn to focus on collectivizing the struggles and self-advocate for a common cause encompassing the specific needs of all types of disabilities.

Furthermore, disability studies needs to intercept with feminist studies to provide a gendered perspective and the implications it has on men and women with disabilities. More research in this direction is required to address the injustice meted out to women and men with disabilities on account of gender and disability (Ghai 2009; Hans 2015). In a series of participatory rural appraisal exercises carried out during 2003–2004 in an attempt to gain a deeper understanding of the differences in attitudes faced by men and women with disabilities, it was found that more men with disabilities were married, many of whom were able to find non-disabled spouses. Women were found to be single and if married were to a man with a disability (UNNATI 2004). Given the stigma and abuse that both men and women with disabilities face in India, it is imperative to undertake research that investigates the nuances and raises questions regarding the effectiveness (or the lack of it) of the State to provide protection and a non-discriminatory environment for both men and women with disabilities to lead a dignified life with self-determination for what one wants to do and become.

Recently, a new law on the Rights of Persons with Disabilities (RPwD) Act 2016 was enacted by the Indian Parliament in an attempt to harmonize the disability laws with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (GOI 2016a). Chapter XVI of this law on Offences and Penalties clearly articulates penalties to be levied on any offensive acts meted out to persons with disabilities. These may range from a fine of Rs. Ten thousand to five lakhs and to a maximum imprisonment of 5 years depending on the nature of the offence. In case of women with disabilities where any medical procedure is directed, performed, conducted without her informed consent or incase of person with severe disability without the consent of the guardian is also punishable.

The New Law has opened the scope of conducting studies on its implementation and in examining if the law has played a role in making a difference in the lives of persons with different types of disabilities. In this landscape, the present chapter draws insights from field practices and makes an attempt to chart out the role of the emerging field of disability studies in India to define a research agenda from the perspective of persons with disabilities, as well as the role of research itself in emancipating the lives of poor persons with disabilities by influencing policy change/environment. Drawing from the researchers own work, it is suggested that emancipatory research practices (Sonpal and Kumar 2012) could contribute to disability studies. This may include capacity building of disabled persons organizations (DPOs) to strive for self-advocacy; engaging various stakeholders' participation to change the attitudes and offer reasonable accommodation in all spheres of life; and striving for governance reform for better service delivery to develop a receptive and conducive society that is tolerant and humane towards persons with differing abilities.

Since the early '90s persons with disabilities and their representative organizations have become active and begun to express their needs and concerns demanding a voice in decision-making process in all aspects that affect our lives. The path breaking United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 now ratified by 177 countries (as of May 8, 2019), has opened up new opportunities with a paradigm shift from a welfare/charity/medicalized approach to a rights-based model (UN 2007; UNNATI 2014) that vests the responsibility of accommodating persons with disabilities in the society and lays emphasizes on empowering persons with disabilities and their representative organizations (WHO 2011; UNNATI 2008, 2014). The CRPD itself is as a result of advocacy by disability rights activists and groups across the globe. This shift in approach has led disability studies to examine its role and the course it needs to take in emancipating and uplifting the lives of persons with disabilities who until now have been being profoundly excluded from the development agenda (Sonpal and Kumar 2012).

Within this CRPD paradigm and drawing from our field experiences, we analyze various methods used to engage persons with disabilities in the research process as equal participants in defining the research agenda, developing and designing the research and in conducting/implementation, analysis and sharing for wider learning. Lessons learnt in each of these approaches are reflected upon along with recommending a research agenda for the future.

Capacity Building of Disabled Persons Organizations

An action research was undertaken by UNNATI Organization for Development Education ([1]www.unnati.org) in 2012–2014 for enabling disabled person's organizations (DPOs) in India to undertake their own situation analysis and capacity assessment (UNNATI 2014) with the support of Sightsavers, UK. Although, the CRPD aims to bring about a marked change in the lives of persons with disabilities, as yet most DPOs, who are expected to be the torch bearers of the disability movement, operate from a welfare/charity perspective. It is still a long way off for DPOs to begin to assume a proactive role and take on the responsibility for creating space for themselves in the development process. An advisory committee was constituted to guide this research comprising of eminent persons from NGOs, independent consultants and mainstream academia working in the field of Organizational Diagnosis and Organizational Behaviour.

The following are some of the challenges faced by the DPOs that have been derived from secondary literature (Sightsavers and CBM 2012; UNNATI 2014) and personal interaction. These, however, vary from region to region based on experience.

- **Identity**: Most often DPOs are aided in all ways by a supporting or mentoring agency and are dependent on these for resources. Hence, the programmes and activities are guided and influenced by the perspective of the supporting agencies. Although in terms of vision and mission they are clear that the inclusion of disability and emancipation of persons with disabilities is their main goal, DPOs have not yet been able to systematically analyze their role to determine their identity so as to be able to draw up long-term plans with clear strategic direction. Most of them are clearly in a nascent stage of group formation and group building.
- **Approach**: Most DPOs are either implementing activities like access to government and social security schemes, access to aids and appliances, access to ration cards, inclusion in BPL list as a single unit or undertaking policy advocacy at the State and national level to gain economic independence. Depending on the circumstances and resources available, the individual DPO develops its programs and implementation plans. Although the composition and formation of DPOs may be from a rights-based perspective, the programs and activities are conceived from welfare-based perspective as suggested by some studies/evaluations and international literature (Sightsavers and CBM 2012; UNNATI 2014). The experiences and lived realities of persons with disabilities most certainly demand economic independence and accessibility as a prerequisite. However, the DPOs have yet to

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[1] UNNATI Organisation for Development Education is a non-government organisation working on issues of inclusion, governance and citizenship rights, and disaster risk reduction primarily in the States of Gujarat and Rajasthan in India.

systemically define a political agenda from the social model[2] (Oliver 1996; Albert 2004) perspective to make an ardent impact on society, and combat the overriding power structures, challenge the socio-cultural beliefs that continue to systematically exclude persons with disabilities. Currently DPOs consider demanding their entitlements as demanding their rights.

- **Capacity/Leadership**: The leadership of DPOs is mostly driven by elite, urban educated individuals and the youth. Most persons with disabilities in India, 69% (GOI 2016b) reside in rural areas and are not well educated or employed. The daily struggle for an independent living and overcoming isolation and structural exclusion limits their participation and contribution for a larger cause of mainstreaming disability and asserting their rights. Most often the concerns and needs of persons with disabilities are not directly represented but are communicated on their behalf by other actors and stakeholders. Persons with disabilities have not developed their political consciousness to be able to critically analyze their situations and their underlying causes, and address their concerns as a collective agency from the grass roots to international forums. In India, the identity of persons with disabilities gets defined by acquiring a disability certificate and those that have less than 40% disability tend to be left out of the process. In any case, having a disability does not necessarily ensure participation in collectively challenging the exclusionary socio-political structures. There are a few examples of persons with disabilities in advocacy positions from a rights-based perspective but the range needs to expand to represent persons from all types of disabilities mentioned in the new Law.
- **Heterogeneity/Intersectionality**: Persons with disabilities are not a homogenous group and the practical needs and the policy advocacy issues and concerns vary with the nature and type of impairment and are influenced by caste, class, gender, religious ethnicity, etc. These factors further compound the disadvantaged position and subject persons with disabilities to marginalization and exclusion. At the DPO level it is only the mild to moderate level of persons with disabilities that are active and at the forefront. In a cross-disability DPO the participation of women with disabilities, hearing impaired, deaf blindness, multiple disabilities and intellectually disabled is limited or nil in some cases. Children and the elderly with disabilities have not received much consideration and it is most often their family members, such as parents of children with disabilities that come to the forefront and speak on their behalf.
- **Alliances**: The closest allies of persons with disabilities and DPOs have been agencies that directly support them. In fact, the genesis of most DPOs is these agencies that have envisioned mobilization and the setting up of collectives, e.g. *Rashtraya Viklang Manch* by Action Aid, Disability Advocacy Group by Handicap International in Gujarat and many such organizations that have set up DPOs by Action on Disability and Development India, CBM. So far most movements and

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[2] The social model of disability propounds that it is the barriers in society—attitudinal, social, cultural physical and economic that limit the function of an individual with an impairment making the situation disabling or leading to disability.

struggles for rights by different sections like dalits, tribals, minority and women's groups have excluded the agenda of persons with disabilities. Similarly, persons with disabilities have also not strived to connect with larger level struggles and broad-base their movements. This further reinforces the belief that disability is a specialized field and needs to be addressed separately.

- **Self-image**: Persons with disabilities belong to and are socialized in the same oppressive society that perpetuates the biased views, prejudices and cultural beliefs and values. Hence many persons with disabilities carry a negative self-image, low self-esteem and self-confidence. Often behaviors and expectations are governed by dependency syndrome and easy recourse to charitable favors. Very little attempts are made to oppose paternalistic attitudes imposed by society, friends, relatives and care givers due to lack of opportunity, exposure and access to information, services and other opportunities that may help break the shackles of dependence and change inter-personal relations with all stakeholders and develop collective identities that act as a radical force to inspire and conscentize other persons with disabilities.
- **Mobilization**: It is a challenge to mobilize persons with disabilities into collectives and sustain their participation in the long run as they are scattered geographically, regionally and comprise all age groups. Poverty, inaccessible transportation and terrain, distances, inadequate information and dependence on others to even attend meetings are the major limiting factors. Other factors such as language and communication, especially in tribal regions where different dialects prevail, further hinder such mobilization. Most often persons with disabilities are not literate or familiar with a common language as they are often secluded from socio-economic life. Among cross-disability groups again persons with hearing impairment, autism and multiple disabilities like deaf blindness tend to get marginalized as they communicate differently and their basic needs for support and management and common interests for advocacy also differ. The reason for forming the groups does not come as a basic need by persons with disabilities as often daily life itself is a struggle. As a strategy to sustain, most DPOs focus on credit and savings as a way to provide continuity to the groups.

In partnership with eight DPOs from seven states of the country, comprising of persons with visual impairment (totally blind, and low vision), hearing impaired and locomotor disabilities, an exercise was undertaken by UNNATI to develop accessible tools on situation analysis and capacity assessment of their respective DPO (UNNATI 2014). Dialogue was conducted in three stages: perspective building and situation analysis, building effective DPOs and capacity assessment. All the 8 partners have conducted 3 trainings each (total 24 trainings). In all there were 160 participants with 104 men and 56 women (24 persons with visual impairment, 6 with low vision, 14 persons with hearing impairment, 6 persons with cerebral palsy, 84 with locomotor disabilities, 14 with other disabilities and 12 non-disabled). It was found that organizational development is the need of the hour for DPOs in India as they need to reflect on their current practices and tune themselves to the spirit and vision enshrined in the CRPD. It was challenging to equip DPOs to be critical and reflect on their actions, thinking and attitudes as most DPOs work in a charity/welfare mode and spend time in accessing benefits of government schemes like pension. It is not to say that pensions are not required but for the younger generation it is important to get access to quality education and opportunity for employment with provisions for reasonable accommodation that generates substantial income to lead a dignified life. Addressing the diverse learning needs of each type of disability was another challenge as in the same group there were persons with visual impairment as well as hearing impaired. The learning needs, tools and pace for them were different and keeping both groups engaged at the same time required facilitation at different levels. This coupled with managing the diversity of language and education levels, along with difficulties of availing an accessible venue for holding these discussions, proved to be additional challenges.

Nonetheless, what emerged was a Toolkit (UNNATI 2014) that provides an outline on how to communicate with persons with different types of disabilities. It demonstrates on how the various tools on this complicated theme could be adapted by simplifying the concepts. For example use of audio and tactile diagrams to show flow charts, use of pictures with key words and local sign language and notes of facilitators for group discussion engaging the participation of persons with different kinds of disabilities. It also indicated and validated the need for capacity building and empowerment of DPOs by harnessing the voluntary spirit inculcated in many of the persons with disabilities and enabling a large section of this marginalized group to claim their citizenship rights (Oliver 1996). For this it is essential that all the members of the DPO understand the relevance and implication of the paradigm shift required to be adopted to meet both the practical day to day needs and the strategic needs that ensure rights to persons with disabilities on an equal basis with others.

Participation of Stakeholders

Next, we describe an action research conducted from 2002 to 2005 in Gujarat, with the support of Handicap International. The main aim was to sensitize stakeholders for making available a conducive and enabling environment for inclusion. In this initiative four key strategies were adopted. The actions undertaken were consciously documented to see what works to make inclusion work and identify the role of each stakeholder for wider learning.

i. **Partnership Building**: strategic partnership was built with various stakeholders like development organizations, designers, architects, builders, disability rehabilitation organizations, mainstream design institutes, media as well as persons with disabilities create awareness and spread positive image about disability. With each of the stakeholder group separate dialogue, sensitization and orientation programmes were organized. Collective strategies for common areas of intervention like advocating for a barrier free built environment, influencing and involving the media to capture the large scale sensitization and awareness for the public with the stakeholders (UNNATI 2008).

ii. **Joint Action for a Barrier-free Environment**: all stakeholders such as architects, builders, designers, development and rehabilitation organizations and persons with disabilities came together to first sensitize themselves on the physical and attitudinal barriers faced by persons with disabilities, understand the technicalities and principles of universal design and collectively conduct access audits of public spaces in the city of Ahmedabad. Next, action was taken by conducting access audits and pursuing modification to make the physical environment barrier-free. The group also undertook policy advocacy to influence and change the by-laws of the city recently.

iii. **Public Education and Communication**: This strategy focused on creating large scale public awareness among various stakeholders with the use of print, audio-visual and as campaign material in several accessible formats. As part of this for getting a deeper understanding on disability a series of participatory rural appraisals (PRAs) were conducted in four districts of the state in collaboration with 13 partner organizations. For designing this research we had the support of eminent persons from mainstream academia who are pioneers in the field of disability research in our country as well as internationally.

iv. **Mainstreaming Disability in the Development Process**: through a series of capacity building programmes the partners developed a clear understanding of the link between poverty and disability, that disability was as a result of socio-cultural, political, economical and physical barriers and that persons with disabilities could be gainfully employed as contributing members of society if the specific needs of each are addressed. Hence the need for involving persons with disabilities in all ongoing activities emerged. While planning and implementing activities with partners and stakeholders, the barriers faced by persons with disabilities and the efforts made to overcome/address these were extensively documented for wider learning. Sector wise role of various stakeholders have been identified for mainstreaming—physical accessibility, access to information, mainstreaming disability at the institutional level, harnessing education and employment opportunities, influencing policy environment, engaging the participation of civil society and finally mobilizing persons with disabilities and strengthening DPOs (UNNATI and HI 2008; UNNATI 2006).

Realising UNCRPD: Learning from Inclusive Practices in Education and Employment

Article 2 of the CRPD has specifically highlighted and defined key terms like–communication, language, discrimination, reasonable accommodation and universal design. However, how will these laudable goals be ever realized if we as a society are unable to transgress the boundaries of 'stigma and exclusion assigned to disability?

Pondering on the question of how to sync CRPD with current practices and policies, an action research was initiated to document inclusive practices in education and employment during study conducted by UNNATI in 2010–2011 (UNNATI 2011). With the aim of collaborating with the academia this research was undertaken with two friends/colleagues form the academic field. In the pilot phase three practices in education—inclusive primary school, vocational training center and inclusion in a State initiated program were documented by dialoguing with all the stakeholders concerned—the management, teachers, government officials, students with disabilities and parents. Likewise, in the employment sphere, three cases one each from the private, public and an initiative in self-employment through a special employment cell were documented. Subsequently, State level workshop was organized where the respective agencies presented their practices before a multi-stakeholder forum comprising of government officials, corporate, development organizations, media and persons with disabilities and their representative organizations. The following key learnings were derived from this action research:

- Promoting inclusive practices in education and employment in the private sector

With globalization, privatization and liberalization, by now, the not-so-new economic policy, downsizing and cuts in government social security program have become the policy trend. Increasingly, basic services for health and education are being privatized and the beneficiary is expected to pay a user fee to access the service. India adopted a range of macroeconomic policies beginning in 1991 which led to an unbridled market economy; increasing transnational capital flows; a weakening of the role of governments and greater privatization of government-owned entities; reduction in public expenditure; increase in imports and foreign investment; liberalization of trade regulations; and structural changes in the economy aimed at export-led growth (Chandrashekhar 2010; Upadhyay 2000). Neo-liberalism has major implications for persons with disabilities; however, disability research and discourse in India have paid insufficient attention to these changes (Kumar et al. 2012a, b). Elementary as well as higher education is being privatized under the garb of public private partnership (PPP) and a larger number of children from poorer families are likely to be left out including children with disabilities (Hiranandani and Sonpal 2010). For employment too, the public sector enterprises are shutting down under the exit policy. Hence the moral responsibilities of private institutions need to be invoked to include persons with disabilities adopting the human development approach to development.

The New Law on disability, the Rights of Persons with Disabilities (RPwD) Act (GOI 2016a), has included all establishments including private bodies in its ambit. Chapter III on Education, clause no 16 and 17 direct all government authorities to take adequate steps and measures to ensure inclusive education for children with disabilities without any discrimination on an equal basis with others. This includes making premises accessible, provide reasonable accommodation, arrange for learning materials in accessible formats in vernacular languages, modify curriculum and provide for teacher trainings. The act further stipulates that to realise the goal of inclusion a survey of school going children with disabilities and their specific needs shall be conducted every five years, with the first such survey to be conducted within the first 2 years of the enactment of this law. The first 2 years are over and still there is no sign of any such survey to be conducted by the government.

Chapter VI of RPwD ensures free and compulsory education for all children with benchmark disabilities till the age of 18 years as stipulated in the Right to Education (RTE) Act 2009. As per the RTE persons with disabilities may be admitted to private schools within the 25% reserved for underprivileged section but within this there is no mandatory quota for disabled children. As for higher education there is 5% reservation for persons with benchmark disabilities with an upper age relaxation of five years.

The RPwD provides for 4% reservation for persons with disabilities in public sector enterprises only. For private sector there are only incentives leaving it up to the economic capacity of the government to ensure that private bodies engage up to 5% of their work force as persons with benchmark disabilities.

- Making terms and conditions of work and employment fair and enabling

Due to the above stated economic reforms, persons with disabilities are being absorbed as ‘cheap labour on contractual basis without any social security benefits. This affects women with disabilities even more acutely. Therefore, disability and gender sensitive supportive mechanisms should be adopted and practiced as part of reasonable accommodation. They should feature in the policy documents of respective organizations and should be widely circulated for adoption and replicability by other organizations.

- Building capabilities of persons with disabilities to protect and promote their rights

Despite the efforts of stakeholders, disability in India and responses to it remain invested in the charity and/or welfare-based frames. It is important that persons with disabilities recognize their individual and collective agency and the dominant systems of marginalization, understand the supportive legislations and public policies, and champion the struggle for their rights, themselves—particularly in their daily lives and at the local levels. In employment situations, for example, persons with disabilities are paid less; work on contractual basis with no job or social security benefits and for longer hours. While these might be common, the growing influences of neoliberal globalization in our political economy is particularly debilitating for persons with disabilities, who are further excluded due to social and cultural beliefs. There is, therefore, a need for building a wider, deeper and more critical understanding of disability rights at the local level, more so in the remote towns and rural areas, so that persons with disabilities can launch their own struggles.

- Improving access to information and the built environment

Access to information and built environment is a precondition to the effective participation of persons with disabilities. However, barriers of various kinds limit their formal education, employment, social security and thus wider participation. For improving the quality of life and access to basic social security services the environment needs to be enabling. Other stakeholders must make intensive efforts for reasonable accommodation by making information available in accessible formats and reducing barriers in the built environment. While it is understandable that this is a work-in progress, in many cases the access to assistive aids and appliances, technology and thus, knowledge remains linked to the class, gender, rural or urban residence of the individual. Thus, there is a need for taking the questions of accessibility beyond the urban areas into the smaller towns and villages to ensure inclusion of persons with disabilities living there. The RPwDA in the Preamble clearly defines 'barriers' that includes barriers related to communication. 'Communication' includes all forms and formats of communication like languages, tactile, accessible multimedia, Braille, sign language and accessible information communication technology. The Act also defined 'public building' to include government and private buildings used and accessed by public at large and 'public facilities and services', includes all forms of delivery of services to the public at large. The Act also defines 'Universal design' that focuses on the design of products, environments, programmes, and services to be used by all to the greatest extent possible. Chapter VIII, Duties and responsibilities of the Government Clause no 44 states that building permission to be granted only if the rules formulated have been adhered to and Clause no 45 states that all building structures to be made accessible as per the standards laid down within 5 years of the enactment of the Act.

- Up scaling efforts for Inclusion

Efforts for inclusion are by and large sporadic and scattered. More such initiatives to document and disseminate inclusive practices among stakeholders will generate wider dialogue, create sensitivity and identify emerging challenges. Given the rapidly shrinking public sector and increasing privatization, persons with disabilities and their participation in formal education (including increasing costs of private education) and employment needs to protected and promoted. Thus, a program like this becomes ever more pertinent, and at the same time, should be backed by wider educational and dialogical programs with: teachers from educational institutions, human resource personnel from the corporate sector and others, to make reasonable accommodation and promote inclusive practices.

- Build a research agenda from a disability perspective

There is a need for systematic research into the lived experiences of inclusive practices, programmes and organisations of persons with disabilities. There should be special emphasis on persons with disabilities from rural areas and from a gendered perspective, and including children with disabilities. The findings of the research should feed into the theory and practice of disability. The research agenda should be emancipatory with the ultimate aim of making a difference to the lives of persons with disabilities. Persons with disabilities must equally control the research process—in defining the research agenda, data collection, analysis and action proposed.

The case studies reveal emerging challenges with regard to inclusion of persons with disabilities. There is a need for greater dialogue, not just around the specific challenges against the key provisions, but also on the objectives of the specific provisions of CRPD, particularly in the Indian context. For example: in a low-skilled, poorly-regulated labour market with uneven access to job security and work related benefits, as it is the workers (including those without disabilities) have little choice in selecting their work, work-places and conditions of work. Though this does not undermine the larger problem of expanding the available choices to the workers, the challenges need to be better understood from a disability perspective. There is an urgent need for building the capabilities of workers with disabilities to initiate their struggles for equal wages for equal work, access to subsidies and incentives from the government, better regulation and protection of their workers' rights.

The CRPD is a broad vision and provides guiding principles for realising the rights of persons with disabilities. The case studies included here should be considered as work-in-progress, with many emerging challenges. The aforementioned initiatives have not been consciously initiated and designed with the CRPD provisions. They are guided by the PWD Act 1995 (in the case for employment) and by the Right to Education Act 2009 (for education); and have emerged from the commitment and experiences of disability organisations and activists, or the individual commitment of individuals and organisations towards more equal, inclusive communities. However, the case studies provide illustrations of ways and means in which inclusive practices can be adopted. This is an encouraging enough outcome. Efforts for increasing access both to the built environment and information, and for promoting the inclusion of women and girls with disabilities need to be consciously built into existing programmes to ensure more substantial realisation of CRPD principles.

In order to implement these principles in reality and to eliminate the existing barriers, present efforts for inclusive practices need to be documented and examined in the light of CRPD on a continuous basis. There is a need for wider dissemination and dialogue among various stakeholders—the government, persons with disabilities and their families, disabled people's organisations, civil society, academia and the private sector at the local and national levels to remove the barriers and enable persons with disabilities to develop their potential.

The above learnings set the direction to work with a DPO in Gujarat and enable persons with disabilities to research, examine, and document 17 inclusive practices in rural areas on the same themes of education and employment. The extent of inclusion practiced and gaps identified were discussed at multi-stakeholder consultations at district level for wider awareness and learning with the involvement of the government machinery from several departments. The DPO then took this initiate and collaborated with other DPOs in three South Asian countries, namely, Nepal, Bangladesh and India to critically examine and debate inclusive practices at the regional level.

Striving for Governance Reforms

In an another example, household level consultation with poor households using the Participatory Poverty Assessment (PPA) methodology (DFID and ODI 2001) with Below Poverty Line Households (BPLs) was conducted during April–July 2014 in two tribal talukas/blocks of a backward district in Gujarat. This was part of conducting the Baseline of a project on 'Improving Access to Information of Public Schemes' supported by the European Union (2014–2018). In each block about 200 households were consulted from three panchayats in each block. The three panchayats were selected on the basis of its distance from the block headquarters—one nearby, one a little away and one remote for each of the locations/blocks. The main aim of this study was to assess the extent of the household's awareness and access to government public programs, related to primary education, primary health and social security and protection, and the costs incurred in accessing or getting the benefits of these services. With over a decade of monitoring of basic services in sample areas in Gujarat and Rajasthan, we can conjecture that two thirds of a poor household's income is dependent on public schemes. As there is very little information/awareness in the community about these schemes, the process of accessing benefits is cumbersome and the outreach of service providers in remote areas is poor. As such, poor families are unable to reap these benefits.

In the baseline, it was found that the percentage of persons with disabilities from among 200 households in block V constituted 2.7% among whom only 41.9% had a disability certificate and only four persons with disabilities had an identity card. In another block P there were 3.4% persons with disabilities among whom only 9% had disability certificate and only one person had an identity card. None of them had any identity proofs like election card, Aadhar card and bank account. Hence none of them were able to access the benefits of government schemes. Five years later in 2018 when the end line was conducted at the end of the project in three other panchayats following the same methodology in block V it was found that there were 1.50% persons with disabilities. Out of these 88.23% had a disability certificate, 88.23 had a identity card, 64.70 had an election card, 82.35% had an Aadhar card and 76.47% had an bank account. In block P there were 1.27% persons with disabilities of which 50% had a disability certificate, 45.83% had an identity card, 70.83% had an election card, 70.83% had aadhar card and 50% had a bank account. This demonstrates that if all the stakeholders put in concerted efforts, there is improvement in enabling persons with disabilities to access their entitlements. For this, systematic and concerted efforts need to be made by all the stakeholders.

In India, benefits of public schemes for persons with disabilities can only be obtained if the person has a disability certificate declaring that s/he has 40% disability issued by a designated authority. Along with a disability certificate the person needs to get an Unique Disability Identity Card (UDID) issued by the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice and Empowerment. As disability certification was identified as a major bottleneck in accessing public schemes for persons with disabilities, we began to identify the causes of the low rate. There were multiplicity of issues ranging from attitudes of doctors to access to information about certification requirements, access to transportation for persons with disabilities to reach certification camps, low awareness among village level service providers as well as community as to the kind of disabilities that could be certified (besides the visible disabilities), and no information about the benefits that could be received.

Based on the findings, strategies for strengthening communities, interventions with government service providers as well as policy advocacy were worked out. Thus, a course of action was charted out at the implementation level as well as the policy level. Dialogue was initiated with the Chief District Medical Officer who is in charge of organizing the certification camps, with the District Collector/District Magistrate to issue a circular for arranging transportation from the Primary Health Care center to the spot of the camp, for trainings of *anganwadi* workers and ASHA workers at the village level for early identification of disability, with the community on general awareness on disability and the benefits that could be accessed from government schemes and with the department of Social Justice and Empowerment (SJE) to issue a protocol for conducting disability certification camps in coordination with the department of Health. A Circular was issued by the Health department specifying the methodology of conducting disability certification camps including early identification of disability by front line workers at the village level, provision of transportation to escort persons with disabilities to the camp site, the preparation required at the camp site and the role of specialists. As follow up strategy, citizen leaders were identified from the community comprising of tribals, women and persons with disabilities. Within a span of 5 years of the project, awareness was raised in the community through which 745 persons with disabilities were able to obtain disability certificates. These persons have also been linked with various public schemes applicable.

In India to obtain benefits a disability certificate is required based on the medical certification. The PWD Act 1995 had specified only seven types of disabilities to be certified. The question here is that with seven disabilities, the all India rate of certification is only 57.95% (as per the Annual Report of the Ministry of Social Justice and Empowerment 2017–18) after more than two decades. What is the time frame in which the central as well as the respective State governments will make the rules for the New Law? How and what will the procedure be to certify the 21 disabilities? What strategies will be developed to reach out the millions of disabled to be first certified to get any entitlements? When and how will the disabled be empowered enough to voice what is it that they want? How will the private sector be motivated to employ 5% of the workforce comprising of persons with disabilities? With downsizing of the public sector how will persons with disabilities educated be gainfully employed? All these questions are and should become an agenda for research.

Conclusion

The various initiatives illustrated above demonstrate how research needs to be defined from the perspective of the excluded group. This ensures the relevance of the research as it aims to make a difference in the exclusionary processes by influencing stakeholders and suggesting policy and implementation level changes. Research must be linked to action and reflection—praxis, as explained by Freire (1970). This is essential in the process of conscientization and freeing the oppressor and the oppressed from attitudinal and socio-cultural beliefs, and thereby enhancing one's self-image and improving one's quality of life. Where possible this research should be done in collaboration with grassroots organizations, DPOs, persons with disabilities and academia to address the most pressing issues and maintain rigour. Evidence based research is also useful for policy advocacy and bring about decisive change in the lives of persons with disabilities. The first research mentioned in this chapter draws heavily on the participation of persons with disabilities in designing accessible tools for conducting Organization Diagnosis and Capacity Assessment of their organization. Through a series of 24 trainings, a toolkit was developed and the feedback and insights drawn from persons with disabilities at locations in the field were consolidated. In the second study persons with disabilities were one of the stakeholders in awareness raising among civil society and contributing equally to the learning process and the documents published as part of the initiatives. In the third initiative the DPO took initiative to not only document inclusive practices but also to debate and discuss the nuances through district and state level workshops. In the last initiative, persons with disabilities as citizen leaders took the initiative to avail the benefits of public schemes. Lastly it must be noted that one of the authors is a person with visual impairment and is deeply interested in research that aims to emancipate the lives of persons with disabilities in India.

Whichever method is chosen, traditional or participatory, generating qualitative or quantitative data, research must aim to redeem the lives of persons with disabilities, from the misery, isolation, neglect, stigma and discrimination that we may be condemned to for life. The research team should be carefully chosen to comprise of researchers to maintain the quality and rigor required and of the oppressed group to maintain the relevance, sensitivity and its utility for finally making a difference in our lives. As persons with disabilities, we protest, deny and refuse to be treated as 'study objects,' we demand to be treated as equal and contributing world citizens, struggling to lead a life of dignity (Charlton 2000; Sonpal and Kumar 2012).

Estimation of the prevalence of disability is a major question to be confronted as several policymaking processes, budgetary allocation processes and estimating the extent of marginalization and exclusion is dependent on availability of actual numbers. The primary area for initial research should be to conduct a disability census. This process should be initiated separately and not be merged with the general Census as we have seen the disastrous results from the past two Censuses conducted in 2001 and 2011, despite advocacy by disability groups. It is only then can we win battles against oppressive regulations, for example the last BPL (below poverty line) census or the Socio-Economic Survey laid down a clause that if a person with a disability resides with an able bodied person then he/she would be automatically excluded. However, it is extremely difficult for a person with a disability to survive alone in our country. In a vast country such as India where there is a shortage of institutional services, families play an important role in the lives of persons with disabilities (Kumar et al. 2012a, b; WHO and World Bank 2011). Therefore, excluding them from BPL on the grounds that they live with an able-bodied person is to push them into further marginalization and deprivation. Families with persons with disabilities are often the poorest of the poor, since disability is a cause as well as a consequence of poverty (Elvan 1999; Yeo 2005). Therefore, such regulations need to be re-examined from the perspective of persons with disabilities. Needless to say, these oppressive clauses and regulations can be avoided if people with disabilities and their organizations are consulted when these rules are framed—here again, the importance of 'Nothing about us without us' is obvious. People with disabilities live with their families and in their communities; hence, the strategy of community-based rehabilitation is pivotal in India to maximize their physical and mental abilities, have access to regular services and opportunities, and achieve full integration within their communities (Kumar et al. 2012a, b; WHO 2004).

The obvious disabilities do get at least a miniscule of the benefits, but the not-so-obvious disabilities like mental illness, autism go unnoticed and are disregarded as a disability. Not to mention the plight of hearing impaired deaf-blindness and women with these disabilities. With the additional like blood disorders, multiple sclerosis, that have been added in the RPwD we need to investigate how these disabilities get included not only in society but also get accepted within the disability discourse and among and within DPOs that work within a cross disability framework. There may be success stories of certain eminent persons with disabilities, but there is a dearth of literature on how the not-so-obvious disabilities or women with disabilities in particular among them are coping and the kind of barriers, fears, level of exclusion faced leaving them to survive in conditions of abject misery and sub-human living. The RPwD like the CRPD recognizes and acknowledges that persons with disabilities, both men and women, including boys and girls, maybe subjected to violence, abuse, cruel treatment and torture but women and girls with disabilities may be subjected to specific types of violence on account of their gender, disability and influences from a patriarchal hegemony. The Act also directs the government to set the prescribed procedure for reporting such incidents, rescue, provide support for legal remedies, rehabilitation. It is these oral histories/stories that we need to recount, record, and document and disseminate widely for ultimately influencing policy changes that are relevant to our country. The RPwD further states that no research on and for persons with disabilities may be conducted without their prior informed consent and that this consent must be obtained through accessible means of communication. The RPwD lays down that in order to conduct research for/on/with persons with disabilities prior permission needs to be sought from a Committee for Research on Disability. This committee needs to be formed in which not less than half of the Members themselves shall be either persons with disabilities or Members of the registered organisation as specified in the Act.

Moreover, the disability rights movement in India has not critically engaged with the dominant wave of neoliberalism and the obsession with economic growth that has swept the country. While many other grassroots movements have campaigned against the adverse effects of neoliberalism, disability activists are fighting for inclusion within the very agenda that causes poverty and disability (Yeo 2005, p. 26). Disability is an arena that is particularly susceptible to the shifting boundaries between the public and private domains. The consequences of dismantling the welfare state are severe, especially for poor and disabled people in developing countries who depend on state provision of basic needs such as education, health care and social security. The disability movement in India has focused on removing barriers to employment without questioning the ableist and normative assumptions upon which the world of work rests, particularly in these neoliberal times—and which obfuscate and further marginalize the disabled identity (Kumar et al. 2012a, b).

Neoliberalism has deepened the crisis in the agrarian realm, which has been well-documented by many studies (see Hiranandani and Sonpal 2010; Kumar et al. 2012a, b). Field-based reports have forced the government to take cognizance of the structural factors of the agrarian distress that have led to an epidemic of farmer suicides since 1997 (e.g. Jeromi 2007; Sainath 2009). However, not much is known about the consequences of neoliberal changes in rural areas for persons with disabilities. Undoubtedly, more multi-sited research and awareness raising is required, where the voices and concerns of persons with different abilities are heard, respected and acted upon. This is especially true for India, where in the name of neoliberal development and economic growth, violation of labor standards has become the norm (EPW 2010). There are many incidents where persons with disabilities are abandoned and are forced into beggary in urban areas. Systematic research and studies in this are required to trace the nuances and then develop interventions to address this situation.

Lastly, every effort and step made towards inclusion needs to be recorded and disseminated widely so that the entire movement for acceptance, accommodation, space for inclusion of diversity can be up-scaled and become widespread to move towards a just and equitable society.

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Chapter 14
The Right to Work for Persons with Disability in India: A Critical Disability Theory Perspective

Nimushakavi Vasanthi

Abstract The UNCRPD sets out the right to work and employment under Article 27 as including the right against discrimination and the right to just and favourable conditions of work. The paper draws upon decisions from the High Court's and the Supreme Court on the Indian Constitution and Labour Legislation, as well as schemes under Central and State Governments to critically examine how the Indian legal system responds to issues of discrimination and the right to just and favourable conditions of work of persons with disability. The central theme of disability studies has been to move away from understanding disability as a medical condition requiring clinical intervention to understanding disability as an academic terrain. This approach uses disability as a category for research and a source of insight to contribute to existing bodies of knowledge. The paper will use a critical disability theory perspective to understand the failure of legislation, schemes and decisions of the courts in fully accommodating the rights of persons with disabilities. The paper will examine the extent to which the new law on the Rights of Persons with Disability Act 2016 (RPD) accommodates a social model of defining disability in India. It will be argued that the language used in the RPD and other legislation affecting the right to work particularly the definition of persons with disability and disability itself does not allow for a conceptually grounded understanding of disability. When cases are decided the paradigm invoked does not allow for the experience of the person with disability to come through but is often transacted in terms of the liberal model of rights. Legislations need to be re examined with a view to include persons with disabilities and it is not enough for the RPD to provide for an overriding effect of the law.

Keywords Disability · Employment · Right to work · Critical disability theory · UNCRPD · RPD Act 2016

N. Vasanthi (✉)
NALSAR University of Law, Hyderabad, India

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Introduction

The United Nations Convention of the Rights of Persons with Disability (UNCRPD) marked a shift from the medical model of disability, which understood disability in terms of a medical assessment of disability; to a social model of disability which acknowledges the barriers that people with disability face that hinder their full and equal participation. The Convention brings in a rights-based model of addressing disability.

Extending the existing framework of rights both under international convention and national legislations to persons with disability has not resulted in fully accommodating rights of persons with disability within the legal framework in India. The existing rights framework based on a liberal framework of rights is incapable of accommodating the needs of persons with disability without stretching the boundaries of the liberal framework. Critical disability theory offers a critique to the rights based liberal framework that is being extended to persons with disability by focussing on the changes that need to be made for such an extension to be successful.

Disability Studies across the world and in India has been an inter-disciplinary area which focuses on the needs, aspirations, contributions of persons with disabilities (Adlakha 2013). The central theme of disability studies has been to move away from understanding disability as a medical condition requiring clinical intervention to understanding disability as an academic terrain. This approach uses disability as a category for research and a source of insight to contribute to existing bodies of knowledge. Towards this end this paper uses Critical Disability Theory as a framework which foregrounds experience over rationality while recognising rights of persons with disability. The premise of the paper is that the current definition of disability under the new Rights of Persons with Disabilities Act 2016 continues with a medical definition of disability and does not allow for a full understanding of the rights of Persons with Disability.

The paper examines how the definition of disability impacts the realisation of the right to work as under A.27 of the UNCRPD. The right to work and employment under Article 27 includes:

(a) the right against discrimination and
(b) the right to just and favourable conditions of work.

This paper is examining the significance of the articulation of the right to work in terms of the right against discrimination and the right to just and favourable conditions of work under the Indian constitution and labour legislations in India. The paper will draw upon decisions from the High Court's and the Supreme Court which are interpreting the Indian Constitution and Labour legislations, as well as schemes under Central and State Governments to critically examine how the Indian legal system responds to issues of discrimination and the right to just and favourable conditions of work of persons with disability. The paper will use a critical disability theory perspective to understand the failure of legislation, schemes and decisions of the courts in fully accommodating these rights. The central argument of the critical disability theory is to move away from a liberal model of rights as it does not accommodate the aspirations of persons with disabilities.

The Contents of the Right to Work

The right to work as an aspirational goal has been articulated along very diverse lines such as: the right to full employment, the right against unfair dismissals, the right against discrimination, the right of employees not to join a Union, the right of migrants to work in the destination country, the right against sexual harassment. The articulation of the right to work which includes livelihood, employment and any form of remunerative work is a crucial link to end social exclusion of persons with disability. While several rights claimed by persons with disabilities are citizenship rights, the recognition of a right to work has important consequences to bring a shift from a charity-based approach to a capabilities-based approach to disability.

The Right to Work has been set out in various International Instruments such as the Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic and Social Rights (ICESR). These instruments set out the right to work in terms of full employment and removal of barriers to employment and within the paradigm of full employment as an obligation on State under Article 6. The other rights at work such as right to association as well as just and favourable conditions of work appear as independent rights under Articles 7–9 not subsumed under the Right to Work. In contrast, the UNCRPD sets out the right to work and employment under Article 27 to include interalia, the right against discrimination, just and favourable conditions of work, labour and union rights, promote opportunities for self-employment, promote employment in public and private sector, and provide for reasonable accommodation. It is interesting to note that labour and other union rights are specifically mentioned along with other rights under the right to work and employment.

Although the right to work has not been expressly set out in the Indian constitution as a fundamental right, it is has been read to be an implicit part of the right to life and livelihood through a series of decisions of the Supreme Court.[1] The right against discrimination under A.15 of the Constitution read with the right to life under A.21 recognise the right to work as including the right to life free from discrimination.[2]

Harvey (2014) traces the origin of the Right to Work to Charles Fourier who described it as a natural right along with rights to derive sustenance from nature. It found resonance in the French revolution as well as in 1936 Soviet Constitution. Its acceptance by both sides of the ideological divide makes its location unclear. Harvey observed that it seems to have been a demand of the poor rather than a philosophically based right. Thus as it appears as a part of the New Deal in the United States it has

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[1] Olga Tellis vs. Bombay Municipal Corporation (1986 SC 18) being an important landmark.

[2] See Vishakha vs. State of Rajasthan (JT 1997 (7) SC 384).

been a pragmatic response to intense distress, its express mention in the USSR's Constitution makes it the basis of a socialist society while in the negative assertions of the Right, that are the basis of the legislations on right to work in the United States which curb union rights, we see an extreme libertarian view.

The shift from the New Deal understanding to the present Right to Work legislations itself, marks the different meanings that the Right has acquired. Its mention in the Universal Declaration of Human Rights and other International Conventions also indicates that as a human right it has different implications. As one of the many human rights, to take an example, the right to association, it needs to be balanced with union rights. This is a very different position from a labour rights perspective as exemplified in the ILO Convention 87 of the freedom of association being a fundamental right that is not confined in terms of other rights.

Notwithstanding the ideological confusions with the idea of the Right to Work, it remains a powerfully evocative term and finds resurgence even in this era of globalization.

The Right to Work in the Indian Context

The Indian Supreme Court in its interpretation of cases on labour has invoked the Right to Work in a variety of contexts such as unfair dismissal,[3] the need to follow procedure under law which must be just, fair and reasonable and holding that unconscionable terms in service agreements were violative of the right to work.[4] In *Meenakshi Mills vs. UOI*[5] the Supreme Court the court relied on the Right to Work and the Directive Principles of State Policy and read it as a fundamental right to life.

In the context of gender based discrimination,[6] the right to work has been invoked as part of the right to seek employment on par with men, and discrimination against women by denying them employment would not only be violative of the Right to Equality and non-discrimination but also her Right to employment, livelihood and work. In cases such as the *Vishakha* case the Court expressly invoked the right to work as the right to work with dignity and held sexual harassment as a violation of that right.[7]

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[3] The Court held that the State and its instrumentalities and the Corporation was an instrumentality, in order to give effect to the Directive Principles of State Policy, must act in conformity with the principle of making effective provision for the right to work. This would mean that the state cannot adopt a policy of hire and fire without reasonable cause. Central Inland Water Transport Authority vs. Brojonath Ganguly 1986 3 SCC 156.

[4] Delhi Transport Corporation vs. DTC Mazdoor Sangh A.91 SC 101.

[5] 1994 AIR 2696.

[6] Vasantha vs. Union of India (2001) IILLJ 843 Mad, challenging the validity of S.66 Factories Act.

[7] Vishakha vs. State of Rajasthan AIR 1997 SC 3011, also see Anuj Garg vs. Hotel Association of India A. 2008 SC 663, Avishek Goenka vs. UOI (2012) 5 SCC 321 and State of Maharashtra vs. Indian Hotel and Restaurants Association and ors (2013) 8 SCC 519.

In India the right to work has been legislated upon in the form of the National Rural Employment Guarantee Act (NREGA) 2005. The Act unique in many ways also has been used by groups of persons with disabilities to further access to employment.

The UNCRPD speaks of the right to work in the terms of a right to other rights including the right against discrimination, just and favourable conditions of work, labour and union rights, the promotion of employment in public and private sector, and providing for reasonable accommodation.

Disability Based Discrimination in Employment

This section discusses the extent of protection against disability-based discrimination both under the Constitution of India and the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 hereinafter referred to as the PWDwhich has since been replaced with the Rights of Persons with Disability Act 2016 hereinafter the RPD.

Discrimination on the ground of disability is covered under the right to equality under the Indian Constitution before the PWD Act came into force. Articles 14, 15 and 16 together provided for a wide spectrum of rights to be treated equally, not to be discriminated against as well as a right to be represented in employment.

Article 14 was first invoked in the case of *JavedAbidi*[8] who pointed out the callousness of various organisation in meeting the needs of persons with disabilities and invoked the jurisdiction of the Supreme Court to give effect to the right to equality of Persons with Disability by seeking directions to implement the Act passed over 4 years ago.

Apart from the general right to equality A.16 of the Constitution which contains a specific right to equal opportunities has also been invoked to seek reservations in education and public employment. Although A.15 does not explicitly recognise disability as a ground of discrimination it has been invoked to provide reservations in public employment. By an order in 1985 the Government of India directed the Standing Committee to undertake the identification of jobs for the handicapped (disabled).[9] The Committee identified 416 categories in Group A and B posts in Government Offices and Public Sector Undertakings, with their jobs descriptions, the physical requirement of each group of jobs and matched them with various categories of disabilities.[10]

In the case of the *National federation* discussed above a Writ Petition was filed for a direction to the Union Public Service Commission to permit blind candidates to appear for Indian Administrative Service and the allied services and to provide them with required facilities to take the exam. It was also pleaded that the posts already

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[8] Javed Abidi vs. UOI 1999 (1) SCC 467.

[9] The use of the term handicap was in vogue then and has been replaced with disability and now the reference to disabled persons is persons with disability marking the shift in language.

[10] National Federation of Blind vs. Union Public service Commission 1993 AIR SC 1916.

identified be offered to them on a preferential basis. The Court directed that they be allowed to write the exam with the help of a scribe or in braille script. Apart from the remark that the lawyer who was visually handicapped has presented the case excellently the court did not enter into any discussion on the issue of discrimination on the ground of disability.

The PWD Act 1995

Apart from constitutional provisions Section 47 of the PWD Act (since replaced with Section 20(4) of the RPD 2016) mandated that the services of an employee who acquires a disability during his service shall not be dispensed with, nor shall he be reduced in rank. It further provides that in case the employee is not suitable for the post he was holding, he could be shifted to another post with the same pay scale and service benefits. The proviso to the section mandates that in case it is not possible to adjust him against any post he may be kept on a supernumerary post until a suitable post is available or he attains the age of superannuation.

Section 47 and the corresponding provision in Section 20(2) is an embodiment of both the principle of non-discrimination as well as reasonable accommodation. The provision intends to address the discriminatory treatment meted out to persons with disability as persons incapable of making any material contribution to the workplace. It puts the onus on the employer to create an environment in which the disabled are not put to hostile work conditions but are allowed to function to the best of their capabilities. By preventing the removal of persons acquiring disability, the provision creates a possibility of exploring alternate methods of functioning in workplaces. The further provision to continue them on a supernumerary post is to ensure that employers do not shirk their responsibilities by claiming that there are no suitable posts that can be filled by a person with disability.

Section 72 of the PWD Act and the corresponding provision in Section 96 of the 2016 Act provides that the provisions of the Act are in addition to, and not in derogation of any other law for the time being in force. Thus the provisions of the labour legislation in India such as the Employees Compensation Act and the Employees State Insurance Act must be in addition to and not in derogation of the rights under this act.

Section 33 and 32 of the PWD Act provide for the identification and reservation of posts for persons with disabilities. Section 32 provides for the identification of posts which can be reserved for persons with disabilities and not less than 3% of posts in every establishment of which one percent each shall be reserved for persons suffering from blindness or low vision, hearing impairment and locomotor disability or cerebral palsy. In the *Union of India vs. National Federation of the Blind*[11] the Supreme Court ruled that reservation of posts for persons with disabilities was a horizontal reservation, i.e., it does not add to the already existing 50% reservation but

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[11] (2013) 10 SCC 772.

cuts across it and that the reservation policy is based on the total number of vacancies and not only in the vacancies available in identified posts. The Court invoked the idea of a welfare state which is committed to promote the overall development of its citizens including those who are differently abled in order to enable them to lead a life of dignity, equality, freedom and justice as mandated in the Constitution of India.

The RPD Act 2016

The Rights of Persons with Disabilities Act enacted in 2016 further expands the protections to persons with disability including in employment. The earlier provisions on protection of employment after acquiring disability have been secured under Section 20(4) of the 2016 Act and Sections 33 and 34 take into account the need to reserve posts in public employment. The percentage has been increased to 4% and is restricted to persons with benchmark disabilities. Chapter IV of the RPD act has a broader set of regulations with reference not only to employment but also to skill development. Section 19 sets out the need for special schemes including the provision of loans, support for self-employment. The schemes shall include persons with disabilities in all mainstream, formal and non formal schemes for vocational training and skill development. Section 20(2) provides for a right to reasonable accommodation and appropriate barrier free and conducive environment in government establishments. Section 20(1) contains a specific non-discrimination clause in cases of government establishments. Section 96 provides for the overriding effects of this law.

Just and Favourable Conditions of Work

Just and favourable conditions of work are not specifically provided either in the Constitution or in the PWD or RPD. Labour legislations in India do provide for fair labour conditions under the major labour legislations.

In India apart from government service rules, the major legislation that operates with regard to conditions of work is the Industrial Disputes Act which provides that workers can be terminated without severance pay and without any procedure on the ground of continuous ill health which apparently includes disability, as there is no other provision that deals with an inability to continue to work in the same position as before on acquiring a disability. There is no clause that addresses disabled workers who seek employment.

In *Anand Bihari vs. Rajasthan State Road Transport Corporation*,[12] a decision before the PWD Act was passed, the Supreme Court laid down a scheme for the continuation in employment of persons who have acquired disability while in service.

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[12] 1991 Labour and Industrial Cases p. 494 (Supreme Court).

The Court did not proceed on the ground of Article 14 but on humanitarian considerations. The drivers of the State Road Transport Corporation had acquired diminished eyesight and hence were removed from service. The workers were covered by the ESI Act, but since what they were suffering from was not a permanent disability, i.e. loss of sight to such an extent as to render the claimant unable to perform any work for which eye-sight is essential, nor was it loss of vision, it did not qualify as a disablement that would be covered by the provisions of the Act as an employment injury nor as an occupational disease. The ESI Act has no provision for compensation for a disability to carry on a particular job.

The Court then had to formulate a scheme on the grounds that the workmen were incapacitated to work only as drivers and not incapable of any other job. It laid down directions that the Corporations shall, in addition to giving them retirement benefits, offer him any other alternative job, or in case no such alternative job is available, to compensate him, and in case an alternative job is available at a later date, it must be offered to him.

The Court observed that

> The workmen are not denizens of an Animal Farm to be eliminated ruthlessly the moment they become useless to the establishment. They have not only to live for the rest of their life but also to maintain the members of their family and other dependents, and to educate and bring up their children. (para 4)

The lack of protection for the rights of persons with disabilities motivated the PWD Act which addressed equal opportunities and full participation for disabled persons.

PWD Act

The PWD Act sets out the rights of persons with disability and persons acquiring disability. The Act provides for reservation in employment,[13] the right against discrimination and the right to continue in employment after acquiring disability.[14]

The PWD Act makes a specific provision with regard to continuing in employment after acquiring a disability. Section 47 of the Act mandates that the services of an employee who acquires a disability during his service shall not be dispensed with, nor shall he be reduced in rank. It further provides that in case the employee is not suitable for the post he was holding, he could be shifted to another post with the same pay scale and service benefits. The provision to the section mandates that in case it is not possible to adjust him against any post he may be kept on a supernumerary post until a suitable post is available or he attains the age of superannuation.[15]

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[13] Section 33.

[14] Section 47.

[15] "47. Non-discrimination in Government employments—(1) No establishment shall dispense with, or reduce in rank, an employee who acquires a disability during his service;

Post the enactment of the PWD Act in *Narendra Kumar Chandla vs. State of Haryana*[16] a sub-station attendant of the Haryana State Electricity Board had become disabled and found to be unfit for the job he was carrying on and on the basis of the medical board's suggestion, a direction was issued to provide him with a clerical or non-technical post. The Supreme Court held that:

> Article 21 protects the right to livelihood as an integral facet of the right to life. When an employee is afflicted with unfortunate disease due to which, when he is unable to perform the duties of the post he was holding, the employer must make every endeavour to adjust him in a post in which the employee would be suitable to discharge the duties. (para 7)

In the Indian context apart from the constitutional protection, employment protection under the Industrial Disputes Act (IDA) and now the PWD, labour rights are also covered under the Employees Compensation Act (ECA) 1923 and the Employees State Insurance Act (ESI) 1948. The ECA provides for compensation for injuries arising out of and in the course of employment and has no mechanism to address their capacity to carry on any other work. While compensation was paid to workers, they have no entitlement to continue in employment. The ESI Act provides for payment of benefits for employment injuries but neither compensation nor continuity of employment is addressed.

These legislations being enacted even before the Constitution have no rights perspectives. Both of them clearly do not address the issue of discrimination on the ground of disability. The legislations are focussed on providing compensation, health benefits and to terminate their services if found medically unfit. More importantly, none of these legislations have been amended after the enactment of the PWD, resulting in a denial of the right against discrimination except in those cases where the workmen have been able to approach the higher judiciary and even had to go to the Supreme Court to enforce a right granted under the PWD Act.

The protection in public sector has however not been extended to the private sector. In *Dalco Engineering pvt. Ltd. vs. Satish Prabhakar Padhye*[17] the Supreme Court was hearing appeals from the Bombay High Court which had held that the PWD must apply to the private sector also. The court held the Bombay High Court decision per incuriam for ignoring two binding decisions of the Supreme Court in *Sukhdev vs. Bhagatram*[18] as well as *S.S. Dhanoa vs. Municipal Corporation, Delhi.*[19]

Provided that, if an employee, after acquiring disability is not suitable for the post he was holding, could be shifted to some other post with the same pay scale and service benefits;

Provided further that if it is not possible to adjust the employee against any post, he may be kept on a supernumerary post until a suitable post is available or he attains the age of superannuation, whichever is earlier.

(2) No promotion shall be denied to a person merely on the ground of his disability:

Provided that the appropriate Government may, having regard to the type of work carried on in any establishment by notification and subject to such conditions, if any, as may be specified in such notification, exempt any establishment from the provisions of this section."

[16] (1994) 4 SCC 460.

[17] Date of the judgment 31 March 2010, downloaded from http://indiankanoon.org/doc/472954/.

[18] 1975(1) SCC 421.

[19] 1981(3) SCC 431.

The Supreme Court disagreed with the view of the High Court in *SatishPrabhakar* by relying on *Sukhdev's* case which held that there was a well-marked distinction between a body created by a statute and a body which after coming into existence, is governed in accordance with the provisions of a statute. The Court while agreeing that socio-economic legislations like the PWD Act should be interpreted liberally, also held that

> The Courts cannot obviously expand the application of a provision in a socio-economic legislation, to levels unintended by the legislature, or in a manner which militates against the provisions of the statute itself or against any constitutional limitations. (para 15)

The Court agreed that marginal notes may not control the meaning of the body of the section but may be a safe indicator to refuse to extend Section 47 to Private Corporations. At the same time it referred to the marginal notes in Section 39 of the PWD Act, the marginal notes of which reads all educational institutions, as including only those which receive aid from the government and not to unaided private educational institutions.

RPD Act 2016

The RPD Act 2016 explicitly provides for the right to reasonable accommodation however it has restricted this right to government establishments only. The RPD Act provides for a overriding effect of the Act and hence all labour legislations must now be read in accordance with the rights in the RPD. However, since the RPD has extended the right against discrimination and reasonable accommodation only to government establishments, labour legislations which operate in the private sector continue to discriminate and refuse reasonable accommodation.

A statistical profile of Persons with Disability in India (Employment of Disabled Persons in India 2009) shows that according to the census 2011, only one-third of persons with disability were employed. The chilling fact was that 31% was as agricultural labour leaving just 2% as employed in public sector or any other employment. This rate has been falling down from 37.6% in 2002 which also saw a downward trend from 42.7% in 1991 (Employment of Disabled Persons in India 2009). The report further puts the percentage of all posts in public sector employment filled by persons with disabilities as 0.37% in 2006–2007. This was when 10.2% of all posts in Ministries/Department and Public Sector being identified as posts suitable for persons with disabilities. This provides sustenance to the claim made by the report that the government has been viewing reservation of persons with disabilities in a very restricted manner particularly in the identification of posts.

The position in the private sector is still worse with no statistics available but studies show that the percentage is much lower and that a majority of firms do not have any policy or guidelines regarding the recruitment of persons with disabilities.

Initiatives by the Government include skill development initiatives, however in the Eleventh Plan while labour and employment for vulnerable groups is discussed disability does not figure. The CII as part of its social agenda has adopted a corporate code on disability in 1998. There is however no information on how many industries have adopted the code or acted upon it.

While the existing legislations on protecting labour rights are of little or no significance to persons acquiring a disability or persons with disability new initiatives under other statutes are being put into operation.

The Government of Andhra Pradesh has issued instructions which operationalise the right to work of disabled persons through the Mahatma Gandhi National Rural Employment Guarantee Act 2005 (Kannabiran 2013). The Act seeks to provide minimum employment to not just able bodied persons as originally contemplated but to households and all Adult members seeking employment. The Act is a huge shift in the understanding of the right to work particularly for persons with disability. Through instructions including directives to consider every adult member with disability who seeks work under the Act as a single member household the right has been extended to persons with disability. They have been issued a separate job card, a person with high support needs is entitled to increased number of days of work. The formation of collectives such as the Disabled Shram Shakti Sanghas entitles disabled workers to higher wages as well as work that they choose and feel are able to perform. They may also be provided with implements to increase the ability to complete the work.

The Department of Disability Affairs was created in 2012 which was changed in 2014 to Department of Empowerment of Persons with Disabilities (Divyangjan). The Department intends to take steps for financial assistance for creating a barrier free environment under SIPDA Scheme. This continues the Accessible India Campaign was launched in 2015 to improve accessibility for public spaces. In addition to this are schemes for Financial assistance for purchase of aids and appliances for PwDs under ADIP Scheme, schemes for early detection and intervention, counselling and medical rehabilitation. Education is a key concern given the serious lack of opportunities for accessible education.

The schemes of the government at the central level include Rehabilitation Schemes which largely concentrate of social and physical reintegration rather than employment. Some of the plans of the department include creating a 'jobs portal' and a toll free help desk which will facilitate the need for information regarding skill improvement opportunities and employment. The Department also organizes fairs which allow for the marketing of products manufactured by persons with disabilities.

State Wise Policies on Disability

There are a variety of Disability Schemes under various states and union territories such as scholarships, early intervention centres for the visually impaired but there are few exclusively on employment. Tamil Nadu is a leader in these schemes. It is outstripping all state and union government in the number of schemes. The range of schemes includes Prime Ministers Employment Generation Program, and an unemployment allowance to Assistance to marrying hearing and speech impaired and a resource and Training Centre for persons with disabilities.

In addition to these schemes, the RPD Act contains provisions which extend other kinds of benefits to persons with disabilities under Sections 34, 37 and 41. Section 34 provides for a 4% reservation of posts for persons with benchmark disabilities in all government establishments. Section 37 mandates that there be a 5% reservation in allotment of agricultural land and housing in all relevant schemes and development program with a special focus on women with disability, 5% reservation in all poverty alleviation and development schemes and a 5% reservation in allotment of land at a concessional rate. Section 41 of the RPD Act 2016 requires government to develop schemes and program which improve personal mobility of persons with disability.

A Public Interest Litigation was filed in the High Court of Karnataka in 2018[20] challenging a notification of the state for selection of LPG distributors. Although other weaker sections were being considered for selection, the High Court did not consider the scheme to be a poverty alleviation scheme and did not find that suitable provisions regarding relaxation of age or other financial assistance as was being made to persons from SC/St communities needed to be made for persons with disabilities.

Virupaksha vs. Karnataka State Public Service Commission[21] is a case filed by persons with hearing impairment who wished to apply for the post of Inspector of Motor Vehicles. They have been denied the opportunity because the position requires that the candidate possess a driving license which is denied to persons with hearing impairment. Thus a catch 22 situation has developed where the post is considered suitable for persons with hearing impairment and the positions are advertised but it is an impossibility that persons with hearing impairment will be appointed as they are denied the basic eligibility required.

Following Section 43, the Karnataka Government inserted Rule 28A in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) [Karnataka] Rules, 2003 which provided an identical mandate and stated that 3% of sites would be reserved for persons with disabilities by all urban development authorities and they would be granted at concessional rates.

The right against discrimination for persons with disabilities in seeking employment, or in retaining them in employment has been upheld by the Courts but the understanding has been largely within the framework of existing equality and discrimination law in constitutional law and has not been widely extended.

This difficulty in liberal theory in understanding and responding to disability necessitates the use of a different approach to rights for the disabled. The Supreme Court has entertained petitions of persons with disabilities and given orders proceeding largely under Article 14 and sometimes under Article 21 and in some cases purely on humanitarian considerations as in *Anand Bihari*. The Court has very rarely engaged in understanding disability and has not even engaged in the distinction

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[20] https://clpr.org.in/litigation/karnataka-rajya-vikalachetnara-rakshana-samiti-v-indian-oil-corporation-ors/.

[21] https://clpr.org.in/litigation/virupaksha-anr-v-karnataka-state-public-services-commission-ors/.

between a medical model and a social model. The terms of engagement are largely driven by anxiety and pity, which matches with Rawlesian theory of understanding of the disabled as not part of the social contract (Devlin and Pothier 2006). The lack of understanding of disability-based discrimination allows the court to restrict the operation of the protection of employment of disabled persons to public employment and in so far as it operates in the private sector is governed by statute alone and not constitutional rights.

The right to work in terms of a prohibition on unjust terms of employment or arbitrary action, non-discrimination, reasonable grounds for removal are not respected in private employment unless statute expressly provides for it. Thus unless changes are made in statues relating to employment and safety and accidents at the workplace the anomalous situation of a constitutional protection to persons in public employment and no protection in private employment continues.

The organisation of persons with disability into unions to seek employment under the NREGA marks an important step in the realisation of rights not necessarily through the framework of the courts but by legislative and particularly administrative action. These initiatives may be seen as moves towards addressing real questions of barriers to access work by invoking a framework that is not located in the physical manifestations of disability but is located in the removal of barriers to access work. To see persons with disability as part of the labour market is an important move towards greater inclusion and participation.

Even in the decision of *Union of India vs. NAB* there is no invocation of the UNCRPD, no engagement with the idea of disability, no restatement of the theory of justice, equality and liberty that is needed to ensure that persons with disability enjoy these rights. It still operates largely in the welfare framework and invokes rights as if there would be no difference in their application for persons with disabilities.

Critical Disability Theory

Critical Disability Theory was proposed as an alternative understanding from the liberal theory of rights which could not accommodate the understanding of disability fully. The basic premise of liberalism has been of an able bodied person and inherently is not capable to repositioning the world from the point of view of the disabled. Critical Disability Theory calls for a repositioning of disability from being the ‘other’ to being the model. This flows from the social model of disability which ceases to accept a medical model of disability and locates disability not in the body of the person but in a physical and social environment that is disabling.

Critical theory as propounded by Horkheimer has elements of both theory and practice at the same time. Hosking (2008) observes that critical theory aims to explain oppression and transform society. He understands Critical Disability Theory as based on elements of the social model of disability, multidimensionality, valuing diversity, rights, voices of disability, language and which calls for a transformative politics.

He attaches critical disability theory to other identity based critical theories for several reasons. He states that critical disability theory does not reject liberal rights but exposes its inadequacies in dealing with disability. Since intersectionality and multidimensionality are an important element in critical disability theory, intersection of disability with other identities and other forms of discrimination are a necessary part.

Devlin and Pothier (2006) on the other hand, set out the need for a Critical Disability Theory that is distinct not only from liberal theory, but is also distinct from other critical theories. They believe that Critical Disability Theory gives rise to a unique set of challenges to liberalism that are not common to other identities. They organise their framework around four central themes: (1) language, definitions, and voice; (2) contextual politics and the politics of responsibility and accountability; (3) philosophical challenges; and (4) citizenship/dis-citizenship.

Notwithstanding the subtle differences in the propositions, critical disability theory offers a unique point of view to analyse the existing legal regime with regard to rights of persons with disabilities. We could examine the present position in terms of the one of central themes used by Pothier and Devlin (2016) which is Language, definitions and voice.

Pothier and Devlin argue that the person first language, as used in the RPD, requires a full and comprehensive understanding of personhood rights for persons with disability. It is an attempt to remove the pejorative and exclusionary origins of the term ‘disability’. The other substantive question associated with ‘disability’ is what qualifies as a disability. The binary conception of disability does not allow for a more fluid understanding of disability. The stigmatisation attached to disability needs to be central to our understanding of disability rather than an inability to perform certain tasks. The retention of the medical model in the RPD raises questions on what has been achieved and what still needs to be done.

In contrast the language used in the NREGA which moved from ‘workman’ to households automatically allowed for the inclusion of persons with disability into the scheme for employment.

Defining Disability: PWD and the RPD

One of the important demands from the new legislation on disability was to accommodate the evolving understanding of disability. The shift from a medical model to a social model was to have been accomplished by doing away with a medical assessment of disability and including all forms of disabilities which may not be amenable to a positivistic and objective assessment such as the 40% disability that was the hall mark of the PWD Act.

The need to accommodate disabilities of different kinds in the workplace finds expression in many cases filed before labour courts and other employment tribunals. Courts have had to deal with claims made by persons who do not fit the categorisation made by the law but the claim for accommodation appears legitimate to the court. Judicial decisions have moved away from a strict interpretation of the law to accommodate claims shattering the iron wall of objectivity.

The decision of the Supreme Court in *Kunal Singh vs. Union of India* is one such case which took a very wide view of the term disability in the PWD Act and the decision has been used in several cases later to widen the scope of protections under the PWD Act.

The Supreme Court by looking at the language of Section 47 of the PWD Act which clearly lays down a statutory obligation to protect an employee acquiring disability during service held that Section 2 of the Act has given distinct and different definitions of 'disability' and 'person with disability' and hence they acquire different meanings. The Court held:

> The argument of the learned counsel for the respondent on the basis of definition given in section 2(t) of the Act that benefit of section 47 is not available to the appellant as he has suffered permanent invalidity cannot be accepted. Because, the appellant was an employee, who has acquired 'disability' within the meaning of section 2(i) of the Act he was not a "person with disability." (para)

The court here does not use the social model of disability that is the crux of the UNCRPD. The Court does not discuss the consequences of this distinction that it is making more so, because in *Kunal Singh* it was clearly locomoter disability and covered under the Act. The court did not have to go into the question of whether disability and persons with disability were indeed to be separately defined for different purposes.

This decision has been used in a series of decisions from the Madras High Court in which it has been used to include persons suffering from disabilities not mentioned in S.2 (i). The decision in *Kunal Singh* has been interpreted to include persons not suffering from 40% disability as required under Section 2(t). The Madras High Court has granted relief under Section 47 of the PWD Act to persons suffering from regular paralysis,[22] sudden illness,[23] heart attack,[24] colour blindness[25] by citing *Kunal Singh*.

These decisions seemingly appear to broaden the scope of the term disability to cover various forms of disability. These decisions of the Madras High Court covering regular paralysis, sudden illness, heart attack, colour blindness as discussed above and the Bombay High Court decision covering renal transplant, however reinforce the medical model. All the cases that the courts have extended the benefits of disability discrimination protection have been cases of medical disabilities and not the stigmatisation that is the root of an understanding of disability in terms of the social model (Mandal 2010).

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[22] K. Janardhan vs. M. D. Metropolitan Transport Corporation Ltd., downloaded from http://indiankanoon.org/doc/43222/.

[23] The Managing Director vs. The Presiding Officer downloaded from http://indiankanoon.org/doc/836256/.

[24] K. Ganesan vs. Managing Director, Metropolitan Transport Corporation Chennai downloaded from http://indiankanoon.org/doc/206916/.

[25] G. Muthu vs. the management of Tamil Nadu State Transport Corporation (Madurai) downloaded from http://indiankanoon.org/doc/1194789/.

In contrast is the decision of *Shirlow vs. Translink* in the United Kingdom under the disability law which includes stammering as a disability.

The social model of disability that is proposed by the UNCRPD has the potential to include several disabilities which are not based on a medical model of disability. To take an example, stammering would not be a disability under a medical model of disability. To be understood as a disability there would have to be an inability to speak or an impairment which does not allow speech. A stammer may not be a physical impairment as much as a psychosocial impairment (Leith 2014). More importantly is the social understanding of normal talk which is fluent and which does not falter or halt at any time or even occasionally. The need to fix a stammer through therapy or to advice a person not to speak rather than allow a person with a stammer to take a little more time to complete what he has to say is the social disability that a person with a stammer would face.

The Equality Act 2010 in the United Kingdom has a definition of disability as a mental or physical impairment which has substantial and long-term adverse effect on the ability to carry on day to day activities. In a 2007 employment tribunal decision in *Shirlow vs. Translink*, stammering was covered under the Equality Act as it has substantial impact on employment.[26]

Conclusion

The Right to work as defined in the UNCRPD has several facets to it. It is clear that the PWD Act has incorporated some of them, such as employment protection and encouragement for employment in public and private sector but neither does it provide for a comprehensive protection for all employment, nor does it have a framework in which the right to work of persons with disabilities may be understood. The RPD which should have done away with the medical model of disability has not done away with the model and more importantly has failed to extend the protection against discrimination in the private sphere thereby not effectively changing the legislations on employment protection which are clearly not accommodating of the rights of persons with disabilities.

The liberal framework on the Indian Constitution also needs a reworking to fully absorb the significance of the claims made possible by the UNCRPD. At present the court continues to use a liberal framework in which the disabled are seen as objects of pity or charity, and continues to view disability as a medical phenomenon; the social oppression argument is not fully appreciated. After the adoption of the social model by the UNCRPD, constitutional challenges in terms of definition, accommodation, and recognition are bound to arise. It is important that we recognise the need for theories that can better accommodate the evolving nature of disability rights.

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[26] http://www.stammeringlaw.org.uk/cases/stammeringcases.htm last accessed on 10th December 2014.

In the context of the right to work the UNCRPD does not provide for the right to work only in terms of a right to full employment but as a right to several other rights. The need to reconceptualise the right to work, particularly in the context of disability, as not only employment or livelihood but decent work and rights would be a powerful framework to address the stigmatisation that disability entails. Right to work not in terms of a right to a livelihood or the means to a livelihood but as an assertion of capabilities and capacities of the persons with disability needs to be specifically recognised. The social model of disability requires recognition of this right to be seen as able and not 'disabled'.

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Chapter 15
'Encounters' with Disabled People: Concerns from Field Work Settings

Mahima Nayar

Abstract Training for a degree in social work requires direct practice. Practice implies that students get an exposure to a wide variety of settings, interact with diverse groups and engage with different socio-economic realities. This elicits reactions in them which range from conflicts, confusions to emergence of latent biases. This paper explores the reactions of students when they interact with disabled people in field work settings. Goffman talked about 'discrediting attributes' and the stigma that disabled people face because of these attributes. In their initial encounters with disabled people and their families, students often find it difficult to look beyond the 'discrediting attributes'. They either talk about feelings of depression and negativity in relation to the disabled person or they eulogize them. Reactions which range from one end of the continuum to the other are usually unhelpful in working with people. This paper traces the journey of students from initial reactions to disability issues to gradual comprehension of the social model of disability. It attempts to bring out the way in which direct contact with disabled people and their families bring out latent stigmatizing concepts in students. These interactions activate the ideas related to the medical model and also give rise to stigma. This paper also presents the process (supervised field work) through which the same situations which activate the stereotypes and conflicts within students also help in ameliorating them.

Keywords Disability · Stigma · Field work · Acceptance · Direct practice

Introduction

Stigma and prejudice often lead to discrimination and exclusion of disabled people in various areas of life including education, employment as well as in interpersonal relationships. Stigma elicits negative responses such as pity, anxiety, avoidance, hostility, and even hatred and disgust (Scior 2016, p. 5). Stigma of disabled people can also occur because of the expectation that people with disabilities are less able to contribute to the good of the family and the community, and the assumption that they are a burden (Mostert 2016, p. 17; Aley 2016, pp. 15, 18). In West Africa for

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M. Nayar (✉)
Independent Researcher, Silvassa, Dadra and Nagar Haveli, India

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example, children with disabilities were not believed to be capable of living independent lives and were expected to require constant help from nondisabled people (Parnes et al. 2013, p. 24). Low expectations as to the potential abilities of people with disabilities can prevent children with disabilities from attending school (Ditchman et al. 2016, p. 34). People with intellectual disabilities and people with severe mental health problems are generally more stigmatised than people with physical or sensory disabilities, although there are also reports that people with sensory disabilities are also among the most discriminated against (Scior 2016).

Stigma can and often does influence all relationships of persons with disabilities. This includes interactions with people who are working in areas related to service provision for persons with disabilities. This paper specifically looks at the profession of social work. It presents student reactions to disabled people when they are in training.

Social work is a practice-based profession and requires the application of theories and concepts learnt in the classroom to real life situations. The International Federation of Social Work (2014) defines social work ‘as a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.’ Apart from the academic inputs, one area which is very important in social work is the field work practicum. This is an important part of the social worker curriculum and pedagogy. Its importance is highlighted in the following statement:

> Essentially social work skills are concerned with problem solving and as such they rest upon knowledge contained in the social and biological sciences pertaining to man and society. This knowledge is gained partly in the didactic sessions of the curriculum but it becomes meaningful only when the student has to test it in situation after situation in the field. Thus, it can be seen that the practical experience must be closely integrated at every step of the way with what the student learns in the classroom (Gore 1966, p. 3).

Social work interventions happen at the micro-level as well as at the macro-level. These interventions take place during direct practice (usually micro level) and indirect practice (at the macro level). *Direct practice* connotes face-to-face contact with clients aimed at supporting or strengthening them as individuals, *indirect practice* was the catch phrase for change efforts involving the environment and the social welfare system (Pierce 1989, p. 167). Direct practice in social work constitutes one-on-one contact with people at the micro level and is usually identified as working with people directly at the individual, group, or family level. Rather than specifying a particular theory, direct practice is seen as an eclectic process structured by the problem-solving process with the guiding underlying principles of sensitivity to social diversity and promotion of social and economic justice (Corcoran 2018).

This paper explores the manner in which stigma impacts direct practice in disability settings. In engagements and interactions with disabled individuals the latent stereotypes get activated and students reveal the manner in which stigma has coloured their perceptions. They are often unaware of these unconscious perceptions till they work in the disability settings. Marks (1991) observes that disabled people constitute a huge problem for nondisabled society precisely because they disrupt the normative individual: The person that dribbles, makes comments, disrupts a culture that emphasizes bodily control and associated cultural norms around manners, convention and bodily comportment. An individual whose speech is difficult to understand is assumed to have a problem because they challenge a colonizing stance of certainty about how people should speak (Goodley 2017). The term stigma originally referred to bodily signs designed to expose something unusual and bad about the moral status of the signifier. This moved on to refer to something that was related to disgrace rather than bodily signs. Goffman (1963) spoke about how society categorizes persons and the manner in which social setting establish categories of persons likely to be encountered there. He explained:

> When a stranger comes into our presence, then, first appearances are likely to enable us to anticipate his category and attributes, his "social identity"…. We lean on these anticipations that we have, transforming them into normative expectations, into righteously presented demands (Goffman 1963, p. 2).

The concept of stigma is related to many situations or conditions which are considered non-normative. In spite of the multiple definitions of stigma one of the most used one was given by Goffman (1963) 'attribute that is deeply discrediting' and that reduces the bearer 'from a whole and usual person to a tainted, discounted one' (p. 3). One such situation arises when postgraduate students in social work are placed for field work in disability settings. One of the main aspects which gives rise to stigma is an inability to accept people who differ from us in terms of views, background, emotional reactions, intellect and body types. In social work practice, the importance of 'acceptance' of the 'other' is the cornerstone of most work. When there is no acceptance then most interventions become self-serving rather than for the growth and development of the client group.

Acceptance of another combines a recognition and endorsement of the other's autonomy (his or her own separate views, goals, feelings, experiences, and capacity to act) with a feeling of affiliation with or connection to him or her (Berlin and Johnson 1989). In this perspective, social workers' recognition of their human connection with clients generates the motivation to offer compassion and care. But, as Sennett (2003) argues, on its own, compassion toward a person in need can easily devolve into condescension, serve as an exercise in self-fulfillment, and leave the recipient feeling resentment, helpless dependent, or both. On the other hand, it is possible to temper the controlling and demeaning aspects of compassion by also recognizing the other person's autonomy and capacity for agency (p. 484). Honoring another's autonomy means acknowledging the things about the other person that are different, that one does not fully understand, and that perhaps one does not even like without trying to change those characteristics or otherwise control the person (Weick and Pope 1988).

The initial days of direct practice in social work entailed the aspect of compassion very strongly in working with clients; the work of a social worker was largely to influence the clients and there was an aspect of ‘benign control’ in the work of people who followed Mary Richmond’s[1] school of thought (Berlin 2005). Gradually the emphasis on dignity increased and the functional school provided a framework which emphasized the notions that every individual has the capacity for personal growth and needs to chart his or her own course without undue interference from others. Within the context of a supportive but also limited therapeutic relationship, the individual will be able to discover the internal obstacles holding him or her back and tap into the motivation to grow. With the growth from the diagnostic model to one that focused on individual autonomy, we see a change in the expectations regarding the role of a social worker. It is especially with this change in role that student social workers have found it difficult to work in disability settings. When the focus was on compassion and provision of services, it was easier for people to fit themselves into certain roles. When the social workers were expected to recognize and respect autonomy of disabled persons then things became more complex. The journey of the students from the initial phase when the ‘anticipations’ and unexpected ‘encounters’ with disabled persons activate their latent stereotypes to changes in their perceptions after working in this area for some time is explored here. This paper brings out the manner in which stigma impacts the social work teaching and learning experience in a disability setting. It attempts to use the concept of stigma to explain the attitudes and subsequent behaviour of students while working with the disabled population. Social work practice involves coming face to face with many new situations, people and institutions which people may have previously not encountered. By its very nature social work training implies working towards social change; this change has to first start with the individual. Therefore, this training requires a student to be reflexive and introspective.

The progression of the student is explained in two parts in the paper. Part I deals with the field work process in social work training in which the objectives, requirements and process will be covered. Part II will discuss the manner in which field work activates certain beliefs and attitudes amongst students and the way in which stigma influences the interactions between students and the client group. This section also presents the changes in belief systems the methods through which they are either modified or strengthened over time.

Field Work Process in Social Work

Social work being an applied social science discipline, the emphasis is on teaching and learning through praxis, that is, a two-way reflective process between theory and the field. This aspect of the educational process is variously captured through processes such as concurrent and block field work, internship and practicum under the broad umbrella of field education (Dave et al. 2012).

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[1] Mary Richmond was an American social work pioneer who worked with the Charity Organization Society and major contributions to the field of social work.

The second Review on Social Work Education in 1980 (Roy 2017) has mentioned the following objectives of field work in Social work education:

1. Development of professional skills through learning to use knowledge for the study and analysis of problems and selection of appropriate means to solve them.
2. Development of skills in problem solving at the micro- and macro-levels.
3. Integration of classroom learning with field practices. Development of skills required for professional practice at the particular level of training.
4. Development of professional, attitudes, values and commitment along with development of self-awareness and professional ideas.
5. Development of self-awareness and professional ideal.

Field work is important in social work education as it provides an opportunity to the students to put her theoretical knowledge into practice during the period of training. Field work has been referred to as 'learning by doing' and forms an important part of social work education and an integral part of the total curriculum. This is the process which helps the students to make linkages between classroom learning and field realities. While classroom teaching attempts to change according to the field realities; it is only in field work situations that the actual impact of social, economic, political changes can be experienced.

It is field work training that distinguishes social work education from other social sciences (Lawani 2009). Field work training in social work education has got specific educational and service objectives which are related to areas of knowledge, skills, attitude, perspective and action within a dynamic theoretical framework (Devi and Prakash 2001). In the first year of the MA programme in Social Work, field work is aimed at developing perspectives, understanding practice roles and learning intervention skills. Student learning is thus directed towards understanding the contexts of engagement and core practice issues. Building on the foundation courses and core social work courses offered in the first year, students are expected to integrate theory with practice, by bringing back their learning from the field to the classroom and vice versa. Field work thus provides students the opportunity for learning, understanding, integrating and applying the different facets of social work practice. Some of the skills that develop amongst students during field work are—learning how to interact and intervene with people (individuals, groups, communities and institutions) in a purposeful manner, ability to analyze and recognize structural and social processes and to be able to identify stakeholders who are involved in particular issues.

Field work deals with not only developing the knowledge and skills of students but also involves a process of unlearning and relearning of attitudes and values. This involves a process of continuous supervision of students. This becomes important as students are placed in challenging situations which are new to them. For them to make meaning of the realities and issues that they are suddenly exposed to, a guided process is required. This guided process is referred to as supervision. Supervision is regarded as a method of teaching social work—a method specifically used in the area of helping the student to put into practice the knowledge gathered by him through classroom instructions (Banerjee 1964). Kadushin (2014) defines supervision as an interactional process. In this supervisor engages in a sequential series of deliberately and consciously selected activities. Supervisor and supervisee establish a small, interlocking social system that is ideally cooperative, democratic, participatory, mutual, respectful and open. It is through supervision that the student goes through the process of unlearning older attitudes and learning newer ways of perceiving people.

This is the space where students are able to bring their doubts, dilemmas and challenges and work through them. There are different mediums through which this happens. Students are expected to submit daily process recordings which are then read by the supervisor and discussed with the student. The process of supervision is carried out through individual and group conferences.

Individual Conferences help in facilitating self-directed learning by the student. It helps the students to integrate theory with practice and in gaining clarity about the concepts related to social work and social work practice. Here the recordings of students are discussed on a weekly basis to enable a student to discuss his/her experiences and feelings and also to plan for the next week. This is the space wherein students are free to bring up their reactions, doubts, perceptions, challenges when they are exposed to a new setting of work. Field work settings in social work are challenging places which expose students to existing realities which may have been invisible to them in the past. The initial recordings of students usually bring out how issues of gender, caste and disability had been invisible to them. Realization and articulation of discourses around these issues initially give rise to a lot of discomfort and requires students to move out of their comfort zone. Therefore, recordings and individual conferences become important.

Another method of learning takes place within a group. Group conferences are aimed at increasing the knowledge base of students through sharing of field work experiences amongst students. Students placed in similar setting can come together for discussion of work, reviewing work and discussing strategies of work. In these conferences' peers can give feedback to each other which helps in cooperative learning. It also helps students to find peer support as they realize that they are not alone in their journey of discovery. Lack of knowledge about an area, stereotypes, biases are often handled through presentations and discussions. Before the students move into the field, they introduced to the area of disability through information-based sessions and brief literature related to disabilities. The information given is related to definition, types and models of disability. Information and discussed based sessions are continued throughout fieldwork.

In *group conferences* in addition to the supervisor, people from the agency are also involved in discussions which help in linking theoretical inputs with field realities. Social work at this stage is assumed to address the problems of individuals to enhance their social functioning. Field work in social work goes beyond the social science's organization of field work which involves developing an understanding of society. In social work, field work also includes the component of 'change' (intervention)—after developing an understanding what can students do to bring about change. They may be expected to take up small tasks or interventions in this regard. Within this aspect of understanding a situation and working towards changing it, there lie a whole set of processes. These set of processes are addressed in the space of supervised field work. Field work in social work is closely supervised because of this aspect of intervention that is required. Knowledge about society and individuals has to move beyond understanding to empathically living the situation through the client and working with them to bring about a change. The manner in which the student is going to bring about the change is dependent on how the understanding has developed through their readings and reactions. Often it is in this movement from understanding to intervention that the student social worker changes as a person. There are also times that when this movement does not happen. The student social workers may find themselves unable to work in a particular setting as they are working through their personal issues while dealing with a social problem. This is the space where their latent stereotypes, biases and inherent structure of the world is challenged. The diagram below (created by the author) is a representation of processes that occur in the situation of supervised field work which moves a student towards interventions. These steps are cyclic in nature and the process continues throughout field work (Fig. 15.1).

When students are placed in disability related setting—these are the stages in which dilemmas, confusion, biases and sometimes even despair come up in working with disabled people. This happens even when students have chosen the particular area of work.

Changes in a student happen over a period of time and this process involves creation of multiple situations wherein students can learn through direct practice. The

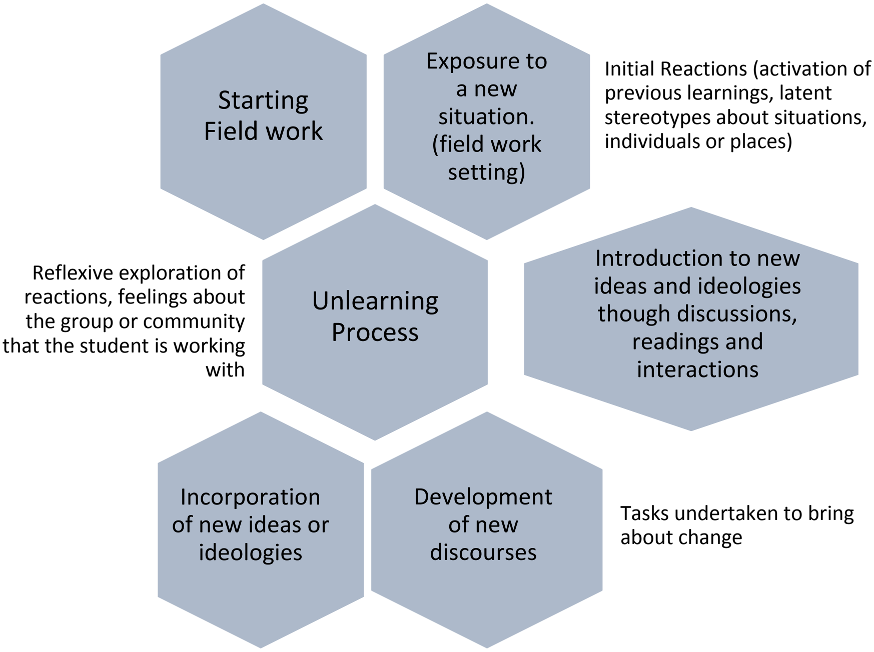

Fig. 15.1 Stages of field work (Nayar 2019)

next section explores what happens during these stages of field work in a particular setting.

Stigma in Disability Context

The previous section describes the process of field work. In this section, field work in disability specific settings will be discussed. Disability specific settings are often the first time that students are exposed to disabled and the issues that they face. The disabled individual is usually perceived through a ‘discrediting’ lens that changes or ‘spoils’ their true identity.

According to Goffman (1963) stigma has to be seen in the context of relationships and not attributes. That is because an attribute that stigmatizes one type of possessor can confirm the usualness of another (p. 3). He saw stigma as a relationship between an attribute and a stereotype. This could be understood as a relationship between an impairment and societal reaction to it. Early field work recordings reveal the student’s constant surprise at the ‘normalcy’ of disabled children. When students face disabled people many of their unconscious assumptions get activated. In their initial encounters with disabled people and their families, students often find it difficult to look beyond the ‘discrediting attributes’. They either talk about feelings of depression and negativity in relation to the disabled person or they eulogize them. The initial days of field work can be seen as enactment of what Goffman (1963) called one of the primal scenes of sociology—the time when normals and stigmatized enter one another’s immediate presence. This is the time they attempt to have a joint conversational encounter and in these moments the causes and effects of stigma have to be directly confronted by both sides. In these direct interactions, the attitudes and beliefs of students regarding disabled people are revealed as they express their surprise about children with disabilities performing tasks of everyday living:

> I was surprised to see the discipline, organization and co-ordination among children. (age group 6–10 yrs)
>
> Children with disabilities performing everyday tasks is a revelation.
>
> They have a beautiful mind that we are unable to see.
>
> He is a case of mental retardation, but understands instructions well. He can eat by himself. It is only his third week at the school. The educator informed that he used to cry a lot when he had joined. This reflects that these children are not very different from others who experience the same anxiety when exposed to a new environment.
>
> As children ate their mid-day snack, the educator asked each of them if she can share their food with her. Some readily offered her, while others pulled back their boxes to refuse. Hence, some know sharing, others don’t- again, a trait very much like other children.

These observations reveal students’ perceptions (stereotypes) about persons with disability (attribute). The resulting relationship reveals the presence of stigma. There is an assumption that children with intellectual disabilities would not understand any instructions. There is an emphasis on a ‘normal’ emotional reaction (initial period of crying) after joining a new school which is similar to other children. The constant re-iteration of the concept of normalcy appears to show how the student is trying to normalize the situation without acknowledging the differences and is not very comfortable with working with disability. This discomfort came out after several weeks of field work in one of the students who said that she could never work in the area of disability as it was too negative and 'sad'. Fine and Asch (1988) identify five assumptions which can help in understanding these negative perceptions of disability: (a) that disability is solely located in biology (b) that the problems of the disabled are due to the disability—produced impairment, (c) that the disabled person is a 'victim', (d) that disability is centred to the disabled persons' self-concept, self-definition, social comparisons, and reference groups, and (e) that having a disability is synonymous with needing help and social support. These assumptions are in line with the understanding of disability from the medical model lens. They also reveal attitudes arising out of ableism; ableism can be associated with the production of able-ness, the perfectible body and by default the creation of a neologism that suggests a falling away from able-ness, that is disability (Campbell 2009). Hahn (1986) testifies there is a close link between the attitude of paternalism, the subordination of disabled people and the 'interests' of ableism:

'Paternalism enables the dominant elements of a society to express profound and sincere sympathy for the members of a minority group while, at the same time, keeping them in a position of social and economic subordination. It has allowed the nondisabled to act as the protectors, guides, leaders, role models, and intermediates for disabled individuals who, like children, are often assumed to be helpless, dependent, asexual, economically unproductive, physically limited, emotional immature, and acceptable only when they are unobtrusive (Hahn 1986, cited from Campbell 2009).'

Apart from the paternalistic attitude, ableism can also lead to a feeling of negativity about working with disabled people. This leads to resistance in working with disabled and in disability settings. Behaviors like reaching late to agencies, criticizing the staff for the kind of care they provide, finding problems in agency objectives come up. This happens within the first few weeks of field work itself when an understanding of the agency and its objectives are at a nascent stage. Therefore, these can be understood as difficulties the students face in a disability context rather than an actual assessment of the agency's work.

Stigma and negative perceptions are attributable not only to student's personal reactions—they could be reflective of the settings where students meet and form relationships with the disabled for the first time. From their study of students in six health professions including occupational therapy, Westbrook et al. (1988) expressed concern about the narrow and pessimistic beliefs regarding persons with disabilities in *evi*dence among their cohort of student health professionals. They speculated that this situation might be attributable to the unrepresentative samples of persons with disabilities with whom students come into contact on clinical placements. For example, students tend to encounter persons who are currently experiencing problems rather than those who are functioning well. Goffman (1971, cited from Gronfein 1999) spoke about the particular ways in which individuals are treated by others and the types of scenes in which that treatment takes place which may be read as an implicit, virtual set of assumptions held about that individual by those others; these assumptions constitute the others 'person' (cited from Gronfein 1999). Therefore, the assumptions of the students about disability and disabled become a part of their person and they respond to them accordingly.

Students' attitudes and views about inclusion of children in society especially in school vary depending upon the kind of disability. Patel and Rose (2014) through uses of focus group measured the attitudes of 30 undergraduate psychology students towards individuals with an intellectual disability. Among the results obtained, they report as a significant variable the form of disability under investigation. They thus conclude that, for the respondents, it was essential to know the severity of disability in order to give their argument in regard to the inclusion of disabled people within society.

Dibra et al. (2013) offer a snapshot on student's attitudes at University 'Luigj Gurakuqi' in Shkodër city, Albania. Students seem to be tolerant towards disabled people since they consider disabled people as able to lead a 'normal' life, but findings show that they hold negative stereotypical views in regard to the personality of disabled people. Furthermore, the authors note that students advocate for the employment of disabled. Nevertheless, according to Dibra et al. (2013), students have a tendency to be more insecure when come to issues like inclusion of disabled children within schools. Greater number of them, reveal that it will be better if children with disability live in special communities. This is seen in field work settings as well in the initial stages of field work. It is difficult for students to move beyond the 'discrediting attributes' of disability and see the whole person.

> I call him a curious case because he does not seem to have any of the major characteristics of a person with autism, and yet is different from others is a unique way. He comes across as a fun loving, active and confident boy.

The implications being that a child with autism is not capable of being fun-loving, active or confident and therefore becomes a 'curious case'. The stigmatized identity of a child with autism results in the individual being viewed as 'curious' when they display the above-mentioned characteristics which would be considered signs of a healthy personality. This is present even though autism is defined as a spectrum disorder implying that the children diagnosed with autism would display a wide variety of features.

There are times that the discrediting attribute is extended to other people around the disabled person especially the family members. 'Courtesy stigma' has been defined as a 'tendency for stigma to spread from the stigmatised individual to his close connections…' (Goffman 1963, p. 30). This is evident when assumptions are made about the agency objectives (as mentioned above) without looking into the resources available for working with disabled. Similar judgements are made about the family members and caregivers. Assumptions are made that family members do not take adequate care of their disabled children without taking into account their social position. In one situation students were asked to go for a home visit for a child who was irregular in coming to school. When they went there the mother said that her husband and mother in law did not allow her to take the child to school. The students initially doubted her and felt that she did not wish to take care of her disabled child. The assumption was she was a disinterested mother without looking into the social location of the mother and power that she had vis-a- vis her husband and mother in law.

In another agency when the child was irregular in coming to school, the students mentioned that the reason for the planned home visit was to motivate the reluctant parents who appear to be uninterested in sending their disabled child to school regularly. It is when they went to the house, they realized that the family lived in the middle of a slum where there was no space for a wheelchair to go through as the lanes were very narrow. The father who was a daily wage labourer had been carrying his son to school, but after a back injury he was unable to do so. This home visit clearly brought out the issues of disability and poverty for the students. Although classroom discussions do take place about the relationship of poverty and disability; it was only through meeting the 'real' people that the connections became more tangible for the students.

It is through the process of supervision (explained in the earlier section) and engagement with disabled and their families that relearning of attitudes and beliefs take place. In general, the tendency for a stigma to spread from a stigmatized individual to his close connections provides a reason why such relations tend either to be avoided or to be terminated where existing (Goffman 1963, p. 30). This can also be one of the reasons for reluctance to work in a disability set up.

With some of the students, there is a clear articulation about the change in their attitudes towards disability. With others a change can, be seen through the changes in their recordings. From initial hesitation in interactions they are able to find common ground. One of the students initially felt that she was unable to communicate with the adolescent disabled girls. Over time she started writing about conversations that she was having and how she was sharing everyday incidents like being bitten by a dog with the girls in the agency. When her field work ended, she was given an elaborate farewell. The student spoke about being surprised that so many bonds had been formed at this place where she initially felt that the children hardly noticed the external environment and her presence. This incident also helped her to introspect how many of her initial ideas were assumptions. Her relationships with the other girls also helped the student to identity the similarity of oppressive conditions faced by her and the disabled girls in the school. At one point during the field work, she had expressed difficulties while working with the agency as she felt that male student was given more responsibility and accepted more primarily because of his gender. This also gave her an insight into how gender would play a role in the lives of disabled girls. Other issues related to employment and accessibility were also highlighted during the latter part of field work placements.

There is recognition of how many of the disabled are able to do only low paid work and they have limited accessibility to most of the places. Issues of disabled which were previously invisible to them come in the forefront. One male student from a Dalit background was able to relate the aspect of limited accessibility to services and privileges as arising from not only the social background but also from gender and disability. For him the concept of intersectionality developed from his work in the field as is evident from the statement below:

> I joined social work to work with Tribals, Dalits and minorities, it's only through field work that there was a recognition of issues related to women and disabilities. What it must be like to be a Dalit woman with a disability.
>
> I did not see people with disabilities now I see them everywhere – it is like they were invisible even when they were in front of me. Accessibility is one of the first things that I think of whenever I go to different places.

The understanding of disability expanded to include the lens of social model as well as the medical model. For most of the students the journey was challenging as it requires incorporating two kinds of views—individual and social which appear contradictory. However, when it is only when we look at both that the complete picture of the life of a disabled person emerges. For some of the students it involves a great deal of struggle to move beyond seeing disability as something which is negative and destructive to seeing hope. The understanding that with adequate rights the situation can change also comes in with greater engagement with people and reflecting about these interactions. When encounters became interactions, an acceptance started coming in which is apparent through change in the way issues were expressed in field work recordings. Ideas related to disability and disabled being 'issues' are replaced with newer ideas about ways in which interaction of impairment with societal set up lead to difficult situations. Beginning of internalization of the social model and understanding of life issues beyond the obvious 'impairment' is apparent through the following statement:

> While conversing with them, it struck to me that even age plays an important role with respect to disability. For example, the parent of a 7-year-old is not as bothered about the child's disability because first, he has a long way to go before encountering deeper issues of life cycle like marriage, career etc. and second, because he is still seen as a "child" in the society and is lovingly and playfully accepted. However, as the child grows older, the child's dependence on a caretaker, his/her future, career and marriage issues start bothering parents more. In addition to it, even the society responds in a different manner.
>
> For example, the experience of people turning around to gaze at the child/whispering amongst themselves was brought out by the mother of a fifteen-year-old girl with disability. In a group discussion while other parents spoke about how 'everyone knows the child, they play and have fun with him, and no one says anything unpleasant'; she brought out the issue of being stared at. The gender of the child may also be a factor here, the child with disability being a girl.

The above statement was made by the same student who during the initial stages was surprised by the 'normalcy' of children with disabilities. Engagement and encounters with disabled persons and their families brought in a nuanced understanding of the issues faced by disabled people. Over time, the field work recordings reveal the recognition of everyday challenges related to age and gender that disabled persons and their families face. Recognition that these challenges were related to societal and ecological factors rather than only biological factors also came in for students. This movement from a purely medical understanding to a social understanding helped the students to move towards planning interventions. Developing a 'social' and 'intersectional' lens helped the students in envisaging a role for social workers in the field of disability.

> Idea of disability changed while working in the field – from seeing parents as people who 'need to be helped' to self-help and empowerment approach.
>
> Lens changed from 'blame' to 'accept'. Was always looking to blame someone – when parents had orthodox beliefs – felt annoyed and helpless. Acceptance is important is problem solving.

Acceptance entails respecting the 'other' while affiliating with them. It is through this acceptance that the understanding of disability being a 'social' and 'human rights' issue apart from being a medical one, emerges. It is also through this acceptance that the student social workers understand the importance of working with disabled people rather than for them.

Conclusion

Disability in our post/modern society is 'described as a multifaceted, complex experience that is integrated into and, ultimately, becomes part of disabled people lives' (Lutz and Bowers 2005, p. 1042). This complex experience is also extended to those who interact and engage with the disabled. This paper has explored the experiences and movement of student social workers placed in disability settings. It attempts to trace the journey of moving from a medical understanding of disability to a more comprehensive model which includes social and a rights-based perspective as well.

This journey of students where stigma colours the initial 'encounters' with disabled and their families is full of struggle. The struggle consists of dealing with attitudes and values which sometimes the students did not know existed within them. The challenge is acceptance of a 'flawed' self rather than of a 'flawed' other. In postmodern discourse, ideas about engaging and learning from people who have different experiences and views are sometimes captured under the label of 'engaged fallibilistic pluralism' (Bernstein 1992, p. 336). Engaged fallibilistic pluralism essentially means recognizing that our own views (and those of others) are incomplete and flawed, that alternative perspectives are worth considering, and that competing views of the same phenomenon can all be valid in some respect. This means that even if we are committed to our own ways of thinking we have the capacity to engage with others without suppressing the otherness of the other. Accepting the differences of others is one of first steps in reduction of stigma. Garrett (1942) explained that real acceptance involves positive and active acceptance of feelings that are expressed through behaviour but not acceptance of unsocial behaviour. True acceptance involves accepting the disabled person but not fearing to critique any unacceptable actions on their part. These descriptions portray acceptance less as a static quality and more as an open, active, searching, and reflexive process. Finn and Jacobson (2003) emphasize that it is not so much about social workers simply having and tapping into their own good relational qualities but rather they actively develop an appreciation for the unique qualities and situations of each individual. This appreciation is cultivated through dialogue, discovery, critical inquiry, action, and reflection on action. Acceptance is developed through interactions in which the participants (worker and client) teach and learn from each other in ‘a participatory process of discovery and critical inquiry’ (p. 165). They also suggest that relational connections to clients are developed and enhanced not by avoiding but, rather, by intentionally engaging in dialogue to explore ‘differences, power, and positionality’ (Finn and Jacobson 2003, p. 165).

When students begin to engage with issues of differences, power and positionality, they also start questioning their ideas and beliefs. This often causes a lot of turbulence within them as it implies that the change has to come from within them. This turbulence moves them to re-examine their perceptions, attitudes and behaviour. It also develops an understanding that stigma is a complicated concept which has multiple components and can be defined in different ways.

Link and Phelan (2001) combine the various components of stigma and explain ‘stigma exists when elements of labelling, stereotyping, separation, status loss and discrimination occur together in a power situation that allows them.’ The components of labelling and stereotyping might be applicable to many ‘identities’; however, it is the aspects related to status loss, discrimination and power which make a particular group of people stigmatized. Developing an understanding about these aspects while working with the disabled population is important because stigma has to be understood in terms of power relations as well. Stigma additionally results in social distance, which we define as deliberate effort to avoid another or exclude that other from social interaction (Lucas and Phelan 2012). This is apparent in the attitudes of students as well who are reluctant to work in the area of disability. Engaging continuously with people with disabilities and their families brings about a change in their manner of viewing disability. Reducing stigma and increasing acceptance of disability and disabled is not a simple task. It involves continuously reflexivity in the field. Through continued engagement in the field, regular readings in the field of disability and discussions the students are able to achieve the processes of unlearning and relearning.

Field work remains an important part of social work education as it enables students to move beyond classroom inputs to actual realities. While looking at student growth, it is also important to re-examine our teaching methods and materials as well. While teaching about disability we need to use or create material which defines different kinds of disabilities through a social and rights-based lens. For students ‘encountering’ the disabled people in their natural settings improves their conceptual and practical understanding of disability issues. The development of a framework which includes disability rights and respects the autonomy of persons with disability leads to the development of a competent social worker as well.

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Chapter 16
Examining the Question of Deaf Education within Disability Studies in Delhi, India

Ritika Gulyani

Abstract The chapter examines the presence of Deaf education in India and the efforts made by the state to promote it. It also talks about the challenges that the deaf as a particular section face, which are unique to them. The absence of institutions, especially for higher education, that can cater to the needs of deaf students is a cause of concern. With Disability Studies gaining a strong foothold in the academic and social circles of the country, the chapter also tries to explore how Disability Studies can aid in this area of education for the deaf.

Keywords Deaf education · Educational policies · Higher education · Disability studies

Introduction

When the western education system was developed, its main aim was to cater to the education of the masses. Since it was developed for the majority, those who were the marginalized and the minorities, such as the disabled, were left out of its purview. It was believed that since disability and impairment were so closely linked with the medical community, owing to the diagnosis coming from the medical field, the onus of who was worthy of education should fall on their shoulders. Educating *per se* was not to be imparted by the medical community, but rather they were to screen the children and those who had physical or sensorial disabilities, such as blindness and deafness were to be kept way from the main stream school. It is for these children that special schools were to be set up where they could be educated in a separate environment.[1] In the later years, with advancement in technologies, this was also followed for those with behavioral and learning disabilities (Jha 2010). However, the

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[1] Tomlinson in 'A Sociology of Special Education' (1982) notes that the special schools were constructed as a safety valve which was to ensure that the regular mainstream schools kept functioning normally in which the 'normal' students can be taught without interrupting the time of the teacher.

R. Gulyani (✉)
Centre for the Study of Social Systems, Jawaharlal Nehru University, New Delhi, India
e-mail: gulyani.ritika15@gmail.com

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notion of special education was not very successful, as pointed out by Oliver (1996, 93):

> Special segregated education has been the main vehicle for educating disabled children throughout most of the industrialized world in the twentieth century. Over a hundred years, a special education system has failed to provide disabled children with the knowledge and skills to take their rightful place in the world, and it has failed to empower them.

So, the question then arose as to what was a better alternative to the special school, and over the years, a significant shift has been observed from special education to the inclusive education all over the world. The integration of disabled learners into mainstream schools has become an alternative to the presence of special schools, especially in the west (Polat 2011). The current schooling systems have thus evolved from the two opposing views of integration and segregation. Integration perspective believed that the adaptation would be made to the normal school and the children with disabilities would be placed there while segregation approach argued that the children should be divided up according to the difficulties they faced and special schools be accordingly set up in line with their needs. The segregation and the establishment of special schools were understood to be akin to eugenics in order to keep the 'misfits' away. But slowly it became the accepted norm as to how minority children acquired education (Thomas et al. 1998). However, over the years, this norm of segregation has changed and a move had been made to understand that such a system stigmatized and degraded the children. Efforts have now been made to move towards inclusive education, where disability is seen as a form of diversity (Jha 2010).

There has emerged two terms in the current school and educational terminologies which are often confused with each other, namely integration and inclusion. Both terms emerge as being opposed to segregation, but integration focuses on the child and how the child should adapt to fit into the school whereas inclusion focuses on the school itself where it is the school which has to make adjustments to make the child fit in. It was this idea of integration and inclusion that changed the way education for children with disabilities is being perceived today. It has led to a growth in the number of categories of disability, and in understanding their rectification, it has led to a separation of education and to certification of teachers in order for the classroom to be more accessible (Thomas et al. 1998).

But even today, the mode of primary as well as secondary education for a lot of deaf and hard of hearing students still remains through special schools. A few hard of hearing students do eventually go the mainstream schools and in integrated set up, but this stops after school. The system of higher education is highly inaccessible for deaf students in India, and owing to an absence of deaf specialized institutes of higher education, majority of the students are forced to look for other avenues after their schooling. This chapter tries to throw light on two issues pertaining to deaf education in India. The first is the presence of 'special' schools for deaf and their understanding as being remnants of a discriminatory practice. But, at present, they are the only means of education acquisition for the deaf. Second, the absence of inclusive institutes of higher education has affected the deaf population the most. Owing to the fact that deafness leads to an altered means of communication, namely sign language, the provision for the same are yet to be made in our higher education, and due to this, a lot of students are missing out on educational opportunities which also affects their future career prospects.

The current chapter draws insights from fieldwork conducted in four educational institutes in Delhi which are for the educational needs of the deaf students. Of the four institutes, two were governmental and the other two were private. Fieldwork was conducted as part of the research work for a Ph.D. thesis during 2016–2017. Within the fieldwork, around 30 deaf students, between the age group of 16–26 were interviewed. Delhi was chosen as field site as being the capital of the country; there was presence of both public as well as private institutions, dedicated to the educational needs of the deaf, as well as the presence of an active disability sector in general.

Status of Education for Children with Disabilities in India

The concern about the rights of people with disabilities was fast emerging in the 1990s in India and this could be ascertained from the legislations that were passed and enacted in the parliament. These included the Rehabilitation Council of India Act 1992, the Persons Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999. The disability rights movement and the role of United Nations that has given an impetus to the developments in the field of legislature as well as laid a foundation for the jurisprudence of disability in India (Addlakha and Mandal 2009).

The disability rights in India right from the 1980s had been following three parallel tendencies; there are the individual-centered organizations who mainly lobby for the provision of services, to create awareness and to circulate information, then there are the NGOs that are managed by the activists for the rehabilitation programmes among the poor of rural and urban areas and finally there are the disability studies scholars who are involved in the production of knowledge (Mehrotra 2013). However the organizations centered on disability rights are usually riddled with concern of the middle-class men (Ghai 2003). For Mehrotra (2013) this becomes a matter of concern when the ‘rights for the disabled’ turn into the rights for only the privileged disabled such as special parking facilities, concession in travel etc. All these, though important, are a far cry from the reality of the majority of people with disabilities who are marginalized even further on account of their caste, class, place of residence and gender. More vital to them would be issues like education, residence, employment, etc. (p. 103).

Education in India is largely the responsibility of the state government but the central government has made various provisions to address the inconsistency of the different state laws. From about 1990, the different ministries and departments have launched various schemes meant for the different groups of children (Singal 2008).

By the 86th Amendment Act in 2002 to the Indian constitution, free and compulsory education to all children within the age of six to fourteen years was guaranteed as a fundamental right. This was the *Sarva Shiksha Abiyan* (Education for All), a programme of the Indian government for the achievement of the Universalization of Elementary Education. It was implemented so as to address the needs of 192 million children and is undertaken with the help of the state governments. Within this programme, new schools were to be opened in those locations which did not previously have a school and also to strengthen the already existing infrastructure such as provision for drinking water, additional classrooms, and toilets. It also provided extra teachers to schools that had inadequate teaching staff. The main focus of SSA was to provide education to girls and to children with special needs (Ministry of Human Resource Development 2018).

Compulsory education schemes may prove to be very useful in the education of children with disabilities, who are otherwise left to their own devices. Nakamura (2006) points out how in Japan, while the government run schools were technically compulsory for all students, those with disabilities were not included in the fold. It was only with the government making education compulsory in 1948, that a larger enrolment of students with disabilities was seen. Though the mandate itself had a lot of loopholes, it at least opened the gates for educational opportunities for children with disabilities, who were till now neglected.

Limaye (2016) points out accessibility for children with disabilities emerges from various avenues such as, the perspectives of the parents, where they either are not aware of the various facilities available, or else are not invested in the educational needs of their disabled children. Additionally, due to the prevalence of gender discrimination, to social stigma, to lack of proper schools as well as teachers, to social conditions like poverty and finally to the policies of the government. Palan (2016) also shows how students with disabilities in higher education also have their share of issues. The presence of unfavorable attitudes as well as the apathy of the bureaucratic staff was a major barrier to attainment of education, which continues on to the workforce later in life.

Educational Opportunities for deaf in India

The UNESCO Education Report for the twenty-first century affirms the importance of higher education in the economic development of a country. In comparison to work done in promoting higher and technical education among the Scheduled Castes, Scheduled Tribes, Other Backward Classes (OBCs), women, very little has been done for persons with disabilities which is reflected clearly in the census. Among the students with physical disabilities, D/deaf[2] students are the most vulnerable when

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[2] A deaf person is one who is medically unable to hear, while a Deaf person is who identifies themselves as being part of a community and part of a linguistic minority rather than a disabled group.

it comes to education, since the current education system in the country is heavily biased towards the hearing. One of the reasons for this woeful scenario, more so in case of education of D/deaf students, is the lack of true inclusion in education of students with disabilities. The handful of students who do manage to make it to the level of higher education face a great deal of hardship due to lack of infrastructure and facilities (Bhattacharya and Randhawa 2014).

About 70% of children with disabilities have still not been identified after more than 10 years of implementation of various policies like, the 'Education for All' programmes, Sarva Siksha Abhiyan (SSA). Additionally there are about 18 million deaf people in India and there are only 550 deaf schools, the majority of which are only till secondary education (Singh 2015). According to the UNESCO report in the 1980's, only 5% of children who were deaf attended any special educational programme (Brill 1986). Applied to the present situation, this would mean that only 50,000 children who are deaf, receive any education while the other 950,000 are left to their own devices (Ulrike et al. 2005) From the very beginning, deaf were considered to be slow cognitively whereas the actual problem lay in the way communication was carried out and the difficulty in the transmission of knowledge (Padden and Humphries 2005).

The first school for the deaf, the Bombay Institution for Deaf-Mutes was founded in 1885. Following this, many schools were set up in different parts of the country either by Christian missionaries or by private individuals. Two of the earliest schools founded in India were in Chittagong and Rajshahi (now in Bangladesh) (Banerji 1949). In 1939 a researcher, K. Bhattacharya,[3] found twenty-six schools offering education to deaf in India. According to Roopa Vohra, twenty-four schools that were operational prior to independence were still operational till 1988, which shows that at least some of these institutions had government funding.

Post independence, the right to education was protected by the constitution. The Ministry of Social Justice and Empowerment has been implementing various programs and policies for the treatment, rehabilitation, welfare and economic development of persons with disability (PWD) with the help of state governments and non-governmental organizations (NGO's). Even Article 41 of the constitution states that, the state shall ensure, within limits of its economic capacity, to make provisions for securing the right to work, the right to education and to public assistance in cases of disablement. Article 45 further notes that the government provide free and compulsory education to all children under the age of 14, ten years from the date of adaptation of the constitution, that is by 1959. However, in terms of deaf population, this is yet to be achieved (Dennis 2005).

The current status of the education of the Deaf in India today is extremely poor. Oralism is still the prevailing method of educating the Deaf. The urgency of the current system is that at present deaf children do not have adequate access to the school curriculum, and the reason for this is that teachers of the deaf, in both mainstream and special schools are not proficient in Indian Sign Language (ISL). As a result, deaf

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[3] K. Bhattacharya, "A Statistical Survey of Education of the Inform in India". *Journal of the Development of Letters* (Calcutta: University of Calcutta, 1939) 21.

children are not taught in Sign Language. The current system of education in India does not prepare deaf children to lead productive lives. The emphasis on the development of oral skills undermines much more important goals, such as development of a language, cognition, social skills and emotional maturity. The main problem is a total lack of meaningful communication between the teacher and student which is the key to education of all children, be it deaf or hearing.

Oralism (or the auditory-verbal approach) advocates speech and lip-reading as the means to communicate with and educate the Deaf child. This means that the Deaf child relies on hearing aids and other technology like cochlear implants to ‘hear’, and the family and/or school teaches the child to ‘hear’ and speak. A spoken language is used as a major force in the child’s personal, social and educational development and signing of any sort is disallowed. The aim is to get the deaf child to function as far as possible as a ‘normal’ hearing child. Deaf learners are disadvantaged further by not being able to acquire the language by hearing it spoken, as a hearing child can. Majority of deaf children have parents who can hear and thus they seldom communicate with their child in ISL, as a result of which the child does not pick up any language. Not acquiring a language can lead to communication isolation, low skills and discrimination due to stereotyping. It is also worth noting that studies have now shown that the portion of the brain that deals with language starts atrophy by the age of three if it is un-utilized as happens with most Deaf children. Post this period, learning a language does not come naturally and has to be memorized, which is the case with most students. However hard the ‘hearing’ majority may try to ‘normalize’ Deaf children and attempt to compel them to learn lip reading and use speech, the fact is that wherever you have a group of Deaf individuals together, they will more than likely be using Sign Language to communicate (National Association of Deaf 2013).

In the recent years however, efforts are being made to make education, especially higher education more inclusive for those with hearing impairments as well. In 2016, The National Institute of Speech and Hearing (NISH) Akkulam launched a diploma course in sign language in 2016, where in students are trained in the main elements of Sign Language (National Institute of Speech and Hearing 2016). This course is aimed towards the hearing as well as the deaf population of the country who can learn sign language and then further teach it to children in schools around the country. In addition, Dr. Shakuntala Misra National Rehabilitation University, Lucknow has established a Centre for Indian Sign Language and Deaf Studies, which is working towards Deaf education in Sign Language and promotion of research in this field (Dr. Shakuntala Misra National Rehabilitation University 2001).

Not just universities, but the Indian state also has lately been involved in the setting up of the Indian Sign Language Research and Training Centre (ISLRTC) and to subsequently come up with an Indian Sign Language Dictionary for the country. The ISLRTC was sanctioned in 2011 by the Ministry of Social Justice, and was housed in Indira Gandhi National Open University (IGNOU) in 2012 (IGNOU 2012). However, the centre had to be closed down within the next year as there were some financial and administrative shortcomings on the part of the university (Hindustan Times 2013). Post this, the centre was set up again in 2015, and at present it offers a Diploma in Indian Sign Language Interpretation. The ISLRTC also took a very monumental step in the beginning of 2018 when it released a Sign Language Dictionary (Ministry of Social Justice and Empowerment 2018). It is the first official dictionary that is available to the D/deaf population of the country and has signs for around 3000 odd words, which are used in the everyday workings of the deaf population.

Policies in Place for Education

In regards to education, India has been consistent to achieve this goal. This has been a part of its development strategy and is very visible in the form of the formation of the University Education Commission (1948–49), the Secondary Education Commission (1952–53), the Education Commission (1964–66) and the National Commission on Teachers I & II (1983–85). Additionally, the National Policy on Education (1986) (later revised in 1992) laid forth a plan for a national system of education where ‘up to a given level, all students, irrespective of their caste, creed, location or sex had access to a comparative quality of education’ (Government of India 2016). Government documents such as that of the Ministry of Human Resource Development show that children who belong to a certain group like the schedule caste, the schedule tribe, from the various religious, linguistic and minority groups, those who are girls and those children who have disabilities are usually more likely than others to be excluded from the schools. The Government of India has made various provisions to sort out these discrepancies along with an effort to equalize the educational opportunities by attending to the specific needs of those whose equality has been withheld so far (Singal 2006).

Of all the laws passed in the country for the welfare of persons with disabilities, it is only three, the Rehabilitation Council of India Act in 1992, Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, and the newly passed Rights of Persons with Disabilities 2016 that mention rights and/or provisions for the deaf population.

The Rehabilitation Council of India (RCI) Act 1992 was passed by the Parliament in order to regulate the programmes in the area of education of children with special needs. The major responsibilities of the RCI was to regulate the training policies and programs in field of rehabilitation of people with disabilities as well as to bring about a standard pattern of training courses for rehabilitation of professionals dealing with people with disabilities, while also regulating a uniform rehabilitation in the country which was achieved by prescribing a minimum standard to the education and training institutions, to monitor and recognize the institutions where educational courses for the disabled are running and to withdraw recognition in case the facilities are not up to the mark (Dias 2013).

The 1995 Act used the broad category of ‘people with disabilities’ and when it was drafted, it was seen as providing a set of distributive measures for the disabled and for this reason, it was essential that the beneficiaries be identified clearly (Kothari 2012). Hence, the law clearly defined the various types of disabilities and even put forth a set of medical parameters which define each of these categories for future assessment. The PWD Act classified disability into seven categories of blindness, low vision, leprosy-cured, hearing impairment, loco-motor disability, mental retardation and mental illness (Addlakha and Mandal 2009). The Act also helped set up the Ali Yavar Jung National Institute of Hearing Handicapped, which has been instrumental in taking care of the needs of the hearing impaired in India at the governmental level. At NIHH, personnel are trained, in accordance with the Rehabilitation Council of India guidelines, in order to provide special educators and interpreters to various schools and colleges across the country. It was under the head of the institute only that a proposal for starting classes in ISL was put forth, though this was done as late as in 2001 (Naik et al. 2013).

Within the newly passed bill of 2016, the government and local authorities will take steps to provide inclusive education to all while making the physical infrastructure accessible and providing reasonable accommodation. Clause 16(v) also ensures that those who are deaf or blind or both will be provided education in the appropriate language and means and modes of communication. It also aims to monitor progress of all students with disabilities and ensure the completion of their education (The Rights of Persons with Disabilities Act 2016).

Challenges They Face

In India, students with disabilities go either to regular schools, where they are expected to fit into the scheme of larger things and cope on their own or else they are sent to special schools. A majority of deaf children are born to hearing parents and as a result, they grow up in partial surroundings of hearing and deafness, which creates settings which are hostile and inaccessible for the child. The professional experts, in this situation, try and put forth the situation where the child is to be changed and molded in the likeness of the parents. The child then must also learn to acknowledge the correctness of the decisions imposed on him/her by the parent or the professional and continue to live with those decisions (Corker 1998, 84).

Major decisions that are taken by the parents include the course of treatment that is adopted, post the diagnosis, which includes whether hearing aids and/or cochlear implants will be used or not, the decision to introduce the child and family to sign language from the formative years and the choice of school to enrol the child in, a hearing or a deaf one. These decisions, all taken before a child is 5 years of age has major repercussions on the rest of the life of the child. A deaf child who has not been exposed to sign language in the early years may face a lot of issues in schooling owing to the lack of any language growing up.

Since it is the parents who are the first instances that lead to exposure to the outside world, it is critical that in the formative years of the child, proper exposure is given. However, if there is a lack of proper communication between the very initial points of reference, then it becomes very difficult to build on anything from this stage further on. Needless to add, there has always been a problem of cultural transmission within the Deaf community, as more than often, the hearing parents of deaf children do not/cannot learn sign language. This creates a major communication gap that exists within the family. This can be easily rectified by teaching the parents sign language. However, the curriculum of sign language is not created keeping the parents in mind but rather it is aimed at the individuals who take up the learning of sign language in order to become sign language interpreters. Also there is a vast difference in teaching the deaf adults sign language and teaching it to native users. To the latter, it is akin to teaching it to a hearing person or teaching it as a second or third language. Sign languages are fast evolving languages and it therefore becomes mandatory for the parents to learn this form of language in order for deaf individuals to access the social networks, information and life in general (Corker 1998, 87).

A major trend observed in the field, pertaining to their education and choice and schools was that the students never seemed to settle for just one school and would constantly be shifting from one school to another. Most students would start with a government school for the first three or four grades, then change schools and finally end up in a private school at the end of grade 8th or 9th. However, closer inspection shows that the main defining factors in these cases were not a choice between a private and a government school but rather between a hearing and a deaf one. Most parents enrolled their children to a hearing school in the hopes that their child would be able to grasp and understand in a hearing classroom itself. But upon realization that the child is not able to study well, a change in the school is made, usually to deaf schools. However, this goes both ways; many parents put their children in deaf schools upon seeing that they are not getting any initiatives from the hearing ones, while many parents choose to enroll their child in a hearing school after they see that deaf schools work in a stereotypical manner.

The structures of the schools are also such that many government and a few private ones, especially the unrecognized, do not have all the grades present in them. Most are only till 5th or 8th grade, as a result of which, post this level, a mandatory change is required. Also, as mentioned above, distance to school, at least in the initial years, is a crucial factor. In this situation, parents are as hesitant to send young girls to far off schools on their own, as they are in sending their young deaf children. The parents however, play little to no part in their child's education once they are admitted into a school. Communication between parents and children is already very limited but post the children reaching slightly higher grades (around 5th grade or so), the parents completely pull away from any academic guidance. This is due to two reasons; the more general reason of the parents themselves not being educated and therefore unable to help. This reason holds true for not just parents of deaf children but of many children who may come from any kind of disadvantageous background. The second reason is specific to just the deaf children, where even if the parent wants to engage with the child and help in school studies, they are unable to due to lack of the proper vocabulary and signs that might be needed to explain a lot of concepts.

Another reason why parents preferred to send their children to government schools post a certain age was due to the coming up of the 'private tuitions', which need to be in place necessarily. Parents reason that when money needs to be spent on the education of the child outside school, why not send the child to a school that is relatively free and cheaper (Mousumi and Kusakabe 2017). But private tuitions are also not popular among these children as there are hardly any people outside of the special schools who are academically aware of the signs for a lot of things. So even if the parents want, they are unable to provide extra help to their children and so are entirely dependent on the schools to impart the knowledge and in this quest, a lot of students end up changing multiple schools.

Barriers Within School

In the course of their education, almost all the students went through a series of schools, which included both hearing as well as deaf schools. While the reasons for choosing one type of school over the other varied for each student, a major thread among all of these was the expectation of the parents. As children at that age are still young, so the major decisions regarding their lives are taken by parents. They would change since the distance was too much, or else, the reputation of the school was not good, and the crowd was bad. But the most important reason that leads to a lot of them leaving a school was the fact that they were not able to understand what was taught in school or else they were not able score well.

According to them, in the hearing school, there would not be any other deaf student in the class and they were the only ones requiring special provisions. In some cases, there would be another deaf student in the school, but in the case of the students interviewed, never in the same class as them. These hearing schools would make a few special provisions for these students. This would majorly include making the child sit in the front row and copy whatever was on the board. Over the course of my field work a narrative that has emerged over and over again was the question as to, did they understand what was being taught in the classroom and how did the teacher teach. The most common response to this would be;

> '*Teacher board write. I copy. If I understand not then ask friend*' (the teacher would write on the board. I would just copy it. If I did not understand, then I would ask my friends.)

Here 'understanding' does not mean that a concept was not understood. It more often than not meant that the student did not understand the writing of the teacher, or the spelling of the word.

> '*Teacher talk and teach. So I understand not. Write on board, then I copy quickly*' (The teacher would speak and teach and I would not understand anything. Whenever the teacher would write anything on the board, I would quickly copy that)
>
> '*Teacher say and teach. I understand not. Ask hearing friend. He tell not. I exam do well not. Hearing friend do well*' (The teacher would talk out loudly and teach the class and as a result, I would not understand it. When I would ask my hearing friends, many times they would not show their copies. I would not do well in my exams at all while my hearing friends would do well.)

Friends were also not a fool proof method of making sure you could get the class notes. Once it had been copied, it would be mugged up for the exams and the answers produced without understanding much conceptually. This method was able to work till class 5th, but post that when things started to get difficult, a majority of them shifted to deaf schools. Upon shifting to the deaf schools, they all got into the habit of conversing in ISL, and those who had not picked up the language previously would be helped to a great extent by their peers. Main forms of communication here among the students would be ISL and finger spelling and in the rare case it would not be understood, they would write it on a paper and converse.

A major reason for favoring lip reading and speaking over learning sign language is also to do with the professionals and educators in the field. The doctors and other professions involved in the early intervention of a hearing impaired child often do not mention Indian Sign Language as an option at all, and even when they do, it is stressed that it will only impede the learning of the child and their normal development. Parents are encouraged to make their children wear hearing aids so as to facilitate the success of education in mainstream schools (Friedner 2015).

Thus, major issue observed in the field was that the classrooms and the teaching environments were not very inclusive. The attempt to provide education to a child with deafness with tools that were developed for hearing students has always been a constant source of much discussion and debate. The presence of English (or any other language for that matter) in the classroom, where it is spoken and/or written puts the deaf children at a very big disadvantage (Lane 1999, 129).

Over the years, a lot of debates have existed over what form of education is beneficial to a classroom full of deaf children. Early audiologists were of the opinion that it was essential that deaf children also be included in the fold of the mainstream and the hearing population. Unfortunately, the decisions about how the deaf students should be educated were taken at events where the deaf were not even invited to. This is not unique to the deaf alone but is a common story for all disabled groups. However, what is even more disturbing is that due to the fact that children who could not hear would also subsequently grow up to be mute, it would be assumed that they did not have the required cerebral acumen to make rational decisions. In such a situation, it was always desired that they be integrated into the hearing world. They were unable to hear, but that did not mean they could not speak. These children were asked to lip read so as to not trouble other people.

In the two schools that were taken for the study, the main policy was that the teacher would write down whatever needed to be explained and then would try to break down those words into smaller signs to explain the concept. While this sounds like a good strategy, it is not actually as successful and useful as one would hope that it would be. In sign language, as is the case with any other language, just a literal word to word translation does not imply the same meanings. Also one needs to have a language as a reference point in order to grasp a new one. In the case of the deaf children however, they have either not been exposed to any spoken language or the language in which they have been talked to at home has not been assimilated in their vocabulary completely. The most natural language for them to pick up would have been sign language, and ideally other languages should be taught keeping Sign Language as base.

These issues, however, at the school level are nothing compared to the challenges they have to face at the level of higher education. While special schools have been considered degrading for a majority of disabled groups, the fact remains that deaf students need an entirely different mode of communication in the classroom, which cannot always be mainstreamed, at least for the few initial years of schooling. Post that, provisions can be made to have an inclusive set up of the classroom where both hearing and deaf students can be educated with the help of other assistive devices such as power-point presentations and the presence of a sign language interpreter. Unfortunately, at the level of higher education, neither a special college, nor accessible accommodations exist. As a result, a very few percentage of the deaf students go on to pursue their graduation from a regular college. The few who do go ahead with it opt for a distance learning approach. Learning from a distance learning platform, be it schooling or higher education, is helpful for them, as it allows the students to be able to pursue it at their own pace. They are able to sit for exams more than once and do not have the pressure of clearing the papers in order to move to the next level. However, opting for an open learning avenue should be a choice and not a compulsion, which is usually the case for deaf students. This absence of deaf students in higher educational settings has started to come to the fore especially when students with other physical disabilities are able to access these institutions. Lack of educated and informed deaf leaders also has been a cause of concern, as has been a lack of common grounds where deaf scholars can meet and interact. These are usually the educational institutions, and as shown by Chander (2011) in his work on blind students and the disability rights movement, it was usually in the schools that the students became aware of the discrimination at the collective level and mobilized themselves against it. However, this is yet to be seen in the case of deaf students and a lack of regular schools and colleges might be one of the reasons for it.

How Disability Studies Can Look at the deaf Question?

Disability Studies as defined by the Society for Disability Studies comes close to an ‘official’ understanding of this new field of study. According to them,

> Disability studies recognize the fact that disability is a key aspect of human experience, and that disability has important political, social, and economic implications for society as a whole, including both disabled and nondisabled people. Through research, artistic production, teaching and activism, disability studies seeks to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to advocate for social change. (Society for Disability Studies n.d.)

Within the disability studies it is believed that an active part should be played by disabled people in the course of the research projects as they are to be considered as an expert with the experiences of their life, feelings needs, etc.

Within the Indian context, as was the case within the western context, the emergence of Disability Studies has been through the Disability Rights movement itself. In India however, the disability rights movement has been predominated by a certain section of the disabled population, namely the blind and then the orthopedically disabled. Due to the heavy influence of the blind activists, the movement has been very centered around their needs and for providing accessibility to them. As a result, most institutions have been, or at least try to be accessible to the blind as well as the wheelchair users. Within the physical disabilities, the needs of the deaf population are not very well catered to. There emerge a plethora of ways in which the institutions and the society at large needs to be sensitized to the needs of the deaf.

One of the most crucial point that needs to be kept in mind while understanding the accessible needs of deaf is that many of them see themselves as being separate from the other disabled groups as they believe that they do not lack in anything physically. Any ‘issue’ with them is internal, is not manifested and visible. So they tend to distance themselves from terms like disabled. Based on this very notion of physicality, their needs then do not tend to be more towards the physical modification of structures, but rather is instilled in the modification of certain ways of doing things, namely, of modification of communication.

Emerging from the current field study, there are many areas where the school and other institutions could have been accommodating.

Proper Training of Teachers

The qualification of a teacher to be hired in a school setting is for him/her to possess a bachelor’s degree. However, the parents in the study by Mousumi and Kuakabe (2017) reported that none of the teachers in the private unrecognised school had any professional training. The principal of the school though earlier stated that the teachers were qualified but later confessed that if they hire a teacher who had a B.Ed. they would have to pay the teacher his/her salary also accordingly. In this case, the school fee would have to be hiked and it would be the parents who would complain (Mousumi and Kusakabe 2017).

Such a discrepancy was not openly observed in the field, but there existed very subtle nuances whereby the teachers, even though were qualified on paper but were unfortunately under-equipped to handle a deaf classroom. Being at the centre of a deaf classroom brings with it its own set of challenges. All the teachers that were appointed in the schools (both government and private) were required to have done at least a B.Ed in Special education, with specialization in Hearing impairment. The government offers this course through the RCI and is present in various colleges across the country. The entry point for such a course is for one to be a graduate and is a course that lasts for two years (four semesters). A quick glance at the course list shows a very comprehensive syllabus that covers a variety of topics that range from what is deafness, how to diagnose it, impact on society, impact on the children and so on (Rehabilitiation Council of India 2015).

What is often not noticed in the sea of these details are some very important observations. Firstly that the course is designed in such a way that the main focus is on how the individual who has acquired deafness needs to be treated at the earliest. It gives more importance to the ‘professional’ healthcare expert over the family. It talks about the counseling of the family members, but the focus is on how the family can help rehabilitate the deaf child over how the family should accept the deaf child as it is. This internalization of the course module by the teachers is very much visible in the classrooms. As one teacher from the government school once remarked to me

> ‘*yeh saari parents ki galti hai. Majority baccho mein toh sunne ka potential hota hai. Ab parents mehnat hi nahi karenge bacche pe toh woh kaise theek hoga? Agar shuru se hi bacche ko bulvane ki aadat dalo toh woh seekh jayega…*’
>
> (This is all the parents fault. In majority of the children, there is still residual hearing. But parents don’t take them to the doctors or do adequate follow up. Now in such a situation how will the child get alright? If you start teaching a child to speak right from the beginning, then he/she will definitely learn…)

The understanding of deafness as a disease which needs to be rectified is a strong sentiment among the teachers and they also hold very low opinions about what the parents do for their child.

Another issue in the curriculum of the special education course was the sheer absence of sign language. Though they are taught that sign language is an important tool which, in conjecture with other methods, can be a great way to educate the deaf children, they are not taught extensive sign language per se. They are given a short course on the various signs, but they do not communicate using the signs till they are actually appointed as teachers in the schools. Also, the signs are very general in nature and may not be able to tackle the technical nature of the course. As senior teacher at the private school informed me

> ‘*Humme kahan aate the saare signs. Itna toh koi bhi nahi sikha sakta. Main toh yahan pe bachho ko hi dekh dekh ke alag alag aur naye signs seekhi hoon…*’
>
> (We did not know all the signs, and to be very honest it is also pretty impossible to know all signs. It was when I came here that I started learning different signs from the children…)

Though she was trying to stress on the fact that as teachers they are also learning, but the bigger question here is, if the teachers are learning from the students, where are the students learning it from? This lack of authenticity of signs is a disturbing trend. Additionally, the paucity of signing in the classrooms by the teachers, does not present a very ideal picture.

Use of Sign Language and Interpreters

Deaf people essentially perceive the world through their eyes, so it is only natural for the Deaf community to develop and use a language that is based on visually perceived signs and symbols in order to communicate; vis-a-vis spoken languages that are based on sounds and characters. Linguistic research that has been conducted across the globe in the past thirty years has demonstrated that despite the general view of Sign Language simply being a series of gestures and signs, Sign Language is in fact a genuine language. It has grammatical rules and a complex sentence structure, and anything you are able to say in a spoken language you can also express through signs. The Indian Sign language is the sixth largest language in the world and there are approximately three hundred sign languages all over the world (Kumar et al. 2015).

As is the case with other Sign Languages, ISL is not a code, or a set of signs that represent specific words of a spoken language, but it operates on the principles of a visual-gestural language. It has its own grammar and idiomatic expression (National Association of Deaf 2013).

A very important aspect for ensuring that the educational avenues of the deaf students are successfully provided, one needs to understand that the most important aspect of their identity is sign language. It is the critical link that allows them to communicate with the world around them and is the first, if not the only, medium of expressing their emotions. Expecting the students to forgo this language and to instead adjust to another form of communication is not at all justified. In order to ensure that the classrooms are accessible for the deaf, the first step is to ensure that sign language is used for teaching purposes, and not a combination of written, spoken and signed words.

In case, it is a classroom consisting of only deaf students, then sign language should be the only mode of teaching. In case it is a mixed classroom with both hearing and deaf students, then the presence of sign language interpreter is one of the most critical aspects. It allows the deaf students to understand the concepts in a way that they are comfortable in and further will also make sure that they are able to grasp as well as question the concepts in the future.

Classroom Setup

The classrooms for the deaf students that were observed within the field were all in a linear fashion with all the seats facing in one direction towards the board. The teacher would be standing in front of the board, facing the class and the rest of the class would be one behind the other. When the students are sitting one behind the other, and one of them have a question, the teacher has to repeat what is being said as the students are also not able to see each other. In cases of it being a classroom based on verbal language, such an arrangement works very well as one does not need to be able to see a person directly in order to understand speech. However, in the case that it is a classroom based on sign language, it is more convenient if the classroom is either circular or semi-circular in nature. Such an arrangement, allows that all the students and the teacher are able to see each and so interact in a better manner.

Additionally when the teacher is often not trained in the sign language, it poses additional problems around what the correct signages of the words are. Teachers in the field would often be at a loss as to what the sign for certain words would be and would use the board or additional words to try and explain the meaning. In such a situation, it would be highly desirable if there is presence of a multimedia technology, which can be used to explain a lot of notions pictorially and graphically. Videos, with the help of subtitles can also be useful in the school environment, especially in a classroom where spoken language is anyway not the norm.

Additionally, the use of power-point presentations alongside normal teaching helps in students grasping the concept faster and they are also able to retain the information for a longer time. Within the field, a privately owned vocational centre was also studied, and there the teaching would be through the use of these technologies. In these places, the students were better able to understand the concepts as compared to the other students of the same age, who were in other educational centres.

Conclusion

Disability Studies and its impact have been very critical for the not just individuals with disabilities but also for all those who are engaged with the issues pertaining to disability. These include researchers, academicians, activists, the NGOs among others. The educational needs and the subsequent life choices that the deaf in India make depend to a very large extent on the kind of opportunities that are provided to them in the present. Therefore, it is critical that the their voices are also made part of the larger disability studies discourse in India so that efforts can made by to make sure that they are included in the changing nature of the education systems. It is here that Disability Studies can play a role by engaging with the difficulties faced by this section of the population and subsequently, thorough its varied means of knowledge dissemination, provide for alternatives. These alternatives may be new creations or alteration to existing norms. It is not just the physical structures, but also ways of looking at social structures, such as ways to communicate, that need to undergo change.

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Chapter 17
Examining the Experience, Barriers and Enabling Measures for Visually Impaired Visitors in Heritage Sites—A Study in the Indian Context to Enhance Accessibility and Inclusion

Kavita Murugkar, Anurag Kashyap and Abir Mullick

Abstract Architecture as the physical backdrop for the society to function, even today fails to address and include the considerations for people with disabilities. Particularly in India, stereotypes, stigmas, ignorance and poor understanding of the abilities and needs of the disabled has continued to marginalise this user group from the mainstream development. The reciprocal relationship between the social identity of persons with disabilities and the built environment has been overlooked in academics and practice, making their inclusion a distant reality. Interdisciplinary research, practise and education which can facilitate intersection of disability studies and architecture can help largely in changing the attitude of the larger society towards persons with disabilities. However, there is very little research conducted so far on Disability issues in the field of Architecture in India. This chapter discusses one such recently conducted research on understanding disability issues in Heritage Environments in India and is a part of a doctoral study in Architecture, under the Savitribai Phule Pune University, Pune. This study examined the frequency of visitation, past experiences, barriers encountered and preferred access measures or enablers by People with Visual Impairment (PwVI) in Heritage sites through a phenomenological approach. It followed an emancipatory disability research approach primarily grounded and exploratory with a quantitative as well as qualitative methodology. A telephonic interview method with the help of a semi-structured interview schedule was employed to get insights from 131 respondents from 41 towns/cities spread across the country. The experiences, perspectives, terms and opinions shared by the respondents were multidimensional highlighting the significance of intellectual access, multisensorial perception and physical access in the order of their impact. The findings of the study can be applied to develop Visitor and Heritage management strategies and related policy framework for People with visual impairment in Heritage sites.

K. Murugkar (✉) · A. Kashyap
Dr. Bhanuben Nanavati College of Architecture, Pune, India
e-mail: murugkar@gmail.com

A. Mullick
College of Architecture at Georgia Institute of Technology, Atlanta, USA

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Preamble

Architecture is not just about creating spaces for functional use and aesthetic experiences; it has a greater role in constructing social identities of people and communities. It impacts our day-to-day living and has been centrally concerned with both people's needs and desires. The design of the physical environment has a strong underlying social commitment, and the potential to facilitate social equity and inclusion by addressing the needs of all sections of the society. Architecture, from its basic purpose to protect human communities from the extremes of nature has evolved into a social medium for representing, constructing and communicating societal identity and cultural belief systems. However, in this course of development, it has largely overlooked the considerations for people with disabilities, thus creating negative identities and stereotypes around disability. Barriers in the built and unbuilt spaces continue to hinder people with disabilities on basic access and activities and marginalise them from the mainstream. The creation of Architecture that is unsympathetic to needs of the disabled has led to reinforce a prejudiced viewpoint towards them as the "abnormal" and forced them to become an almost invisible section of the society. Further, Disability is not institutionalised in the architectural discipline because the design practice, whose aesthetic focus is grounded in the 'perfect body' like the 'Modulor Man' (Le Corbusier 2004), has difficulty dealing with the aesthetics presented by disability. Disability is persistently framed, both by 'normal' social and spatial practices and by architecture's own internal discourse that affects the usability of disabled people, in a way what Tanya Titchkosky calls 'included as excludable' (2011). Such an attitude has further overshadowed the role of built environment as an agent of empowerment for persons with disabilities.

Particularly in the Indian scenario of architectural education and practise, the idea that the physical environment must be designed for all types of people irrespective of their abilities and differences is rarely taught in the schools of architecture and minimally practised by professional architects. Owing to lack of knowledge and awareness, majority architects treat disability in a stereotypical and mechanical way, and as an 'add-on or after-thought' with minimal significance to the design process. There is an urgent need to sensitise and educate architects on this issue along with a need to change the ways in which built environments are designed and facilitated, in order to promote inclusion and avoid environmental barriers responsible for discrimination and environmental oppression. Without such a fundamental change, architecture shall continue to create and reinforce misrepresented identities of people with disabilities and deprive them of their right to live with dignity. Architectural discipline grounded in socially responsive education and practice must downplay the market-driven emphasis, for the opportunity to create design innovations adopting a focus on disability, human differences and cultural diversity. Interdisciplinary research, practise and education which can facilitate intersection of disability studies and architecture can help largely in changing the attitude of the larger society towards Persons with Disabilities and in creating inclusive policies. Disability focused research on environmental design can further the awareness and knowledge about the abilities and needs of people with disabilities in the field of architectural education and practice. However, very less research has been conducted on Disability issues in the field of Architecture in India. This paper discusses one such recently conducted research on understanding Disability issues in Heritage Environments in India as a part of a doctoral study in Architecture, under the Savitribai Phule Pune University, Pune. The larger intent of this study is to apply the interdisciplinary research for developing socially inclusive Visitor and Heritage management strategies and related policy framework for People with Disabilities in Heritage sites.

Introduction

Conservation and Management of Heritage monuments and sites is a growing niche in the architectural practice in India owing to its rich repository of ancient cultural and built heritage. From the common man's view, Heritage sites are becoming popular places to visit, providing recreational, social and educational experiences apart from being sites of presentation and protection. Scholars worldwide have acknowledged Heritage as a Universal cultural resource, belonging to all and have catalogued the potential benefits of Heritage site visits which include education, relaxation and opportunities for social bonding (Beecho and Prentice 1997; Dierking and Falk 1992; Masberg and Silverman 1996; Prentice et al. 1992). Correspondingly, Heritage sites are regarded as one of the most significant and fastest-growing components of tourism (Alzua et al. 1998; Herbert 1995). Many scholars have argued that Disabled people are entitled to same cultural life as the rest of us and their right to it is inalienable (Weisen 1991) and that Heritage sites must provide 'equal opportunity to enjoy the benefits'(Groff and Gardner 1989). International and national policies have also pressed upon inclusive heritage management practices to address the needs of the disabled. For example, the UNESCO-ICOMOS charters (1999) mandate ensuring physical, intellectual and emotive access to Heritage sites to all visitors irrespective of their differences. The United Nations Convention for Rights for Persons with Disabilities (UNCRPD 2006) clearly advocates to make all world heritage sites, national monuments and historical sites accessible to all. Indian laws namely the Rights for Persons with Disabilities Act (RPwD Act 2016) and Ancient Monuments & Archaeological Sites and Remains Act, 2010 have made it mandatory to make all public buildings and amenities including Heritage sites accessible. However, Heritage sites worldwide have historically deprived equal and dignified participation of people with disabilities as a virtue of their design, setting and management and still continue to exclude them.

With 37 World Heritage sites listed by the UNESCO and 44 on the tentative list, India is gaining rapidly in tourism value internationally. Apart from the World Heritage Sites, there are more than 3650 ASI (Archaeological Survey of India) listed national monuments spread across the country and countless state and local level heritage sites. But as a matter of fact is that even today, not one of the World Heritage Sites in India has been made universally accessible to the entire spectrum of People with Disabilities, including the most visited Taj Mahal. Changes to the historic environment continue to be guided by conservation theories and principles in which disability interests are not formally represented (Goodall 2006). Any adaptation of a heritage environment to accommodate accessibility measures for the disabled has been perceived as a threat to its historical and architectural values. The outcome of this is seen in the form of significantly less participation of people with disabilities in cultural life (Darcy and Taylor 2009); the primary reason being poor understanding of their needs, abilities and nature of experience (Darcy 1998, 2003).

A large part of research on heritage tourism and management has focused on understanding the motivations, needs, behaviour and experiences of able-bodied visitors (Urry 1990; Barbara and Silverman 1996; Poria et al. 2003). However, very few have studied visitors with disabilities contributing to the subject of Accessible Heritage tourism (Darcy 1998, 2003). Few research works that have focused on visitors' experiences, mention that there appears to be a lack of understanding of 'visitors' perspective on the experience of visiting a heritage site' (Silverman and Masberg 2001), and also of how visitors define a heritage site and what the activity of visiting a heritage site means to them (Moscardo 1996). However, people with disabilities were not included as visitors in the studies mentioned above. Thus, Disability has been a neglected subject within tourism enquiry and cognate fields (Aitchison 2009) till recently where one can see a growing focus in tourism on social justice, equality and citizenship (Cole and Morgan 2010). Darcy (2002) too detects an emerging interest amongst scholars, probably in response to the greater 'visibility' of Disability issues in mainstream societies, yet disability research remains on the margins of tourism scholarship.

Further, past studies point out that there is an inherent bias towards the experiences of those with physical impairments. As it is apparent in both the policy and academic literature, much of the discussion around access in Heritage sites pertains to access for the physically impaired. Amongst the impairment groups, people with vision impairment (PwVI) are particularly marginalised in tourism scholarship (Small and Darcy 2010).

It is normally expected that the people with visual impairment may not be able to comprehend an unfamiliar built environment like for instance 'the heritage sites'. Such a viewpoint leads to attitudinal barriers that result into no efforts taken to incorporate their needs in the heritage management plans, thus depriving people with visual impairment from experiencing the heritage sites. There are studies that have explored the visitor's perspective—their own terms, discussions and meanings related to heritage site visits (Silverman and Masberg 2001; Richards 2013). Studies which examine the heritage site experiences of People with visual impairments are very few and none in India. As per James Gibson's Theory of Affordance, the interaction between people and the built environment depends not only on the physical form of architectural elements but also on the observer's past experiences, beliefs, preferences, etc.

Non-availability of primary data about visitation of people with vision impairment in Heritage sites in the Indian context and little or no understanding of their abilities, needs, nature of experiences were the issues that became the motivation behind this study. Accordingly, this research was designed to inform about the present nature of visitation and experience of people with visual impairments in Heritage sites in the Indian context, including the barriers encountered by them and their preferences with regards to accessibility while visiting and exploring heritage sites.

Objectives of the Study

There were four objectives. Objective one was to examine the frequency of visitation of PwVI in Heritage sites in the Indian context. The second objective was to document the opinions of PwVI about their past experiences and satisfaction levels of visiting heritage sites. The third objective was to identify the exact nature of barriers and obstacles affecting the accessibility of PwVI in heritage sites. The fourth objective was to identify the preferences/needs of PwVI in terms of access measures or enablers that can enhance their experience of visiting heritage sites.

Methodology

Past researchers have emphasised on the potential of applying the phenomenological approach in studying visitor experiences as it uses the perspective of the individual experiencing the phenomenon to discover the structure of the phenomenon (Husserl 1911; Heidegger 1962). In words of Masberg and Silverman (1996)—'Understanding emerges from information, rather than being directed by theories, laws and concepts'. Individual values and mental constructs are studied to derive meanings through a phenomenological approach (Wilson and Slack 1989; Seamon 1982). Research based on quantitative approaches could be 'divorced from everyday life' (Fishwick and Vining 1992) and may not give accurate results with respect to visitors' experiences (Pickles 1985; Schreyer et al. 1985). Hence, a phenomenological and exploratory research with an emancipatory disability research approach (Kitchin 2000) was adopted to collect qualitative as well as quantitative data related to the enquiry. The study's emancipatory disability research philosophy placed visual impaired people's voices at its heart as the study's co-researchers or experts, iteratively guiding and informing the research and analysis, and aspired to conform to Barnes' (2004) test of truly emancipatory research, namely that it is empowering and creates knowledge that has meaningful and practical outcomes for people with disabilities. It used the telephonic interview method with the help of a semi-structured interview schedule consisting of open-ended and closed questions to get a holistic understanding of the experiences, barriers encountered and access needs of visually impaired visitors in heritage sites. The respondents in this study included People with Visual Impairment between the age group—18 and above, both people with blindness (by birth and late) and people with low vision, mainly from urban and semi-urban areas from across the country.

The sample of respondents represents a diverse population of people with visual impairments with respect to the personal characteristics such as age, gender, type of visual impairment, braille literacy, status of mobility training, light perception, education and occupation. The relationship between the personal characteristics of the PwVI and their frequency of visitation, past experiences, barriers and access needs were also statistically studied.

Since the study dealt with human subjects, ethical protocols were followed. Confidentiality and anonymity were mentioned in the consent letters and approval for the tools and protocols sought from the ethical committee.

Post a pilot face to face interview stage, the semi-structured interview schedule was prepared. This was then administered telephonically to 131 respondents with visual impairments spread across the country by network sampling, to collect data on the frequency of their visitation, past experiences and barriers/obstacles encountered in Heritage sites in India. The qualitative data consisting of descriptive answers, collected from open-ended questions was analysed using constant comparison method. The responses collected were read repeatedly until a comprehensive set of themes and subthemes emerged for each question. Routine to any qualitative research, the aim of the data analysis was to 'understand the people studied' and extract meaning from the responses shared (Patton 1990) to arrive at 'categories and themes that were grounded in the collected visitor's experiences' (Silverman and Masberg 1996). The quantitative data collected was statistically analysed by coding and using IBM SPSS 23 software.

The key questions posed were—

For studying the frequency of visitation—

- How often do you visit a Heritage site?
- If you have never or rarely visited a Heritage site, please share the reasons for the same.

For studying the past experiences in heritage sites—

- How would you rate your past experiences of visiting Heritage sites? Please share reasons for the same.

For studying the barriers encountered—

- Rate the inconvenience caused by barriers/obstacles you encountered within the Heritage site premises during your past visits? (A list of 19 barriers was given and respondents were asked to rate them on a 5 point likert scale.)
- If there are any other barriers/obstacles you have encountered, but not listed above, please describe.

For studying the preferred access measures/enablers for enhancing the experience in heritage sites—

- Rate the importance of the following accessible facilities in a Heritage site visit? (A list of 16 access measures was given and respondents were asked to rate them on a 5 point likert scale.)
- What more measures will you suggest (other than the above listed) for improving the experience and accessibility of a Heritage site for a visually impaired visitor?

Analysis

A total of 131 respondents were interviewed and included for the purpose of analysis. Out of the total respondents, almost three-fourth (73%) of the respondents had total blindness while more than one-fourth (27%) had Low Vision. Amongst the totally blind, 38% had blindness since birth followed by 35% of them having acquired/late blindness. The sample comprised of 61% men and 39% women of which maximum that is 38.8% of the male respondents had acquired/late blindness while maximum that is 47% of the females had blindness since birth.

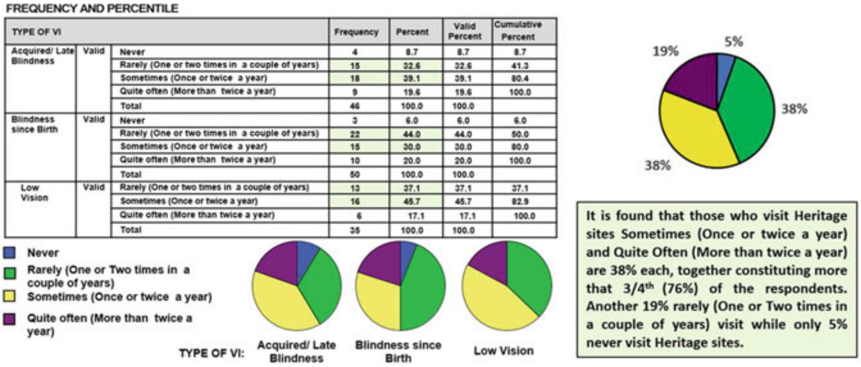
Frequency of Visitation to Heritage Sites

It was found that more than three-fourth (76%) of the respondents have been visiting Heritage sites with about 38% visiting sometimes (once or twice a year) and another 38% visiting quite often (more than twice a year). Another 19% rarely (once or twice in a couple of years) visit while only 5% have never visited heritage sites. The results indicate the interest in visiting Heritage sites by maximum respondents. The results also challenge the stereotype assumption that PwVI hardly visits heritage sites. Cross tabulation results across age groups reveal that with increasing age, the number of sites visited by respondents is also increasing. Increasing frequency and interest in visitation was found among respondents from 18–25 years to 26–45 years age groups, while maximum frequency of visitation was found among the 26–45 years age groups (Table 17.1).

Qualitative analysis of the descriptive reasons shared by respondents for never or rarely visiting Heritage sites revealed many reasons. Inaccessible information, inaccessible physical infrastructure, lack of trained guidance and lack of opportunities for multisensory experience were the primary and most common reasons for the same. Personal issues such as lack of time, poor interest, fear, dependence and old age were also cited as reasons for poor/reduced visitation to heritage sites.

Some of the respondents' views for never or rarely visiting heritage sites, that bring out the above reasons that discourage PwVI from visiting heritage sites, are as follows:

Table 17.1 Frequency of visitation to heritage sites



FREQUENCY AND PERCENTILE

TYPE OF VI			Frequency	Percent	Valid Percent	Cumulative Percent
Acquired/ Late Blindness	Valid	Never	4	8.7	8.7	8.7
		Rarely (One or two times in a couple of years)	15	32.6	32.6	41.3
		Sometimes (Once or twice a year)	18	39.1	39.1	80.4
		Quite often (More than twice a year)	9	19.6	19.6	100.0
		Total	46	100.0	100.0	
Blindness since Birth	Valid	Never	3	6.0	6.0	6.0
		Rarely (One or two times in a couple of years)	22	44.0	44.0	50.0
		Sometimes (Once or twice a year)	15	30.0	30.0	80.0
		Quite often (More than twice a year)	10	20.0	20.0	100.0
		Total	50	100.0	100.0	
Low Vision	Valid	Rarely (One or two times in a couple of years)	13	37.1	37.1	37.1
		Sometimes (Once or twice a year)	16	45.7	45.7	82.9
		Quite often (More than twice a year)	6	17.1	17.1	100.0
		Total	35	100.0	100.0	

It is found that those who visit Heritage sites Sometimes (Once or twice a year) and Quite Often (More than twice a year) are 38% each, together constituting more that 3/4th (76%) of the respondents. Another 19% rarely (One or Two times in a couple of years) visit while only 5% never visit Heritage sites.

Fear of getting hurt and fear of getting undue importance.

I don’t enjoy much because I can’t understand it much even if only explained as it is not a first-hand experience.

I really like visiting heritage places but the problem is that there is no one to describe. If I am given a good and a proper description and told then I would enjoy a lot. Also, these spaces are not that accessible to go on your own. So, you need someone to take you. And even if you take someone, these people are interested in seeing it themselves than patiently describing the various elements to you.

It does not excite me to visit such sites. Because the guide only talks about the historical facts, he is not descriptive, they generally do not describe the architecture, culture, style, colours, textures etc.

Firstly, the information can be taken from net and other resources. At most of the places touching the elements is not allowed so it becomes difficult to understand.

It could be because there is nothing more that a VI can do there, there is very less that we can learn and know about it because of lack of information and guidance in accessible format. This very reason has reduced my interest in visiting heritage sites. Only when some family member takes me, I visit.

I used to visit a lot before I turned totally blind in 2013. But after that I have not visited any sites, reason being I have to depend on somebody to take me, secondly sites are not accessible, I don’t get information, hence no satisfaction.

The guides at the site are ignorant of our needs. They should be able to give an imagery about the site, so that we can imagine the place. Only touch can’t give the total experience of the architecture of the site. We only get a birds’ eye view of the site. I should feel mentally comfortable, more than accessibility. These places make me feel literally like a disabled person.

When I visited Taj, it was extremely crowded. The Taj being a tomb, the voices echoed, and it was claustrophobic. It was extremely uncomfortable, and I wanted to get out of there. I study disaster management so when I look at them from that point of view, it gets me worried. I don’t like contrivance too. I visited a manufactured village, I found it very fake and exploitive. I usually avoid going to places where there no provisions for people like me. I like to travel alone or with one or two people, so when I am travelling alone there are barriers, I feel disappointed.

Not many but merely one respondent felt that his visual impairment was the reason he refrained from visiting heritage sites. One of the respondents shared that only out of compulsion would she visit a heritage site. She says—

> I would visit only out of compulsion. When somebody is available to accompany me, I go. I don't get enough information, so it is more like just walking. So I rather prefer to read at home about it and prefer to skip it. Experiential visits interest me (Table 17.2).

Cross tabulation with respect to gender reveals that male respondents have visited more Heritage sites than female respondents. It also points out that females not seen visiting as much as males, probably due to safety concerns and more dependency, thus hesitance in travelling alone and in groups unless accompanied/assisted by someone reliable and known.

Satisfaction and Past Experiences of Visiting Heritage Sites

Survey on the perceived satisfaction level of the past experiences of visiting Heritage sites revealed that 40% of the respondents had largely unsatisfactory experiences of visiting Heritage sites in the past and 7% had no satisfactory experience, while 38% of them had largely satisfactory experiences and 15% had fully satisfactory experiences.

Qualitative analysis of the descriptive reasons shared by respondents revealed the following as the primary factors for the high satisfaction levels based on frequency—

1. Availability of good informational accessibility;
2. Visiting Heritage sites was a new experience, change from the routine, mundane life;
3. Opportunity for multisensorial experience; and
4. Provision of infrastructural accessibility.

Qualitative analysis of the descriptive reasons shared by respondents revealed the following as the primary factors for the poor satisfaction levels based on frequency—

1. Poor maintenance and site management issues leading to discomfort;
2. No or lack of informational accessibility thus creating dependence;
3. Lack of multisensory experience;
4. No or lack of infrastructural accessibility;
5. Personal limitations like visual impairment, insufficient or no preparation before visiting the heritage site, etc.; and
6. Insensitive and stigmatising behaviour by sighted visitors and untrained staff.

The above factors for the poor satisfaction levels have been abstracted from the numerous and detail feedbacks given by the respondents. Some of the most insightful ones are mentioned below:

Table 17.2 Reasons for satisfaction/dissatisfaction in past experiences of heritage site visits

Variable	Total frequency/percentage	Super-ordinate themes	Sub-ordinate themes
Positive			
Reason for past experience satisfaction level (Positive)	69/53%	Informational accessibility	Liked the information and related experience
			Information provided by companion
			Information by sensitized guide
			History
			Can pass the information gained to my students
		For a change/new experience	Holiday/meet new people/companion
			Sense of accomplishment/new experience/change of routine
			Self planning
			Mobility devices
		Multisensorial experience	Ambiance of the environment/architectural design
			Experiential/sensory elements
		Infrastructural accessibility	Good infrastructure
			Service design
Negative			
Reason for past experience satisfaction level (Negative)	62/47%	Maintenance/site management	Management and discipline/crowd management
			Lack of maintenance
			Stigmatizing behavior and attitude of people
			costly facilities
		Informational Accessibility/dependent	Insufficient/inaccessible Information/directional signage
			Lack of good and sensitized guides

(continued)

Table 17.2 (continued)

Variable	Total frequency/percentage	Super-ordinate themes	Sub-ordinate themes
			Need to depend on human guides, companions who might not be that interested in the site
		Lack of sensory experience	Lack of tactile experience
			Can't experience element out of hand reach
		Infrastructural accessibility/dependent	Inaccessibility infrastructure
			Inaccessibility to reach the site
			Own blindness/site itself is inaccessible
		Other reasons	Insufficient or no preparation

There is no way through which the place is described to us. When people are with us they like to see places and do not describe it to us. It is often said that the "place is beautiful." It is never understood what is the thing that makes the space beautiful in the terms that I can understand. Is the shape beautiful? If it is described, I can then decide whether it is beautiful for me or not.

We ourselves can't experience as much as a sighted can. Most of the places are not allowed to touch so we can't experience them directly.

Tactile experiences are lacking

No access to information… no alternate arrangements for communicating to the blind.

VI person uses the other senses to perceive, mainly by touch and environment, but the heritage site is so huge that the concept is never completely understood, you can touch only a part of it. Unless a model is provided… e.g. at Taj Mahal the whole structure model and its details are available to touch and feel outside the monument same for Petronas Tower. Since Tactile Models are not provided at any of the sites, the experience is incomplete.

There are barricades everywhere and opportunity to touch is very limited and I have to argue everywhere with the authorities to allow me to touch.

A proper explanation, synopsis should be available in audio format, which is never available.

Lack of empathy from the surrounding people, staff…. people make me feel awkward.

No exemption from queues.

Lack of accessibility, a lot of visual experiences only - no multi-sensory options, not allowed to touch a lot of things at lots of places.

1. Inaccessible environment.
2. No clear information is provided.
3. Have to cope with others in the group who are not that interested in the site

> Insensitive people at the site (Ask why have you come when you can't see?). The company with whom I go is the only reason for satisfaction.
>
> My negative experiences include things that hit me on my head, foot, but I don't mind it, I enjoy this. My friend could give me only limited information and I am keen on getting more information.
>
> During my visit to Jantar Mantar a few of our group members lost track. We were looking for them for about an hour.

Cross tabulation results showed that satisfaction was decreasing with reducing vision and least amongst respondents having blindness since birth. This finding indicated that absence of vision as well as substituting accessibility measures negatively affected the quality of experience for PwVI leading to poor satisfaction. Cross tabulation results also showed that satisfaction for past experiences of visiting Heritage sites was increasing with age, indicating more tolerant and adjusting nature with age and less complaining attitude. Awareness and expectation related to access rights and needs are less in senior groups, hence satisfied with merely the opportunity to visit. Further, senior age groups have better wayfinding, navigation and coping skills, 'world view' developed over time, leading to better perception and experience and hence satisfaction. Whereas younger groups were found more aware and vocal about their expectations from the Heritage sites and absence/lack of accessible information and infrastructure was found affecting their satisfaction levels. Another reason for age impacting the satisfaction level of the experience could be the quality of assistance and companionship. As senior age groups mostly visit with companions/families who serve as guides, human assistance, their satisfaction levels are higher compared to the younger groups who move in their own groups of same age and exposure, mostly with friends, who rarely guide in depth and detail. It was also observed that satisfaction has decreased with more educational background, indicating awareness about their access rights and needs is increasing with more education and thus more exposure. Hence expression of disappointment over non-provision of accessibility measures.

Satisfaction was also found to be less amongst the respondents who have taken mobility training compared to those who have not taken mobility training. This finding revealed the influence of mobility training on a PwVI's expectations. Mobility training brings along with it the awareness about possible accessibility provisions, and their absence makes them handicapped in spite of having the skill to independently navigate and experience a heritage site. However satisfaction of visiting Heritage sites had no relation to braille literacy of the respondents as similar pattern was found within all groups, indicating lower tendency to prefer and use braille information, for reasons like it is time consuming to read braille, not all read braille, difficulty in locating braille information and preference to audio information.

Barriers to Access in Heritage Sites

Respondents were asked to rate the extent to which the suggested barriers/obstacles affected their access and hence the perception and experience of visiting heritage sites, on a five-point Likert scale. A list of 19 barriers was given to the respondents covering barriers for physical as well as informational access. It was found that absence of trained guides at Heritage sites is perceived as the most affecting barrier for majority of the respondents followed by absence of informational access measures such as audio signage, absence of audio tactile map/model and accessible information, followed by absence of handrails and presence of physical barriers like overhead obstacles, unguarded elements, slippery pathways and abrupt level differences. Overcrowding and chaos were also seen being rated as one of the most affecting barriers as much as physical barriers. Further, poor colour contrast, inadequate lighting, and absence of braille signages emerged as barriers for lesser number of respondents. However, they are still barriers for some proportion of the respondents particularly visitors with low vision (Fig. 17.1).

Qualitative analysis by constant comparison method of additional barriers identified by respondents, affecting the physical and informational access in the heritage site for a visually impaired visitor can be grouped in the following categories, numbered based on highest frequency: 1. Inappropriate Site Management and Services, 2. Inaccessible Physical Infrastructure, 3. Lack of support and insensitive attitudes, 4. Lack of or no Informational Infrastructure, 5. Environmental Issues (Table 17.3).

Some of the category-wise important concerns/barriers shared by respondents in addition to the list of barriers presented to them are as follows—

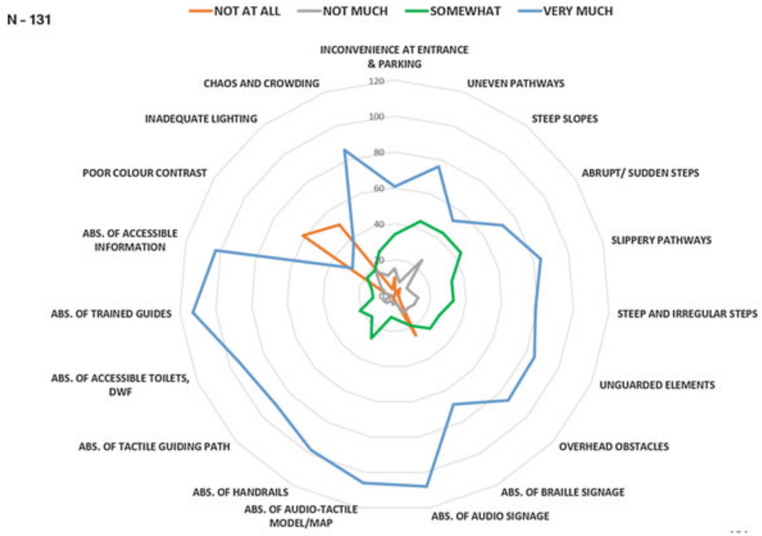


Fig. 17.1 Barriers to access in heritage sites

Table 17.3 Additional barriers to access in heritage sites as suggested by respondents

Variable	Total frequency/percentage (N-131)	Super-ordinate themes	Sub-ordinate themes
If there are any other physical barriers/obstacles you have encountered, but not listed above, please describe?	53/40.45%	Site management and services	Stray animals/vehicle parked everywhere/people bumping/unprotected construction going on the site
			Uncovered drainage/cleanliness and maintenance
			Sensory overload/loud speakers
			Things that are out of our hand reach or not allowed to touch/under glass cases and covered displays
			Costs that i have to pay for aids, human assistance, guide
			Inconvenience due to queues
		Physical infrastructure	Thresholds/no colour contrast at the steps/no curb ramps at the end of pathways, collapsible gate
			Faulty accessibility provisions—improper installation of TGP/inaccessible toilets/handrails not provided on both sides
			Narrow pathways/vehicular and pedestrian route conflicts
		Human support and attitudes	Stigmatizing attitudes by people extra care by people, guide/irresponsible guides/misbehavior by people

(continued)

Table 17.3 (continued)

Variable	Total frequency/percentage (N-131)	Super-ordinate themes	Sub-ordinate themes
			No human assistance at heritage site
		Informational infrastructure	Absence of large fonts/insufficient information/directional cues
		Environmental issues	Glare/harsh sunlight

Inappropriate Site Management and Services

> Stray animals. Some animals lying down on the way a few times during my visit to few sites.
>
> Crowding also creates a lot of noise, so a little organised crowd can make things easier.
>
> Vehicles parked in the way, vehicular and pedestrian route conflicts, specially while crossing the roads, cannot identify the place, it's entry point.
>
> Sensitization and training of managerial staff is very important…their unawareness creates a lot of issues.

Inaccessible Physical Infrastructure

> Sudden drops and drains which are difficult to identify, also sudden edges, protrusions. These can be dangerous.
>
> Poor Quality of Tactile Path. Improper depth to the tactile tiles, thick shoes cannot identify the tactile tiles well, thus does not become useful for wayfinding.
>
> Toilets without audio signage. I use a tumbler full of water, pour it out and follow the sound to identify the WC.
>
> Physical barriers are the greatest hurdles for a blind.
>
> Things under glass cases, cupboards, display cases are not accessible…

Lack of Support and Insensitive Attitudes

> People decide for us, where we should go, where not to go etc., this is not acceptable.
>
> Inconvenience caused in asking for human assistance. ID card to be shown. Lot of quarrels happen over this and spoil the whole experience.
>
> Comments by people – "look there is a blind walking, move out…" We don't like to showcase our disability. The inclusion must be smartly handled.

> Sometimes the staff are overcautious, so create a mess then, the attitude and perception of people.
>
> Irresponsible/untrained guides have led to accidents in the past (being misguided). Have head injuries, have fallen.
>
> People are the main barriers between us and the accessible facilities.

Absence or Lack of Informational Infrastructure

> I don't prefer Braille boards much. I prefer the guides more. I can't keep sitting and reading it in Braille. It takes a lot of time to read in Braille. Also, I don't want to look different. I don't want to become a centre of attraction. I want to know the information in brief and move on for the next part.
>
> I do not rely on the human description by the companions or the guides because it may vary from person to person and the state of mind, they are in. I am weary of second-hand experience.
>
> Braille is must near toilets, otherwise I have to ask somebody for every small thing.

Environmental Issues

> Too many colours disturb me, it creates an illusion, it makes me feel giddy. Mainly the stairs. Also too much sound becomes confusing and doesn't help more.
>
> Loud speakers, distance can't be identified because of loud voices.

Preferred Measures/Enablers for Enhancing Experience and Accessibility in Heritage Sites

Respondents were asked to rate their importance/preference of the various accessible facilities at the heritage site that could augment the perception and experience of PwVI in heritage sites, on a five-point Likert scale. A list of 16 access measures was provided. It was found that audio signage and navigational systems have been given the highest preference by maximum respondents, followed by provision of trained guides, audio tactile model/map and handrails and railings. Colour contrast is the least preferred accessibility measure owing to its non-usefulness for the totally blind respondents. However, it was found equally of much importance for respondents with low vision (Fig. 17.2).

Qualitative analysis by constant comparison method of additional preferences suggested by respondents that can augment the perception and experience of PwVI in Heritage sites are grouped in the following categories and numbered based on

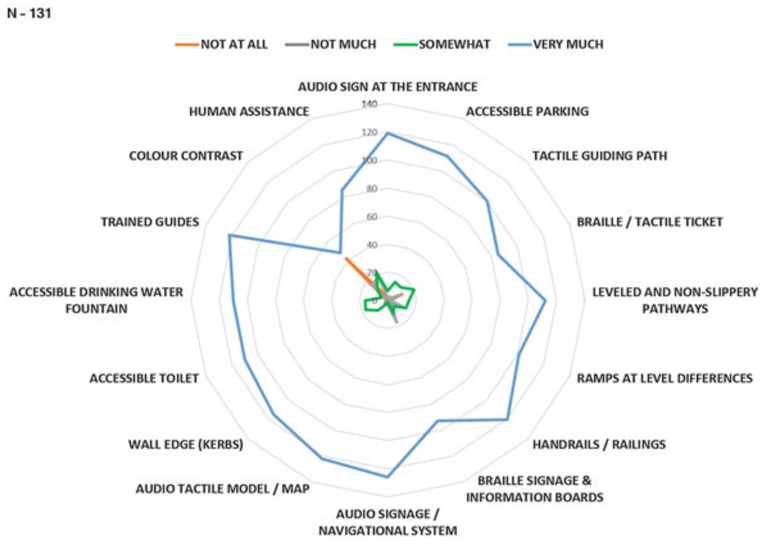


Fig. 17.2 Preference to access measures/enablers in heritage sites

highest frequency: 1. Informational Infrastructure, 2. Human Support and Attitudes, 3. Site Management and Services, and 4. Physical Infrastructure (Table 17.4).

Some examples of the category-wise concerns/measures/preferences for improving experience and access, suggested by respondents in addition to the list presented to them, are as follows:

Informational Infrastructure

> Complete, detailed information regarding the monument should be given to us, otherwise an incomplete image of the monument is formed.
>
> Stages of evolution of the historical site must be also conveyed through audio - tactile models. The previous and the present will be understood only through such an experience. I would also like to know how the site has reached its present state and what it was years before.
>
> Mobile app for easy and independent navigation, information finding and exploring on my own.
>
> Tactile models, audio guides help in a way if they provide necessary and more description. The speed of the audio guide does not match most of the times. They can bring a space alive. Braille boards are good but the percentage of users is very less. Also the realization of a Braille board being present is important. Whereas audio guides are more universal and not only are the blind benefitted, also are the sighted.
>
> Online information about the site and it's accessibility.
>
> Latest technology like beacons can be used for navigation system, as it is a good value addition without disturbing the heritage site, also at a nominal cost.
>
> A short film or documentary about the site can be shown before the guided tour.

Table 17.4 Additional Access measures for improving experience in heritage sites as suggested by respondents

Variable	Total frequency/percentage (N-131)	Super-ordinate themes	Sub-ordinate themes
What more measures will you suggest for improving the experience, understanding and accessibility of a Heritage site for a visually impaired visitor?	61/46.56%	Informational infrastructure	Mobility aids within the site/audio beacons/magnifying provisions for details/seating provisions at the site
			Interpretation centre, virtual reality, facilitation centre etc.
			Website accessibility
		Human support and attitudes	Training and sensitization of staff and caretakers/management
			Intent and implementation are two different things/maintenance
			Training and sensitization at school level and in masses
		Site management and services	Permission to touch
			Service designed tour for site, short film before the tour/making sure if construction is going on to guard it properly
			Crowd management
			No cost implications
			Separate queue lines at service counters
		Physical infrastructure	Accessible means to reach the site
			Wider pathways

Audio guided tours mostly consist of the historical information, does not really describe the appearance, aesthetics, also the local culture, the dynamic values are better explained by human assistance.

The description must include information about colours and visual features in detail.

Smaller replicas of large installations can be showcased for the blind.

Human Support and Attitudes

> Disciplining, sensitizing people and making them aware about the purpose of these provisions, as most of the times, people are the main barriers between us and the accessible facilities.
>
> Training and sensitization of existing staff is important, rather than providing special guides at additional cost.
>
> Because it is a new environment, human assistance will still be required as it can save time to navigate and see the whole site.

Site Management and Services

> Open display and permission to touch as many things as possible. Replicas i am not so fond of, as it can only give an idea, but not the real feel. Even audio can help in a very limited way….
>
> Non latex surgical gloves can be used to touch original artefacts where necessary.
>
> If some kind of facilitation centre is provided where according to our needs facilities are provided with regards to information and other facilities it would really help.
>
> Facilitation counter, a well-planned movement and service design that can save time and effort…sensitization and training of the staff, caretakers.
>
> We should be granted permission to visit even the smallest of all the places. If there is a risk involved, then proper security should be present.
>
> Proper maintenance is extremely necessary, the litter, the stinking smells are intolerable.
>
> Cleanliness and maintenance of accessibility provisions specially handrails.
>
> Special tours should be arranged for the visually impaired.
>
> Guidance about route, time management.
>
> Exemption from the queues.
>
> All provisions must be given for free to the visually impaired, not to be charged or at a cheaper cost.
>
> Getting an entry ticket in a crowded environment is extremely herculean task, online ticketing must be practised everywhere.

Physical Infrastructure

> Disabled people must have access to all areas of the site, it is very disappointing to hear, “You can’t go there.” Wherever a sighted person can go accessibility for the disabled must be extended.
>
> Beepers at obstacles, so that the intensity of the beeper helps you to understand the obstacle.
>
> The nearness, convenient accessibility of toilets and drinking water fountains is very important. Locations far away cause lot of inconvenience.
>
> Magnifying provisions at the site to enjoy detail at the site.

> The tactile path must be constructed properly. A wrongly made path can lead to accidents. Maintenance and sustenance of the accessibility measures is equally important.

The array of responses listed above covering the length and depth of the access needs of PwVI can be extremely useful pointers for developing not just appropriate informational and physical infrastructure but also for upgrading the overall upkeep, maintenance and human support much needed for PwVI.

Discussion

This investigation related to the experience of people with visual impairments in Heritage sites in the Indian context offers a comprehensive understanding of how often the PwVI visit heritage sites; what have been their past experiences; what according to them are their major barriers/obstacles that hinder their experience and what are their expectations/preferences for enhancing their experience and accessibility in heritage sites. The results reveal the multidimensional nature of the experiences of PwVI in heritage sites. The study as a whole, yielded a significant amount of data to draw general conclusions, both from the point of view of the heritage conservation and management as well as the user experience in heritage sites.

- On the question about the frequency of visitation of PwVI in heritage sites, the research findings indicate sustained and growing interest and visitation to Heritage sites by PwVI, in spite of their visual impairment. Further suggesting that PwVI is a potential tourist/visitor segment that can be tapped for Accessible Tourism. However, inaccessible information and physical infrastructure, and lack of opportunities for multisensory experience were found as the primary reasons given by respondents for rare or negligible visitation in spite of their great interest in Heritage sites and their architecture.
- Insights shared by participants about their past experiences revealed that Heritage sites in India are barely accessible for people with visual impairments and their needs are not considered in planning and providing wayfinding, interpretative and visitor facilities in heritage sites.
- Barriers affecting experience and accessibility preferences for people with visual impairments in Heritage sites were discussed with the participants. Inappropriate site management and services; inaccessible physical infrastructure; lack of support and insensitive attitudes of ground staff and sighted visitors; lack of or absence of informational infrastructure; and finally environmental issues were the major barriers suggested by the visually impaired respondents. Pressing need for physical and intellectual accessibility in heritage sites, inclusive of site management strategies and training of ground staff were found to be major and urgent concerns amongst all the respondents.
- Human assistance was also found to be a critically important aspect in shaping the experience and perception of people with visual impairment in heritage sites, irrespective of their type of visual impairment.

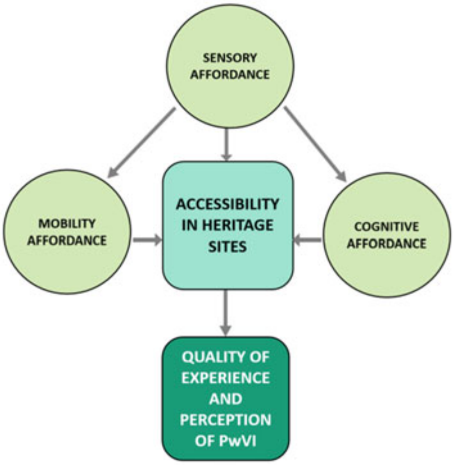
- While the domain of this research majorly deals with environmental and cognitive psychology and spatial behaviour, the absence of appropriate assistive technology in the form of multisensory interpretative aids was found greatly affecting the experience of visiting heritage sites.
- The findings also bring out the dire need to mobilise sensitisation and training of ground and managerial staff at Heritage sites particularly the tourist guides with respect to needs of people with visual impairment. Based on the expectations voiced by the respondents, training courses for guides and interpretative media can be appropriately designed considering visually impaired visitors in Heritage sites.

Based on the above findings, the study proposes a theoretical model called 'Triad of Affordances' for application in Heritage sites for enhancing their affordance for facilitating satisfactory, accessible and educative experience for people with visual impairments. Affordances are offerings of an ecological setting that make the habitat suitable for an organism (Gibson 1979). Affordances can be negative and positive. Affordance therefore can be a useful tool (Zaff 1995) to improve the positive affordances of a heritage site for persons with visual impairments based on their effectivities. The theory proposes the following appropriate measures to be taken in Heritage sites to achieve three types of Affordances viz. Sensory, Mobility and Cognitive.

1. Sensory Affordance—The original sensory stimuli/qualities and environmental cues in the heritage sites must be preserved, conserved, enhanced scientifically to enable the PwVI to get a close to real and comprehendible non-visual perception of all the architectural aspects of the heritage sites.
2. Mobility Affordance—The physical fabric of the heritage site must afford safe, dignified, intuitive, equal, affordable and perceptible access and independent mobility for the PwVI. The environment must be free of access barriers that instil fear, anxiety and feeling of 'disablement' and discrimination for PwVI.
3. Cognitive Affordance—The heritage site and visitor management strategies must include provision of immediate and contingent information supporting perceptual and self-directed learning and action, through availability of perceptible, accessible and multisensory interpretative means and methods including guided participation and experience. Use of assistive technology and tools should be explored as they are least intrusive and be seamlessly integrated in the historical fabric of the heritage site in a reversible manner (Fig. 17.3).

Lastly, respondents also opined that training and exposure of People with visual impairments to more Heritage sites and multisensory interpretive media, right from young age, can improve their understanding and perceptual abilities, hence their experience in heritage sites.

Fig. 17.3 Proposed theoretical model of 'Triad of Affordances'



Conclusions

The study through its phenomenological approach, captures the voices of the People with visual impairments and puts lights on their motivations, physical and informational barriers affecting experience and accessibility-related expectations of the in Heritage sites, which can be crucial in formulating related policies, guidelines and best practices for facilitating inclusion of people with disabilities in heritage environments in India. The proposed theoretical model of 'Triad of Affordances' can be applied to develop socially inclusive visitor and heritage management strategies and related policy framework for People with Visual Impairment in Heritage sites. It also illuminates the need for further detailed inquiries into multisensory experiences to offer universally accessible communication strategies rather than relying solely on visual communication strategies for facilitating a satisfying and enriching experience for the People with Visual impairment in Heritage sites.

Finally, through its outcome, this research intends to create an empathetic and unprejudiced understanding of the spatial experiences, abilities and needs of people with disabilities by presenting a case of people with visual impairment. The study also presents new insights of a visually impaired person's perspective on the built environment as a basis for a critical reflection by architects and designers on the conventional way of thinking about the design of spaces. The large range of detail insights shared by the respondents covering general as well as specific solutions for overcoming barriers and enhancing experience and access reveal the significance of a participatory approach of problem-solving with regards to architectural issues of people with different needs. Involving and hearing from people with disabilities can certainly lead to more effective and appropriate strategies, thus making the design process 'Inclusive' in real terms.

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