DISABILITY AS DIVERSITY IN INDIA

THEORY, PRACTICE, AND LIVED EXPERIENCE

Edited by
Sandhya Limaye, Christopher J. Johnstone,
and Misa Kayama

Disability as Diversity in India

This book critically analyses diverse experiences related to disability in India. Drawing upon intersectionality theory, it explores a range of issues regarding everyday experiences of disability in relation to gender, religion, social experiences, and India's neoliberal economy and its built environment. From theoretical to deeply personal, this book discusses themes like invisible disability and identity; women with disabilities in India; bodily frustrations and cultural stigma; emotional stability and self-esteem of children with disabilities; neurodiversity and queerness; and overcoming the barriers. It also emphasizes the impact of the writings of women with disabilities on their personal experiences. The volume discusses perspectives and practices of schooling, curricular transactions, and inclusive education that have evolved for children who are deaf in India.

Conversational and interdisciplinary, this book will be of interest to scholars and practitioners of disability studies, social care, mental health, social psychology, gender studies, social work, and special education.

Sandhya Limaye is a Professor and Chair of the Centre for Disability Studies and Action, School of Social Work, Tata Institute of Social Sciences, Mumbai. As an Erasmus Mundus, Nehru-Fulbright, and Rockefeller fellow, she presented the alternate report on women with disability in India at the UN, Geneva. She also is involved in C 20 Summit for Diversity, Equity, and Disability groups in India.

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**This book is dedicated to all persons with disabilities in India.
We also dedicate this book to those who play an ally role,
whether as a family member or professional.**

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Misa Kayama Ph.D., MSW, is an Associate Professor of Social Work at the University of Mississippi, USA. Her research focuses on the cultural shaping of children's experience of stigmatization due to disability in Asian countries and the U.S. and other intersectional issues such as race and immigration status, through cross-cultural, ethnographic approaches. The findings have been published in a number of peer-reviewed journals and two academic books.

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Suchaita Tenneti is an independent researcher who works at the intersections of gender and disability. She has a Ph.D. in Sociology from the Jawaharlal Nehru University (Delhi).

Foreword

Lina Kashyap

I felt both honoured and humbled when Professor Sandhya Limaye requested me to write a foreword for her co-edited book titled, “Disability as Diversity.” It took me back to the year 2006, when the Tata Institute of Social Sciences (TISS), Mumbai underwent a major restructuring process. As I had some experience in the field of disability studies, I was requested by the then-Director of the Institute to establish a new Centre for Disability Studies and Action (DSA) within the School of Social Work. Having accepted the task, I invited two of my colleagues, Dr. Sandhya Limaye and Dr. Srilatha Juvva (one of the authors in this book) to assist me in establishing this new centre which is the first of its kind in a university setup.

In 2008, the centre launched a two-year master’s programme in Disability Studies and Action which was again the first of its kind in India for training social workers in this complex and vibrant field. The curriculum aimed to develop a cadre of trained social workers with specialized competency in working with people with disability and all stakeholders through building an anti-oppressive, empowerment-based, partnership practice. Disability studies as an academic discipline was at that time at a very nascent stage in India. While drawing up the curriculum, we were well aware that though the foundational base was no doubt drawn from Western models, we needed to work towards adapting these frameworks and creating new ones based on two aspects: our social, cultural, and political realities; and the lived experiences of persons with disabilities in India. Also, the heterogeneity of Indian experiences with a disability called for micro-interventions using a rights-based approach as well for multiple and systemic interventions at the macro level. Soon after in 2009, I had to move out of the centre as I had been given other responsibilities at the Institute.

With the growing scholarship in disability studies in India, this M.A. programme has also evolved and become more in line with our social, cultural, and political realities. It has attracted a very diverse group of students from other disability-related professions as well as a few persons with disability, which has greatly enriched the teaching-learning process. I am pleased that over the years, the Centre for Disability Studies and Action, its M.A. programme, and other activities have received due recognition both nationally and globally due to the relentless efforts of my colleagues, especially Professor Sandhya Limaye.

The past two decades have seen significant developments in the emerging field of disability studies in India. It is today a vibrant and diverse academic discipline that has attracted many debates on the various facets of disability discourses entwined with our sociocultural and political matrix. Increasingly, people who identify as having a disability are speaking out for themselves, providing an insider's perception of their lived experiences. It is therefore very important that such developments should in turn be reflected and integrated in the direction taken by Indian disability studies scholars, and practitioners. This edited book is very timely and provides a holistic view of disability through the theory, practice, and lived experience of the authors, at the same time fully appreciating their plurality of voices, assertions, and experiences.

It was with great interest that I read this edited book's collection of scholarly papers. It gave me great satisfaction to note that they do depict the diversity and complexity in the theoretical, practical, and standpoint perspectives of contemporary Indian stakeholders in the growing field of disability studies in India. The multiple voices that speak to this book's readers do highlight the heterogeneity of Indian experiences with disability as they intersect with a range of dimensions including gender, social, economic, and environmental. These voices have also validated for me that disability is only one of the characteristics of some of the authors of this book. I salute all the authors of the chapters in this book who have shared very candidly, their own lived experiences and convictions as well as those authors who enabled us to read about and value the narratives and perspectives of their research participants. I am richer by the insights I have gained by reading and reflecting on this collection of scholarly, practical, and autobiographical contributions.

This book is indeed unique in that it weaves together voices from academia, the diverse range of experiences of practitioners working in governmental and non-governmental organizations, and autobiographical accounts. It is a valuable addition to the slowly growing literature in the field of disability studies in India. The three editors have done a commendable job in their presentation of the scholarly contributions of this exceptional group of scholars and practitioners. In my opinion, it is very aptly titled, "Disability and Diversity." In today's context, Indian society is highly pluralistic and it is my belief that our education and practice need to incorporate a diversity perspective which is not only about understanding difference, but it is also about understanding dynamics related to privilege, power, inter-group relationships, and oppression and their effects on individual's wellbeing within our social contexts.

Lina Kashyap
Emeritus Professor and Former Deputy Director,
Tata Institute of Social Sciences, Mumbai

Foreword

Meredith M. McQuaid

In 2006, the World Health Organization (WHO) advanced the possibility that "disability" was not an issue of the mind or body, but an interaction between identifiable or recognized human conditions and societal barriers. I first learned of this concept in 2014, while reading a grant proposal submitted by Christopher J. Johnstone (then a staff member in the College of Education and Human Development at the University of Minnesota), and I was utterly intrigued. I was intrigued by the idea that disability was not necessarily a fact, but a circumstance or a context that bore investigation. Christopher's proposal, "Examining the Intersection of Disability Identify and Civil Society Disability" sought to further explore the intersection of cultural conditions and Indian discourse around rights and empowerment with the circumstance of identity. This book is a product of that initial proposal, of the work of three talented and thoughtful intellectuals, with the initial support of University of Minnesota funding.

My office, the Global Programs and Strategy Alliance at the University of Minnesota, sponsored a series of "Global Spotlight" grants focusing on geographic regions of the world. In 2014, our focus was on South Asia, and Christopher's proposal received significant funding due to the theme and the concept.

This book is a compelling example of what university funding can precipitate in inspiration and outreach, but it is also evidence of the importance of partnerships to the internationalization of university faculty and staff. This book, with its inclusive approach to the topic of disability; the need to consider theory and practice, but also lived experience, is a brilliant example of what institutions of higher education can accomplish by linking with nonprofit organizations, specific individuals, and practitioners who have been immersed in issues, exploration, and the quest for solutions.

Meredith M. McQuaid
Retired Senior International Officer
University of Minnesota

Preface

Whose stories get told in academic books? Whose do not? These questions were the basis for the organization of this book. Three editors, whose identities and disciplinary backgrounds are as diverse as the authors in this book, came together to ask these questions. The answer originally came from a call for papers and discussions in a Tata Institute on Social Sciences (TISS) forum in late 2016. The meeting was decidedly pre-pandemic, with abundant face-to-face discussions and networking opportunities.

Many of the invitees to this meeting were part of Sandhya Limaye's network, but many also responded to an open call for presentations. The original discussion at the meeting on TISS focused on disability identity. The discussion evolved into many of the chapters of this book and extended far beyond identity. Based on the collection of contributions, we (the editorial team) decided to rename this book *Disability as Diversity* to honour the theoretical, practical, and standpoint contributions made by our authors. We acknowledge that theory, practice, and lived experience interface with one another and that these interfaces may be contradictory, in conflict, or complementary.

We then humbly request our readers to read this book holistically. However, rather than a holistic view that attempts to synthesize or identify artificial convergences, we recommend reading through a *diversity* lens. This book attempts to provide a holistic view of disability through theory, practice, and lived experience, but does so in full acknowledgement (and appreciation) of the plurality of voices, assertions, and experiences found in its chapters. We are greatly indebted to our chapter authors for pouring their intellectual grit and their hearts into this work. The authentic expressions found in these chapters left us with a feeling of tremendous honour and responsibility to pull together the final product of this book.

Our goal, as engaged scholars, women with disabilities, and their allies, and friends, was to provide a platform for conversation on disability in India across multiple levels of analysis, through the inclusion of multiple voices. We hope we have succeeded and look forward to continuing conversations with our authors and readers.

Sandhya Limaye, Christopher Johnstone, Misa Kayama

Acknowledgements

We especially wish to acknowledge the authors of chapters of this book in this effort, along with others who supported early drafts with their reviews – Angela Adams and Liz Greene. An end to disability stigmatization requires both personal advocacy and a willingness for those with power to rethink their positions to reorient cultural and professional spaces.

Abbreviations

ADA	Americans with Disabilities Act
CBR	Community-Based Rehabilitation
CEDAW	Convention on the Elimination of all Forms of Discrimination against Women
CP	Cerebral Palsy
DS	Disability Studies
DSA	Disability Studies and Action
LD	Learning Disability
NCERT	National Council of Educational Research and Training
LGBTQ+	Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning
NGOs	Non-Government Organizations
PWD	Persons with Disabilities
PwDs	Persons with Disabilities
RG	Restricted Growth
RPWDA	Rights of Persons with Disabilities Act
TISCO	Tata Iron and Steel Company
TISS	Tata Institute of Social Sciences
UNCRPD	United Nations Convention on Rights of Persons with Disabilities
US	United State
WHO	World Health Organization
WWDIN	Women with Disabilities India Network

Part I

Building theory

1 Introduction

Sandhya Limaye and Misa Kayama

This edited volume, intended for scholars and practitioners, examines disability from a variety of dimensions. Over the past several decades, disability-related scholarship has moved from highly medicalized interpretations to social examinations of the phenomenon. This book locates itself within the scholarship of Disability Studies, with a specific focus on diverse experiences related to the phenomenon of disability in India. In many ways, this book draws upon intersectionality theory (e.g., Collins & Bilge, 2020) and its application to Disability Studies, i.e., the understanding of disability as a characteristic that is negotiated within gendered, vocational, familial, caste, and religious contexts, rather than as an essentializing element of one's life (e.g., Meekosha & Shuttleworth, 2009). Intersectionality describes how different factors of discrimination such as gender, type of disability, location, class, and culture, can meet at an intersection, how these diverse factors interact in the life of a person, and consequently the impact of such simultaneous experiences of oppression and discrimination on the person (Sukhramani & Shweta, 2013). All these factors combine in various ways to aggravate or change the individuals' experience of disability (Vernon & Swain, 2002). We approach such diverse experiences of disability by focusing on the *praxis* (reflective practice) of research, service organizations, and individuals in relation to impairment and disability, building on Ghai's (2002) work on feminism and disability. Indeed, we agree that "[w]hat is needed is not merely a strong commitment to creating spaces where different voices can share their realities and be heard, but also an active integration of differences among and within…" (p. 64).

The understanding of disability as diversity is complex. In this book, the complexity of the social construction and lived realities of disability are presented with a commitment and recognition that diversity is a strength to make society more cohesive. To acknowledge the importance of such diversity, scholars need to dig a bit deeper to understand some of the most important aspects of the experiences of disability, particularly, the insider perceptions among people with disabilities.

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Understanding Diversity in Disability

Disability presents a widely diverse set of experiences. Indeed, as the authors of chapters in this book describe, how people with disabilities view issues around disability falls into very different patterns. Is it, then, possible to find the consensus between how people with disabilities understand themselves and what "we," including those without disabilities, want to know when we so rarely agree with each other? Some obvious differences stem from experiences with different types of disability. We are aware of various categories of disabilities, such as visual impairment, hearing impairment, locomotor disability, cerebral palsy, autism spectrum disorder, and so on. Each category comes with its strengths, stereotypes, and intensities of discrimination. Thus, such differences powerfully shape how we understand and respond to a disability, how we view our place in society, and how we relate to our fellow people with disabilities.

Readers of this book can expect a diverse range of experiences and forms of expression in the chapters that follow. For example, Part II (Chapters 2–6) focuses on emerging directions in Disability Studies. Several of the chapters enact theory and provide examples of trends in Disability Studies scholarship in India today. Part III (Chapters 7–11) focuses more on contemporary practice, interrogating how stigmatization impacts the ways disability services are conceptualized and implemented in India. Part IV (Chapters 12–14) includes first-person narratives by persons with disabilities themselves. Chapters 12 and 13 critically examine topics of intersectionality, colonization, and gender binarism, while Chapter 14 is a personal account of resilience.

These different disability journeys profoundly affect how people with disabilities understand virtually every situation they encounter throughout their lives. They learn so much about disability, its intersectional issues, and how they navigate them throughout their lives; life lessons that able-bodied people rarely experience. What wisdom have we learned from them? First, our lives can be stressful. The stories in this book, however, teach us a number of lessons, for example, the importance of patience that the authors and research participants have exercised throughout life. Some, for instance, grabbed the status of "being different" as an opportunity to make changes in their own lives and the community. They may hold a belief that showing weakness is not entirely negative and redefined their lives living with disabilities. Many also are resilient and have creatively developed coping strategies. The following sections provide an overview of the broad themes that are found in this book. These are followed by an in-depth chapter-by-chapter description of the contributions made by the book's authors.

Narrative Personal Stories

The voices of people with disabilities have become an important yet ambivalent tool for the recognition of disability. The transformative potential of their voices is dependent on a political commitment to directly listen to them (e.g., Meekosha & Shuttleworth, 2009). Able-bodied people think about disability from their abled perspective. They may understand having severe disabilities as unmanageable suffering, a life that is subject to constant dependency and without value. It is only by listening to and valuing the perspectives of those who are living with disabilities that able-bodied persons can begin to understand that even a severe disability does not necessarily prevent us from having a joyful and desired life. Thus, it is particularly important for people with disabilities to express their voices, for example, through writing stories and telling others about various experiences, such as how they have acquired disabilities and how their understandings of disability have evolved. Each experience brings with it a different sense of loss and identity, shame and pride, pessimism, strengths, and hope. It is also significant that most people with disabilities are introduced to, and have adjusted to, their lives with disabilities through their interactions with those without disabilities. Most of us, for example, first learn about the meanings of disability from our parents, doctors, therapists, teachers, non-disabled neighbours, and popular culture. Further, as the authors of this book describe, some of them begin learning about disability with strong, empowering support and a sense of great optimism, especially if they have supportive parents who advocate for them.

Hans, in Chapter 3, for instance, argued that understanding the subjectivities, and narratives of women with disabilities, are important. Although women in self-narratives and writings rarely specify who are the patriarchs, they do indicate the impact of discriminatory male-established society and state. Their writings, both in narratives and exploratory research, indicate that patriarchy must be removed. However, a deeper discourse is required to create a new understanding of State-sponsored patriarchy playing at different levels using different methods to control identities.

In this book, we present two groups: one that has conducted research on diverse experiences of disability by using narrative stories, including Ghosh (people with dwarfism), Nayar (women with psychosocial disabilities), Satpathy (women with locomotor disabilities in villages of Odisha), and Kapoor (youth with learning disabilities), and another that consists of authors with disabilities; for example, Sarkar (locomotor disability), Tenneti (neurodiversity) and Amitabh Mehrotra (men with cerebral palsy) who tell us about themselves using narrative stories.

The authors who shared their experiences in the narrative form explained their life as up and down. Each one has its own way of expressing one's societal pressures and personal struggles characterized by trials and triumphs. They have experienced society's negative attitudes and oppression in various ways. At the same time, however, they find strength in the community. Others are staunch in self-reliance and individuality, moving towards a kind of disability pride and ambition later on. Cultural factors that affect disability and experiences using the framework of intersectionality will differ based on the type of disability (Belgrave et al., 2019) and the responses of people in immediate family, work, and local communities.

Gendered Perspective

Given that both gender and disability are social constructs (Olkin, 2003), the experiences of being a woman with a disability are significantly affected by particular social factors. Women with disabilities are more stigmatized than men with disabilities. Women with disabilities face many disadvantages including dual oppression; i.e., oppression of being female in a sexist society and having disabilities in an ableist society: if they inhabit another minority identity, for example, a queer identity, they experience even more oppression and stigma (Kuemmel et al., 2019).

Women with disabilities differ from men with disabilities in that they are viewed as vulnerable, more dependent, socially excluded, and poor, but never as feminine, nurturing, or fit parents (Nairo-Redmond, 2010). For women with visible disabilities, their encounter with social challenges is common, while women with invisible disabilities are likely to go to great lengths to pass as "non-disabled" to avoid disclosing their disability status and falling prey to this stereotyping (Davis, 2005).

Society expects women to fulfil a number of roles and expectations. Women with disabilities, however, are excluded. Whether the role disruption is actual or perceived, disability threatens many of these cultural expectations. Role changes also affect men with disabilities. Yet they differ based on gender expectations for men (Kuemmel et al., 2019). A sense of being without a role can certainly affect emotional functioning and self-esteem. Women with disabilities may feel a sense of loss of womanhood.

In this book, Satpathy, Hans, Ghosh, and Nayar all discuss the position of women with disabilities in the Indian context. Gender inequality has placed women in a subordinate position to men. The social, economic, political, cultural, and civil status of women has been subverted for a long time, and they have been discriminated against in all spheres including education, employment, wage, and health (Satpathy, Chapter 10). Ghosh, in Chapter 7, reported that while disability identity is itself stigmatized, gender identity often adds to this experience of marginalization in social life in different ways. However, Hans, in Chapter 3, informed that recognition of gender identity makes women with disabilities more visible, and they start to make rapid inroads into both feminist and disability movements. There is a critical struggle ahead for disability, gender, and intersectional scholarship so that women with disabilities can establish their due recognition of equal gender identity in disability.

Thus, it is crucial to understand the challenges women with disabilities face with sexuality, their vulnerability to abuse, and existing barriers to the fulfilment of social roles and expectations. These factors play significant roles in making the experiences of women with disabilities inimitable (Kuemmel et al., 2019).

Multiple Identities and Experiences

Intersectionality seeks to understand how multiple social identities intersect within the individual to account for multiple interacting levels of social inequality (Bowleg, 2013, cited in Belgrave et al., 2019; see also Collins & Bilge, 2020) and affect how we experience and process our disabilities. It is obvious that disability overlaps with other social identities, such as lower caste, LGBTQ+, or being poor, and we experience multiple layers of stigma and discrimination. For example, Tenneti, in Chapter 13, explores the cultivation of a disability consciousness in the absence of a clear diagnosis of a disability and the simultaneous exploration of queer consciousness. Such exploration helps us understand how multiple identities interact, and simultaneously, rather than independently, affect the lives of those with disabilities. It also accounts for the elevated rates of stigma, discrimination, and poverty among ethnic minority members with disabilities who are considered double minorities (Belgrave et al., 2019).

Individuals must not be defined by their disabilities alone. Rather, disability should be regarded as one characteristic among many, and often a minor one (Dunn, 2015). We raise this issue in this book, including the examination of a workplace issue, implicit attitude, disability identity and pride, family and parenting matters, self-determination, and resilience. Disability is only one of many layers of identities and experiences, and some of us have to deal with more barriers than others because of issues associated with disability. Ghosh, in Chapter 7, informs that stigmatization experienced by people with various disabilities in public spaces such as schools, markets, and public transportation systems continues to become an issue in their employment prospects and opportunities in adulthood.

Combining the concept of ableism and the experience of multiple identities, one can say that people face oppression and discrimination based on any of their identities or memberships in any of the diverse groups. Each person may experience discrimination or oppression in different contexts or at different points.

Social support is not merely a commodity, but also a dynamic exchange that flows within and between individuals and networks that are bound by cultural norms, attitudes, roles, and trust (Chronister, 2019). Juvva and Sharma, in Chapter 5, indicate that in everyday experiences, individuals have various resources that help them cope with stress, including internal resources, such as strengths and values related to fortitude, resilience, self-determination, and self-confidence, and external resources that are available through the social support systems, such as strong family, peer support, and enabling environments.

Paradigms and Disciplines

On top of all these practical and personal differences, individuals' understandings of their own disabilities are shaped by their fundamental philosophy of disability, which also are drawn to a wide variety of disability-related characteristics, modes of thinking, and activities. In practice, however, Mehrotra, in Chapter 2, states that the diverse needs of persons with disabilities who have intersectional identities associated with their multiple social locations and status pose challenges in how to define Disability Studies, and how the field evolves in different institutional frameworks.

The most commonly cited differences in our understanding of disability are between the "medical" and "social" models of disability. Roughly speaking, the medical model focuses on disability as a medical experience, a set of impairments to be treated, with the goal being something as close as possible to "normal" functioning (e.g., Mackelprang & Salsgiver, 2016). The social model views disability primarily as a matter of combating discrimination, ensuring equal access, and making sure that people with disabilities receive the support necessary to sustain their independence and live lives on their own terms (e.g., Llewellyn & Hogan, 2000). In general, the medical model places responsibility for improvement on individuals with disabilities and their personal efforts, while the social model emphasizes collective action and social responsibility to make society better and more accepting of people with disabilities, both individually and as a group.

Most people with disabilities and disability organizations fall somewhere on a spectrum between the two disability paradigms. Both approaches are useful for somewhat different purposes and attention; for example, to individuals or society. These two broad paradigms can be further refined through different disciplines. For example, working through debates on social and medical, rights and rehabilitation models, Mehrotra, in Chapter 2, argues that a negotiated model is often in operation at the ground level.

According to Mehrotra, Disability Studies research in India has been drawn from scholars with disabilities/non-disabilities in diverse disciplines. For example, scholars from disciplines such as Ghai from psychology, Dhanda and Kannibiran from the law, Adlakha, Mehrotra, and Staples from Sociology and Anthropology, Juvva, Limaye, and Nayar from social work, Anand from Literature, Adlakha, Hans, Ghosh, and Ghai from feminist perspectives (including Women's Studies), are contributing to the field of Disability Studies in their own ways. These diverse ways of understanding the disability community are not definitive. They simply suggest some of the main fissures, contrasts, and different tastes that exist among people with disabilities. Further, through it all, despite all divisions, there is still a strong pull towards greater unity, and a lot of ground for common understanding.

India is at a crossroads between traditional collective identities in family life, religion, caste, and village identification, and there is an increasing focus on individual rights fuelled by recent disability legislation as a result of westernization, such as the Rights of Persons with Disabilities Act in 2016 (India Code, 2016), and a broader focus on neoliberal economic policy (Chaudry, 2016). Recent conceptualization of the intersection of disability and identity in India reflects a focus on complex understandings of disability within layers of social contexts. The aim of this book, however, is not to make a theoretical contribution to "identity," but to provide a platform for disability-focused scholars and practitioners to reflect on their work and personal experiences.

In this book, we seek to identify those complex layers through the contributions of scholars, practitioners, and first-person narratives. The contributing chapters from these individuals describe theoretical and practical identity negotiations which are intended to highlight the heterogeneity of Indian experiences with disability. The book is thus unique in that it weaves together voices from the academy, the front lines of service agencies, and autobiographical accounts.

The various contributions of authors are bookended by introductory and concluding chapters that characterize, in a taxonomic fashion, the complexity of disability in India. Although the aim of this book is not to draw a summative statement on the state of disability in India, we highlight its diversity, its intersections, and complexity through the combination of scholarly, practical, and autobiographical contributions. Our attempt to set diverse voices on equal footing in this book is purposeful and presents an epistemological stance that knowledge about disability is found across multiple domains.

The presence of disability impacts individuals, families, communities, and societies in a variety of ways. Further, the lived experiences of persons who identify as having disabilities have close relationships with a person with a disability. Our work with a person with a disability is also diverse and mediated by broader social structures and cultural ways of knowing. Thus, we focus on the *praxis* of disability (see Ghai, 2002), drawing on the intersectionality theory of disability (e.g., Meekosha & Shuttleworth, 2009). As we described above, individuals' experiences of disability reflect not only their own personality and characteristics, but also the sociocultural contexts within which they are situated, including gender expectations, religion, access to education and employment opportunities, and socioeconomic status, which can contribute to diversity in the experiences of disability. The chapter contributors each write their experiences, and understandings of disability from a reflective stance, whether it be theoretical, professional, or personal. Our intention is to capture the diverse experiences that individuals encounter in relation to disability and locate these within the broader sociocultural practices of India.

The Structure of the Book

The inspiration for the book came about through conversations and observations of the 'verticality' of disability discourse in India. From highly theoretical and critical discursive studies of disability and disability practice in India to personal narratives of disability that are both emotionally and theoretically informed, this book represents the diversity in understandings of disability in India as they intersect with a range of dimensions including gender, religion, social experiences (see also Ghai, 2015), and India's neoliberal economy and environment. This chapter introduces each of the following chapters, explaining how they all align and stand in tension with one another.

The contributing chapters are organized into three of the five parts. The first of these, Part II, highlights contributions from scholars in the field of Disability Studies and other social sciences. These chapters provide a theoretical framework for the rest of the book, framing chapters in a social model of disability (Barnes & Mercer, 2004) and identifying the social milieu in which disability resides in India. Part III focuses on the work of practitioners in disability-engaged fields such as social work, architecture, and education. Finally, in the spirit of first-person narratives that are privileged in Disability Studies, Part IV presents first-person narratives from persons who identify as having an impairment. In summary, we present a product that aligns with Kumar and Subudhi's (2015) assessment that understandings of disability are in "…a fluid state or condition, and the ontological strand of the model is modified, redefined over…time" (p. 23).

Part II: Emergent Disability Studies Scholarship

Part II explores the emergent Disability Studies scholarship in India. In Chapter 2, Mehrotra examines the ways in which Disability Studies programmes have evolved and institutionalized in the Indian context and argues that the rights-rehabilitation dichotomy does not serve at either a theoretical or a practical level for understanding the situation of persons with disabilities in India. The diverse needs of persons with disabilities who have intersectional identities shaped by their social status and locations also pose challenges in how to define Disability Studies and how it evolves in different institutional frameworks. Professionalization in the field of Disability Studies also needs to take the history of its emergence seriously and document the role of ideas about disability institutions and individuals who play significant roles in building it. The development of Disability Studies, for instance, is a process of negotiation between rehabilitation and the rights of persons with disabilities in diverse lived realities.

In Chapter 3, Hans argues that the recognition of gender identity has made women with disabilities more visible. They have started to make rapid inroads into both feminist and disability movements. There is a critical struggle ahead in which specifiers need to be identified so that they can establish their due recognition of equal gender identity in disability. According to Hans, writings of women with disabilities, both in narratives and exploratory research, are valuable tools that reveal the impact of discriminatory male-established society on women. However, deeper discourses are required to change the State-sponsored patriarchal understanding that have affected our society at various levels using different methods to control their identities.

Chapter 4, written by Gathoo, focuses on the perspectives and practices of schooling, curricular transactions, and inclusive education that have evolved for deaf children in India. This chapter provides the 'what' and the 'how' of deaf education, from then to now. She emphasizes the need to make education inclusive truly by adopting a need-based approach that ought to be followed in education, the use of human resource development, and the provisions of various policies and laws including universal design for learning (UDL), as well as teacher preparations, and pedagogical and curricular development.

Juvva and Sharma, in Chapter 5, deal with an often-ignored aspect of spirituality in the lives of persons with disabilities. It describes the importance of integration and synthesis of identities for wholeness, drawn from the practice wisdom of the two authors. The differences presented by impairments and consequent limitations in the functioning of people with disabilities lead to their exclusion from mainstream society, relegating them to the margins and thereby affecting identity formation. According to the authors, spirituality provides people with disabilities with the strength necessary to cope with the stresses of being different from the rest of society.

In Chapter 6, Das recognizes that design exclusion can posit a disempowered disability identity. This chapter also examines diverse approaches underlying the design for disability: adaptable design, assistive design, accessible design, inclusive design, and universal design of products, systems, services, and environments. This chapter, then, highlights the importance of design interventions and the body's role in creating identity, claiming disability identity, and creating positive and affirming counter-narratives.

Part III: Disability and Diversity in Practice

Ghosh, in Chapter 7, explores the identities of people with dwarfism through the examination of various issues, including their experiences of the physical spaces that marginalize them; social ideologies regarding dwarfism; and the ways in which they respond to, and challenge the dominant norms of height and exclusionary practices in an ableist society. It also presents narratives of four individuals with dwarfism/restricted growth/little people and examines ways in which gender and ability discourses mediate the experiences of these people both in private and public spaces.

Chapter 8, written by Nayar, explores the 'transitioning self' of women who have received a diagnosis of a severe mental disorder. Through the examination of narratives of women, this chapter aims to elucidate the process of becoming a "non-person" and the loss of privileges this entails. It is the lens through which society sees women with psychiatric diagnoses that can result in the loss of personhood, rather than the direct consequences of the disorder on the individuals.

In Chapter 9, Mohita Choudhary discusses various barriers faced by persons with disabilities in their access to employment in Delhi through interviews. This study was undertaken to understand employees' experiences at corporates in reference to attitude, awareness, and perception regarding persons with disabilities, emphasizing employees' perspectives. The findings suggest others' negative attitudes as the major barrier they come across in obtaining jobs. Multiple barriers hinder the integration of persons with disability into the mainstream. Disability does not mean being less abled. Rather, disability is a challenge, which makes a person stronger and smarter to endure despite overwhelming obstacles.

In Chapter 10, the findings of Satpathy's research on women with disabilities in Odisha village revealed the paternalistic attitude of the society towards women with disabilities who were required to constantly shuttle between two contradictory perspectives of being undesirable as "disabled" and not to attract attention as women. Within this paradigm, however, some of the women navigated, subverted, and resisted society's expectations for them to remain invisible and voiceless by leading multidimensional lives. The social expectation of women with disabilities that lead them to have a quiet life of marginal subsistence on the periphery of society is dismantled by these women who have refused to be limited by their disability or gender.

Kapoor, in Chapter 11, discusses narratives of the life experiences of four individuals with learning disabilities and their journey from identification to acceptance of their disabilities. These individuals described how they perceived their disabilities, their concerns and coping with identification crises, and their experiences at home and school. They also described how they have moved on to building a positive frame of mind and affirmations that led slowly to moving towards acceptance, their journey from stigmatization to understanding "Who am I?"

Part IV: Personal Narratives

Chapter 11, written by Sarkar, addresses the relationship between language, power, and practice; and how these interact to produce epistemological and methodological concerns in inclusive education research in India. It discusses three perspectives, i.e., translation, methods, and identities. These perspectives help us address the challenge of exploring culturally sensitive understandings of inclusion and disability in a context where the local language discourse around disability can be stigmatizing and the official discourse is often exclusionary. Sarkar combines personal reflections and poetry with an extensive overview of existing research to address how her Western-educated, 'colonized elite' researcher-self interacts with her identities as female, disabled, upper class, upper caste, multi-lingual, Indian in conducting research on disability and inclusive education.

Tenneti, in Chapter 13, explores the cultivation of a disability consciousness in the absence of a clear diagnosis of a disability; and the simultaneous exploration of a queer consciousness that is rendered precarious through its evasions of a clear inclusion within contemporary LGBT+ socio-political spaces in India and the epistemic guilt emanating from occlusion of easy inclusion that ensues. Tenneti, then, expands the explanatory potential of queerness and disability and transforms them from minority to universal/general perspectives that carry epistemological and phenomenological insights for all forms of existential states.

In Chapter 14, Amitabh Mehrotra talks about his journey as an individual with a disability. He perceives that challenges due to his cerebral palsy have made him stronger, more determined, and more enterprising. He faced significant discrimination and the unsympathetic and callous attitudes of society. These circumstances were enough to break him, and he underwent a long spell of depression in his formative life. However, with the help of his family and friends and peer support, he coped with them and moved further. He currently states that nothing is impossible if a person's willpower is strong, and he/she has the guts to make their dream change into reality. If one has strong grit and determination, one can surmount all barriers in life.

In Part V, the final chapter, 15, we end the book with a discussion using Pierre Bourdieu's concept of field. More specifically, we discuss the diagnostic, social, and political fields in which the cultural habitus of India, related to disability, reflects positions of power and tradition. This final chapter illustrates each field, using examples from contributing chapters, comments on the cultural production and habitus within them, and reflect on the ways that the field is being shaped and contested, resulting in cultural production. It also provides guide points for future research in disability studies, policy, and action.

As noted in the peer reviews of this book, readers will find this is an "eclectic mix" of chapters ranging from deeply theoretical to deeply personal, and everything in between. We hope the chapters of this book, and its entire collection of contributions, provide conversational fodder in Disability Studies programmes, communities of practice, and among readers who identify as having disabilities. The most likely readers of this book are those in academic circles – we suspect this book may be used as a text in Disability Studies courses or end up in academic libraries. We hope, however, that it is also accessible and useful for practitioners and advocates. There are many lessons to be learned from the author contributors of this book, and we hope you enjoy the contents of the chapters that follow.

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