Disability studies and the law: In conversation with Professor (Dr) Nilika Mehrotra

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Abstract

The field of disability studies in India is fledgling, yet burgeoning. Professor (Dr) Nilika Mehrotra is an exemplary scholar from this field, who has played a pioneering role in situating the scholarship on persons with disabilities (PWDs) in a distinctly South Asian narrative. She has not only written extensively on the South Asian experience of disability but has brought together important scholarship by several academics in this area in a recent edited work. Her research on the intersectionality between gender and disability, as well as on the contribution of the state's schemes on enhancing the rights of PWDs, has shaped the post-coloniality of the discipline in India. As an anthropologist, she has sought to place the experiences of the disabled at the heart of her theorisation, critiquing a top-down approach to representing disability. In this interview, she discusses the inherent interdisciplinarity of disability rights studies and the evolution of disability rights movements in India.

Keywords Disability studies · Disability rights movements · Global South · Gender and disability · Disabled identity · Law and disability

1 Introduction

Disability studies and disability rights movements in India are still at a nascent stage, despite having been introduced into civil society consciousness in the 1980s.¹ Disability is often not seen as an axis of discrimination in the same way as gender, caste, and religion in

¹ See Jagdish Chander, 'The Disability Rights Movement in India: Its Origin, Methods of Advocacy, Issues and Trends' in Nandini Ghosh (ed), *Interrogating Disability in India: Theory and Practice* (Springer India 2016).

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India are.²

Professor (Dr) Nilika Mehrotra is amongst one of the few scholars working on disability studies in India since its inception. Some of her pioneering work has been towards moving the research on disability away from the binary between the medical and social models of disability that had hitherto dominated the academic discourse.³ As a professor at the Centre for the Study of Social Systems (CSSS) at the Jawaharlal Nehru University (JNU), Delhi, she uses an interdisciplinary approach to the study of disability. Her methods combine the sociological with the anthropological as well as the ethnographic; she foregrounds her research in the particularities of South Asia, especially in the context of rural communities in India.

Professor (Dr) Mehrotra spoke to us in October 2021, in the wake of mushrooming conversations on the manner in which PWDs are conceptualised by the Rights of Persons with Disabilities (RPwD) Act 2016. Through our interview with her, we wanted to understand how the intersection of several axes of identity—namely gender, caste, class, and region—influence the construction of a disabled identity in different socio-economic settings in India. In this interview, she shares her insights into the growth and transformation of disability scholarship in India and its relationship with disability rights movements. Her reflections on the fissures within and between academia and the movements, the shortcomings of standpoint epistemology,⁴ the value and pitfalls of competition over funding, and her discussion of the attempts made by several scholars (including herself) at institutionalising disability studies in centres of higher education form the crux of this conversation.

We have annotated the interview with detailed citations to help the reader follow and look up the incidents, events, works, and concepts discussed herein.

² See G C Pal, 'Disability, Intersectionality and Deprivation: An Excluded Agenda' (2011) 23(2) *Psychology and Developing Societies* 159; CLPR, *Intersectionality: A Report on Discrimination Based on Caste with the Intersection of Sex, Gender, Identity and Disability in Karnataka, Andhra Pradesh, Tamil Nadu and Kerala* (Centre for Law and Policy Research 2019) 14. <https://clpr.org.in/wp-content/uploads/2019/08/Intersectionality-A-Report-on-Discrimination-based-on-Caste-with-the-intersections-of-Sex-Gender-Identity-and-Disability-in-Karnataka-Andhra-Pradesh-Tamil-Nadu-and-Kerala.pdf>. Accessed 25 October 2021.

³ The medical model looks at disability as a pathological condition to be cured. On the other hand, the social model focuses on the social barriers that accentuate a particular physical or mental impairment. This difference between the medical and social models of disability has been explained in Tom Shakespeare, 'The Social Model of Disability' in Lennard J Davis (ed), *The Disability Studies Reader* (Taylor & Francis 2017).

⁴ Standpoint epistemology is the construction of knowledge about marginalised peoples/communities from the perspective of the marginalised themselves. See Olúfẹ́mi O Táíwò, 'Being-in-the-Room Privilege: Elite Capture and the Epistemic Deference' (2020) 108(4) *The Philosopher* ("What is We?").

2 Interview

1. **Ankita Gandhi (AG):** *Your PhD thesis was on women's organisations and activism. Some of your earliest writings focused on women's movements and understanding feminisms in the Global South.⁵ How did the transition to writing about disability studies happen? In what manner has your research on women's movements informed your scholarship on disability studies?*

Nilika Mehrotra (NM): I am really thankful that somebody is engaging with my work. In the last two or three years, I have found many legal researchers getting interested in my work. In the social sciences, of course, they were looking at my work earlier, especially sociologists and social workers. But it is satisfying to see legal researchers also taking interest in my work. I wrote a very small piece, long back, based on my earlier work, in a small book which was brought out by the National Law School Bangalore. Also, I took part in a panel discussion where I talked to people who are looking at intersectionality in law—the organisation Centre for Law and Policy Research (CLPR).⁶ They used one of my papers really intensively, especially on the intersectionality between caste, gender, and disability.⁷ So, I have been talking to legal researchers.

Getting back to your point about what brought me to disability studies from women's studies. It is an interesting shift because when I was looking at women's organisations in the late 1980s, what was surprising to me at that point was how middle-class centric the women's organisations were. Although they were working with working-class women, I nevertheless felt that there was a very clear middle-class orientation. There were a number of things which were missing, for instance the question of caste. Very clearly it was not there. Religion was another one. They were not willing to engage with religion. It began from Shah Bano,⁸ but since the Roop Kanwar sati case,⁹ the debate became quite heated, especially in the context of the Babri Masjid demolition.¹⁰ I think that the feminists realised probably that the divisions were very stark and clear. So, it was not really a matter of postmodernists trying to tell us that differences existed among women, but that these differences were too sharp to ignore. For instance, there was a very small thing—like most of us activists

⁵ See e.g., Nilika Mehrotra, 'Grass Roots Women Activism: A Case Study from Delhi' (1997) 27(2) *Indian Anthropologist* 19; Nilika Mehrotra, 'Perceiving Feminism: Some Local Responses' (2002) 51(1) *Sociological Bulletin* 57.

⁶ 'About Us: Our Story' (Centre for Law and Policy Research). <https://clpr.org.in/our-story/>. Accessed 29 October 2021.

⁷ Jayna Kothari, Almas Shaikh, and Aj Agrawal, *The Intersection of Disability and Caste: A Policy Paper* (CLPR 2020).

⁸ Express Web Desk, 'What is Shah Bano Case?' (*The Indian Express*, 23 August 2017). <https://indianexpress.com/article/what-is/what-is-shah-bano-case-4809632/>. Accessed 25 October 2021.

⁹ Madhu Kishwar and Ruth Vanita, 'The Burning of Roop Kanwar' (1988) 30(1) *Race & Class* 59.

¹⁰ The Wire Staff, 'Babri Masjid: The Timeline of a Demolition' (*The Wire*, 06 December 2020). <https://thewire.in/communalism/babri-masjid-the-timeline-of-a-demolition>. Accessed 25 October 2021.

came from educated English-speaking backgrounds, and those who we were working with were largely women who hardly had any education but had aspirations to speak in English and behave like ‘us.’ These were very clear-cut differences.

Coming from anthropology, especially because it centred a lot on tribal issues, the issues of indigenous communities was one particular absence I found in the women’s movements. Everything was clubbed and lumped under the category of rural. The distinction between say peasants and tribal communities or nomadic communities, those differences were not at all paid attention to. Since I had some experience with Naga women during my Masters, I think I had very a different experience of analysing how we looked at these communities. For instance, the Nagas were seen to be a very masculine and patriarchal community; however, women had a special place there. Communities which were very far off from the mainstream, and also distant in terms of the imagination, of how they lived, continue to live, how they go about, and how they negotiate with patriarchal systems, etc. were some of my concerns.

From my PhD, I moved on to looking at some of the concerns of indigenous women. But when it came to early 2000, I moved to JNU from the Delhi School of Economics where I taught for around five years. It was around 2001 that a senior colleague from the CSSS suggested that there was funding available with the government. I was looking to do something new, and he said, ‘This is the Department of Disability Affairs. (I think it was not called the Department of Disability Affairs, it was something else—Social Justice and Empowerment). They had funding so why don’t you take up a project.’ And I said that I had not done any work on disability, so I really did not think I could propose a project. So, he said why not try. So, I said okay, and then I started to look at the literature and I was really horrified because in sociology and social anthropology, the disciplines I teach in and have been working in, there were virtually no references or were very few, and that too whatever I found was obviously from the Global North, like the theories. So much of material from there but almost nothing from here.

Because I had been concerned with women’s studies, working with women’s studies, and teaching gender, I thought to myself (and that was the point when there was a lot of debate about skewed sex ratios in North India), ‘What happens in states where there is already a skewed sex ratio (like Haryana, for instance) and what are the chances of seeing children with disabilities, especially female children with disabilities?’ I assumed that they would not stand any chance of living. I think that is how I started thinking in terms of intersection between gender and disability. I wanted to work in a rural area because my PhD, and much of the work, was largely urban-centred. That was also another point. I thought Haryana being very close by, it would be easier for me to do fieldwork.

When I started to work and look at things from a feminist perspective, I realised that this is one category which is completely missing. I came across Anita Ghai’s work where she has talked about absence of women with disabilities from the women’s movements.¹¹ I think this was a paper or in some interview she had said that and it struck me again that within the women’s movements, is it true that we are not talking about some

¹¹ Anita Ghai, ‘Disabled Women: An Excluded Agenda of Indian Feminism’ (2002) 17(3) *Hypatia* 49.

of the concerns of women with disabilities? They were virtually invisible in the feminist discourses as well as in the social sciences. So that is how my interest began.

Gradually, I was teaching a course on family and kinship and also teaching a course on gender and I realised that after the publication of one or two papers of mine, students who wanted to work on disability issues started to gravitate towards it; they brought in a very fresh perspective and I just started getting immersed in this field, and here I am 20 years later, having looked at so many different aspects of not just gender and disability but also movements, politics, policies, etc.

2. **AG:** *Is the field of disability studies in India as old as your interest in it? Could you offer some historical sense of how disability studies emerged as a field of scholarship in India?*

NM: I do not know whether you have seen my recent work, *Disability Studies in India: Interdisciplinary Perspectives*.¹² This is the book that I have wanted to write for a very long time because when I was at the University of California, Berkeley, on a Fulbright Fellowship, the idea was to explore the ways in which the disability studies programme came up in the United States (US). So, I did fieldwork in three places in the US. Syracuse University had a very important centre for law and disabilities and Professor Arlene Kanter has been one of the pioneers in this field.¹³ Berkeley, of course, is almost a birthplace of disability rights movements.¹⁴ University of Illinois at Chicago again had a very important disability studies centre.¹⁵ What I learnt from there was the value of documentation. They have been documenting, especially at Berkeley. They have documented narratives of parents of children with disabilities, and the early activists. Documentation is very important in writing the histories of people who presumably have no voice.

I had undertaken a similar project in India also in the years 2015–2017. In that, I was looking at disability studies programmes in India and this was almost on the same lines as I saw in the US; but in the US, the field of disability studies is much older and they have well developed programmes.¹⁶ This project's findings are coming up in the shape of articles. One of the articles is where I have mapped disability studies programmes in Hyderabad.¹⁷ It is a part of the book volume I edited.

¹² Nilika Mehrotra (ed), *Disability Studies in India: Interdisciplinary Perspectives* (Springer Nature 2020).

¹³ 'Disability Studies at Syracuse University' (Syracuse University). <https://soe.syr.edu/disability-studies/>. Accessed 25 October 2021.

¹⁴ Anne Brice, 'Campus Archives Reveal Genesis of US Disability Rights Movement' (*Berkeley News*, 20 October 2020). <https://news.berkeley.edu/2020/10/20/campus-archives-reveal-genesis-of-u-s-disability-rights-movement/>. Accessed 25 October 2021.

¹⁵ 'Disability and Human Development' (College of Applied Health Sciences UIC). <https://ahs.uic.edu/disability-human-development/>. Accessed 25 October 2021.

¹⁶ See Cecilia Capuzzi Simon, 'Disability Studies: A New Normal' (*The New York Times*, 01 November 2013). <https://www.nytimes.com/2013/11/03/education/edlife/disability-studies-a-new-normal.html>. Accessed 25 October 2021.

¹⁷ Nilika Mehrotra and Ritika Gulyani, 'Mapping Disability Studies Programmes in India: A Case of Hyderabad, Telangana' in Mehrotra (ed), *Disability Studies in India* (n 12).

Another one is coming in a book edited by Sandhya Limaye where I have looked at the disability and action centre at the Tata Institute of Social Sciences (TISS), Mumbai, trying to understand why rehabilitation is such a persistent theme in disability studies. The third article in the making is where I look at Delhi and JNU.

This project was a kind of a study of the programmes across the country and I realised that some of the oldest programmes have been at TISS and at NALSAR (started by Professor Amita Dhanda).¹⁸ In Hyderabad, things are just coming up, and in Delhi and JNU, things have again not taken a concrete shape. There has been a lot of activism, also academic engagements, but there are no disability studies programmes as such in Delhi University and JNU. There are multiple reasons for this like academic invisibility, administrative apathy, lack of faculty, etc. Now disability studies programmes are supposed to be there in every university because of the mandate from the UGC.¹⁹ The programmes are just coming up. I found that in 28 academic institutions, some kind of disability studies programme existed and out of these 28, 17 institutions were functioning as academic centres and provided trainings, conducted workshops, seminars, conferences, etc., in the field of disability studies. 6 institutions work largely on rehabilitation of the PWDs. 5 worked mainly in the field of special education.

What I found was that TISS as well as NALSAR are the two prominent places where there is a proper focus on disability studies. In TISS, there are faculty who are trained in disability studies, having done research on disability issues, and they have a very large component of MA in Social Work with a special provision for disability studies training. In NALSAR, the disability studies centre is small, but they have been doing commendable work. Their contribution to the RPwD Act 2016 was that they actually came up with the draft that underwent so many changes before being passed by the Parliament. These two places have been amazingly active for more than a decade or so. My book has Amita Dhanda's paper on NALSAR and the growth and evolution of disability studies in NALSAR.²⁰ Other papers, like Srilatha's paper, document how disability studies have grown within the social work sector.²¹

This book was put together by thinking about how disability studies have grown within different disciplines. Shilpaa Anand has been doing a lot of historical work in the field of English literature through fiction and also through other kinds of secondary sources. Within sociology, for instance, I have been looking at Renu Addlakha.

¹⁸ 'Centre for Disability Studies and Action' (Tata Institute of Social Sciences). <https://www.tiss.edu/view/6/mumbai-campus/school-of-social-work/centre-for-disability-studies-and-action/about-7/>. Accessed 25 October 2021; 'Centre for Disability Studies' (Nalsar University of Law). <https://nalsar.ac.in/centre-disability-studies>. Accessed 25 October 2021.

¹⁹ University Grants Commission, *Guidelines for Persons with Disabilities Scheme in Colleges XII Plan (2012–2017)*.

²⁰ Amita Dhanda, 'Establishing a Disability Studies Centre in a Law University: Recounting the CDS NALSAR Experience' in Mehrotra (ed), *Disability Studies in India* (n 12).

²¹ Srilatha Juvva, 'Disability Social Work Education: Emerging Trajectory in India' in Mehrotra (ed), *Disability Studies in India* (n 12).

She has, in a paper, talked about the sociology of disability; though she does not focus so much on India.²²

Also, I would say that in terms of the growth of disability studies, it is very new, it is still trying to find its feet, largely centred on individuals like Amita Dhanda and Anita Ghai. Ghai has been trying for a very long time, rather for more than almost a decade, and I have been working with her for starting disability studies at Ambedkar University (AUD). Finally, they have been able to get disability studies at AUD, especially a PhD programme.²³ As far as JNU is concerned, I have tried several times to start a centre in the School of Social Sciences and presented petitions to the Vice Chancellors.

Before I started to work in this field, there was another person—G N Karna. He was very active; he was located in the field of international studies and was very active in promoting disability studies. Somehow, this Disability Centre was shifted to International Studies, which hardly made any sense to me. They advertised for a professorship also. It was connected to human rights in JNU. But it never took off. He [Karna] has passed away recently. In the English department at JNU, Professor Navneet Sethi was trying to start courses.

In my own Centre, some students have done research on disability studies but there are no courses as such. I have been trying to incorporate a disability studies perspective in almost all the courses that I teach, and I plan to start courses but because of administrative work (I was the Chair of the CSSS for three to four years), there is so much work that I have not been able to start on my own.

It [the field of disability studies] is still in infancy, I would say. In some places, it is also working in tandem with equal opportunity offices which provide assistive devices and assistive services to students, so there is no distinction between the academic branch and the service branch. It is a kind of mixed bag, and we are still working at it. There are few individuals who are working at it. It takes a long time to build institutions.²⁴

3. **AG:** *What, according to you, is the relationship between the theoretical understandings of disability and disability rights activism that you see in India? How have understandings of the term ‘disability’ evolved within these two realms? In what way do you encounter this relationship between theory and practice and work with it?*

NM: If you look elsewhere, especially in the western contexts, disability studies and the disability movements have worked very closely together. In the beginning, if you look at the disability rights movements in the US, the activism part was very

²² Even though the title of the article gives the impression that its focus will be on India, the discussion of India is limited. See Renu Addlakha, ‘The Sociology of Disability: Conceptual Ethnography of an Analytical Category in India’ in Sanjay Srivastava, Yasmeen Arif, and Janaki Abraham (eds), *Critical Themes in Indian Sociology* (SAGE Publications India 2019).

²³ School of Human Studies, *Bulletin Information PhD Programme (Disability Studies) Admissions 2020-21* (Dr B R Ambedkar University of Delhi). <https://aud.ac.in/uploads/4/admission/admission-2021/rs-admission/phd-disability-studies-2021-flyer-converted.pdf>. Accessed 25 October 2021.

²⁴ For details, see Mehrotra (ed), *Disability Studies in India* (n 12).

clearly evident and the activism by blind and later, persons from cross disabilities, was seen to be active in India also. In law, I would say Amita Dhanda's pioneering work on mental health was one very important intervention. In the social sciences on the other hand, discussion about disability occurred in social work or psychology or rehabilitation studies etc., but not in history, sociology, or social anthropology. There was hardly any attempt to define disability because people were not really interested in working in this field.²⁵

In movements, what I saw was that they drew a lot from work happening in the Global North, especially from movements that were based on the social model. In disability studies too, in the beginning, you find that the social model has been very dominant, and the focus was obviously on social institutions and oppressive structures.

But if you look at the ground level, the research was largely in the field of special education and rehabilitation studies. For instance, if you look at the TISS centre, they are often accused of working with the rehabilitation model,²⁶ and in my own research project (in 2017) I found that a large number of disability studies centres work with the rehabilitation model in mind. Welfare and rehabilitation were the key words in order to understand how the research was proceeding.

You find a number of disability rights activists also taking interest in disability studies research, like Jagdish Chander. He went to Syracuse. His work looks at blind schools from a very clear social model perspective. Anita Ghai's work has also been informed by western theories and philosophy. Renu Addlakha's work has also drawn a lot from the Global North theories. They were also trying to bring back some of these ideas to the movements.

India is so complex and there is no one movement, there are many movements, and there are many NGOs and many international NGO-informed movements. I would say that the work [between theory and practice] has not been going together. It has been in two different directions except for a few works like Unnati,²⁷ for instance. It is a very good example from Gujarat where they have tried to bring theory and practice together. But most of the movement work, if you see, and it is not just with disability studies, but sometimes the movement work is based on rhetoric and not so much on evidence and facts and the way we look at experiences etc. I will just give you a small example from when I started working on rural women with disabilities. Before that, the movement literature was largely talking about how women with disabilities are never married or they find it extremely difficult to marry; they are not expected to be mothers. So, sexuality and motherhood were supposedly denied. These are largely from an exclusion/oppression model where you essentially see them as victims. But in my own work, I saw them as agents. I saw that people with disabilities and their families might be finding it difficult to find spouses, but

²⁵ See Anita Ghai, 'Ignorance of Disability: Some Epistemological Questions' in Mehrotra (ed), *Disability Studies in India* (n 12).

²⁶ The rehabilitation tradition goes beyond the medical model to focus on the conditions of "recovery". See Deborah Marks, 'Models of Disability' (1997) 19(3) *Disability and Rehabilitation* 85, 87-88.

²⁷ 'Vision' (Unnati Organisation for Development Education). <https://www.unnati.org/>. Accessed 25 October 2021.

my work suggested that nevertheless, there are cultural strategies and ways in which they find partners. They also become mothers. I could see a disconnect between what I saw in terms of movement literature and what I saw on the ground.

But when I look at some other movement literature, I sometimes find that the language of victimhood or victimisation and oppression is used. Often, PWDs are not seen as agents who also know how to handle their lives and who have their own negotiations. That is one problem I see between disability studies and disability activism because the latter might scoff at any attempt at saying that not everybody sees oneself as a victim. For instance, some elderly women in my work would refute these things. I was young and when I asked in conversations if they saw themselves as oppressed, they were extremely self-assured and confident. I did not see them wallowing in self-pity.

The second disconnect I found between disability studies and disability movements/activism was that it was unlike women's studies, where most of the women's studies scholars were also activists, or where activists actually took up research and became researchers—they were doing these two things together. I find that in India, especially, disability rights activists are not essentially researchers and except a few, most might be working in two very different directions. In my work, for instance in this new book, I tried to bring in some people who are activists to write papers, but activists do not like to write, and researchers do not like to be in the field.

That is the kind of disconnect you see in all other fields also. But in disability studies, there are very few people who reach higher education settings and who are able to do research. I had two or three students with disabilities who I thought should work on these areas, but they were not happy doing it. They declined. One of them is working on environmental pollution and the other is working on social enterprises; they saw these topics as more marketable and interesting. They said that, of course, they had their own battles and struggles but they did not necessarily bring in their personal lives to their research. There should be some separation between the self and research. It is very difficult to generalise, but I do see a kind of separation.

When we think about the RPwD Act, it has gone through so many drafts. I am sure disability researchers have also contributed to the way the definition of disability has evolved. You will see that if you look at the 1995 Act and the way disability was defined in terms of those with more than 40% disability being considered to be disabled,²⁸ to a definition of disability where it is more about long-term mental, physical, and other environmental factors working to create barriers for people to actually enjoy full participation. But I will not say that it is only because of the Indian disability studies researchers. It is the research which is happening all around the globe. The WHO Report of 2011²⁹ and the World Bank Report

²⁸ See Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 s 2(t).

²⁹ World Health Organisation and World Bank, *World Report on Disability* (World Health Organisation 2011). https://www.who.int/disabilities/world_report/2011/report.pdf. Accessed 25 October 2021.

of 2007³⁰ have been extremely important. Several such reports are there. I think research does contribute to movements and movements, of course, throw up questions which need to be answered by research. It is a kind of two-way process but a tenuous kind of a process; it is not an easy process.

4. **Surabhi Singh (SS):** *You have written previously,³¹ and mentioned earlier in this interview, that there is a dearth of original research and literature in disability studies that is not based on the medical model, but instead focuses on models where women's agency is not necessarily taken into consideration. To what extent do you think that socially-lived theorising³² is utilised in the epistemology of disability?*

NM: I think it is now that more and more people are interested in lived realities. If you see from the mid-90s onwards, especially in development research—whether under the influence of international organisations or not—qualitative methodologies actually became more important, more than numbers, due to critiques of economics research largely dealing with statistics and not life histories. Numbers, at least in disability studies, are very important, because if we do not have numbers, we cannot frame policies.

But again, in terms of generalisations, when we only look at numbers, it becomes difficult too because it erases specificities. That is why lived experiences are important. And coming from anthropology, I have been saying that we need more ethnographic studies. We need lived realities of people. Let me just give examples. One of my students, Shubhangi Vaidya, has written on families with autistic children.³³ It's a very fine work, an ethnography of families, how they cope with different aspects of living with an autistic child.

Another one of my students is Mahima Nayar, whose work *Against All Odds* has also been published with SAGE.³⁴ She has been looking at psychosocial disabilities and how macroeconomic factors actually accentuate psychosocial distress for women in resettlement colonies. And it is also a very fine-grained work because it is hard to imagine how small things have an impact. For example, you can see this in one of the stories that we wrote together, about 'Bela' who constantly complains

³⁰ Human Development Unit South Asia Region and World Bank, *People with Disabilities in India: From Commitments to Outcomes* (World Bank 2007). <https://documents1.worldbank.org/curated/en/358151468268839622/pdf/415850IN0Disab1ort0NOV200701PUBLIC1.pdf>. Accessed 25 October 25, 2021.

³¹ Nilika Mehrotra, 'Disability Rights Movements in India: Politics and Practice' (2011) 46(6) *Economic & Political Weekly* 69.

³² Socially-lived theorising is the creation of knowledge from the everyday experiences of the marginalised. See Milian Kang et al., *Introduction to Women, Gender, Sexuality Studies* (University of Massachusetts Amherst Libraries 2017) 22.

³³ Shubhangi Vaidya, 'Disorder, Disability, Difference: (Re)presenting Autism in India' in Mehrotra (ed), *Disability Studies in India* (n 12). See also, Shubhangi Vaidya, *Autism and the Family in Urban India: Looking back, Looking Forward* (Springer 2016).

³⁴ Mahima Nayar, *Against All Odds: Psychosocial Distress and Healing among Women* (SAGE 2019).

of aches and pains.³⁵ Hers is a household where the daughter has lost her husband and she has returned with the children to Bela's place. The husband is ill, the son wants to travel by Metro, and wants a new model of mobile phone, etc. All this kind of pressure creates so much psychosocial distress in Bela that she's constantly complaining of aches and pains. And no medical intervention actually talks about what poverty does to people or living conditions do to people, especially women, and what pressures they bring to women. These two are just examples of students who did ethnographic work.

I have many other students who are working on their PhDs similarly. Pooja Singh has examined the intersectionality of caste, religion, gender, and disability in rural Farrukhabad, Uttar Pradesh.³⁶ One student has just finished her work on how the psych disciplines, especially psychiatry and psychology, look at LGBTQ+ persons and their mental health. It's a very interesting work again. Most of these people have done some research either in communities or organisations. And they bring to us those complexities which are not really captured in movement literature. Movement literature tends to homogenise. This is a tendency that we have inherited from the movement literature of the Global North, where this was also happening in women's studies, that we were refusing to see the differences. The same thing was happening in disability studies also.

Theory, by definition, should have a universalising implication. But we also know that no theory has a totally universalising potential. We speak of theories from the Global North, theories from the Global South, etc. And these theories must bring in the differences and plurality of life situations, the multivocalities and inequalities within the communities. For instance, in development discourse, you often hear that we should listen to the community. But as women's studies researchers, we know that within the community, women's interests are often undermined, especially when we talk about community rights. For example, in personal law in India, we have seen what is happening, especially with all these debates over women's participation and rights, for instance debates on women's rights in minority communities like Muslims³⁷ or tribal communities from the Northeast.³⁸ I find that a good theory is one which is able to at least explain and examine more than one situation. It is able to at least bring out some kind of similarities between a number of situations, but not necessarily explain everything.

I also think that this sensitivity to specific histories and cultures enriches theory. It does justice to people, especially in intersectional terms. Earlier, we were not using this term 'intersectionality' when we were students and even till I would say five to ten years ago. We were hardly using it. But in our work as anthropologists,

³⁵ Ibid. 92.

³⁶ Pooja Singh 'Exploring Intersections of Disability, Caste and Gender in Rural Farrukhabad, Uttar Pradesh' (Unpublished PhD Thesis, Jawaharlal Nehru University 2018).

³⁷ See e.g., Nida Kirmani, 'Claiming Their Space: Muslim Women-led Networks and the Women's Movement in India' (2009) 11(1) *Journal of International Women's Studies* 78–79.

³⁸ See e.g., Lianboi Vaiphei, 'Equality and Tradition Clash as Naga Women in India's Northeast Fight for Political Representation' (*The Conversation*, 15 January 2019). <https://theconversation.com/equality-and-tradition-clash-as-naga-women-in-indias-northeast-fight-for-political-representation-73804>. Accessed 25 October 2021.

we have always looked at the intersections. And these intersections definitely make for difficult reading. They make for a difficult interpretation of social reality also. Often policymakers tell us that you give us two-three points, four points, to draw a policy on. But that is not what life is all about. Life is dynamic. And that is the main problem with our research sometimes. By the time we finish our research, life has moved on. So, in all, theory from the Global South has to take cognisance of differences—different cultures, different ideas, values. At one level we might think similarly, at another level very differently. So, think and live both.

5. **SS:** *This next question is related to this idea of theorising that you just spoke of. You have previously written³⁹ that some scholars think that non-disabled scholars ought not to be writing about disability. Similar concerns about who constructs knowledge, have also been raised by women's studies scholars and Dalit studies scholars. However, this approach may be seen to be limiting by some who critique the shortcomings of identity politics. According to you, what can be the possibilities as well as limitations of each of these two approaches?*

NM: I'll just give you an example of my very first meeting that I had attended at NUEPA⁴⁰ in 2002. This was the first meeting on disability studies that I had attended. What was interesting to me then was that there were a number of PWDs present, who were not necessarily trained in this field. They were scholars from other fields, and they were brought in because it was felt that they had something to say. For me, I thought it was a bit self-defeating because with many of them, we had to start from the very definition of disability. So, if I have a disability, it does not mean that I can also theorise about that, unless I am also a researcher. There is a value in research, in methodology, and in systematically engaging with a subject. Only because I am a woman or I am a Dalit or I am a PWD, it does not really entitle me to claim that I could come up with a theory. And this has happened with me quite often. I was earlier working with the women's organisations and there I saw these differences like for instance, caste, and class differences were pronounced. I also worked with a colleague for North East studies. And we built up a North East Studies Centre at JNU,⁴¹ and there again, I was being treated as an outsider since I did not belong to the region.

After a certain point, obviously people start coming in from the field itself. And I have absolutely no problem with that. I would much rather have this. It is how in

³⁹ Mehrotra, 'Disability Rights Movements in India' (n 31) 69.

⁴⁰ NUEPA is the National University of Educational Planning and Administration, an autonomous institute and a deemed to be University. Its functions are carrying out research on educational planning, imparting training to educators, amongst others. 'National University of Educational Planning and Administration' (Ministry of Education, Government of India). <https://www.education.gov.in/en/national-university-educational-planning-and-administration-nuepa>. Accessed 26 October 2021.

⁴¹ 'Special Centre for the Study of North East India' (JNU). <https://www.jnu.ac.in/scsnei>. Accessed 25 October 2021.

disability rights movements, we say ‘nothing about us, without us.’⁴² PWDs must participate at every step. Even in research, we look at people as collaborators and participants and not as subjects or respondents.

Of course, there are also ethical issues involved when we say that PWDs should be involved at every level of consultation. But I think by claiming that you have a certain kind of condition, you cannot actually claim expertise also. Research expertise is needed in social science research. Like it has taken me 20 years to be able to say that I know a little bit about this field.

So, I do think that identity politics has a limiting aspect. But at the same time, I also see today some very young activists with disabilities writing very well, bringing in their experiences and enriching the literature. However, does that create conceptual clarity? That is my concern. Like my ex-PhD student, Shubhangi Vaidya, who did her work on families with autistic children,⁴³ she herself is a mother of an autistic child. Often, I have had to tell her to be a little objective because, for me, objectivity still retains some value in research. Situational objectivity as well as subjectivity has its own problems as well as contributions. Earlier, Shubhangi would not understand this need for being objective. However, once she called me after many rounds of discussion on this and said, ‘Now I know what you mean by being more objective.’ I asked her what had happened. She said that in one of the families that she was working with, one of the two children had autism and now the other had cancer. That pushed her to her think about objectivity. She was able to see what crisis does to the family, how families cope with this kind of a crisis. What I am trying to say is that experience narratives have their own role in research, but in social science, we are also concerned with facts and patterns in short regularities.

Facts and evidence are also required, especially if we think about policies and creating laws. For instance, if you want to have amendments in the law, how will you show the need for the same? Similarly, even in feminist studies now, we have something called ‘governance feminism’,⁴⁴ which talks about evidence and facts. So, what is really needed is to bring everything together. And research has its own value, and it should not be just reduced to identity politics.

I would say that in the case of India, what happened is that there were very few people with disabilities as scholars when I began working. Now this number is growing, which is a very good thing. When I began work, some of my colleagues

⁴² In the context of the disability rights movement, author and scholar James Charlton attributes the origin of the slogan ‘Nothing About Us Without Us’ to South African disability rights activists Michael Masutha and William Rowland, who had in turn heard it being used by someone at an international disability rights conference. The slogan is a demand for control, which as per Charlton appeals to the disability rights movement ‘because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of powerlessness, poverty, degradation, and institutionalisation.’ See James I Charlton, *Nothing About US Without US: Disability Oppression and Empowerment* (University of California Press 2000) 3.

⁴³ See Vaidya, *Autism and the Family in Urban India* (n 33); Vaidya, ‘Disorder, Disability, Difference’ (n 33).

⁴⁴ Governance feminism is the inculcation of feminist ideas in legal-institutional power. See Janet Haley et al., ‘From the International to the Local in Feminist Legal Responses to Rape, Prostitution/Sex Work, and Sex Trafficking: Four Studies in Contemporary Governance Feminism’ (2006) 29 *Harvard Journal of Law and Gender* 335, 340.

welcomed my work because there was such little literature available. But I am sure over time, like in the next 10 years or so, some other very good work will come, which will completely either erase my work or my work will become historical. So that is how knowledge grows and so I do not see why we should not have the so-called non-disabled people writing on disability. Also, in my case over the last 20 years, from a person who did not see a disability from a very close angle, especially in personal life, I have seen my sister living with disability now. I too am suffering for the last three years with spinal issues and living with chronic pain. If you look at disability as a part of the human condition, we are going to be there sometime today or later. And that perspective should be kept in mind. If you are able bodied today, it does not mean that you will remain as able bodied always.

6. **AG:** *In 2011, you wrote, ‘PWD were and are a divided group signified by diversity. Disability cuts across race, caste, and class divisions and therefore the likelihood of framing groups was not a simple possibility.’⁴⁵ However, to gain recognition by the state, the language of shared injury and creation of a separate identity, even if for strategic purposes, becomes imperative. Do you think that the disabled identity can overcome divisions of gender, race, caste, and class? In what way can the disability movements maintain a tangible identity while providing space for the discussion of intersectional discrimination?*

NM: You spoke about diversity and the impossibility of forming a group. When I was writing this paper, I did not see a lot of coming together. Even today, I work in JNU, I see groups that are cross disability. But more functional are those groups that are based on a single disability. For instance, the blind/visually impaired students forum is very active on the ground, and the other JNU Disabled Persons Association (DPA) is less active.⁴⁶ I do not find people with different disabilities always coming together.

It could be possible that in the last five-six years, JNU has seen so much⁴⁷ that movements have also taken a low profile. But I would say that 2010 to 2015 was a very good time in JNU when I saw students of different disabilities coming together and forming a disabled identity. They were negotiating with the administration also. For the last few years there has been lukewarm, tokenistic response to disability issues in JNU. This is just a small example I am giving. Because this is so close to me, I have seen how these activists would take their demands, and they were also engaging with the faculty like me and others, we were doing conferences and workshops etc., and it was a very good moment. I would say that there are moments of camaraderie, moments of coming together. But in those moments also, what one realised was that they knew so little about each other. Saying that the so-called non-disabled do not know about them but within the disability community also, if there

⁴⁵ Mehrotra, ‘Disability Rights Movements in India’ (n 31) 65, 66.

⁴⁶ ‘JNU Disabled Persons Association’ (JNU). <https://www.jnu.ac.in/jnudpa>. Accessed 25 October 2021.

⁴⁷ IANS, ‘JNU: Hub of Controversies’ (*The New Indian Express*, 16 November 2019). <https://www.newindianexpress.com/cities/delhi/2019/nov/16/jnu-hub-of-controversies-2062679.html>. Accessed 29 October 2021.

is a community, everybody seems to say how victimised they were, or that they were more victimised than the other group.

I think it was also contestation of a sort of political interests, of taking forward their demands, their disability-specific demands, and very little desire to engage with say, for instance, a lot of people with psychosocial disabilities. They have always complained that they are not taken seriously because they look “fine”. Reshma Valiappan, who has been writing so much, has always said that she has more barriers because she cannot get married, she cannot get a job but she looks fine, she talks fine but her problem is here [pointing towards the head] so people do not understand what she goes through.⁴⁸ Bhargavi Davar has also written a great deal on issues of psycho-social disability and legal barriers.⁴⁹

People with intellectual disabilities are hardly represented in the disability communities, so either their parents are speaking for them, or very high functioning autistic individuals or neurodiverse individuals are speaking for the whole community. So, there will always be differences of some kind or the other.

Within the blind community, there would be a distance. Some would feel that people with low vision get more priority over those who are 100% blind and so on. These are the dissensions you will find. Michele Friedner has written a great deal about the deaf community and how they are completely marginalised from the disability rights movements.⁵⁰ One of my students, Ritika Gulyani, has done her work on deaf youth.⁵¹ She talks about how difficult it is for them to have other kinds of social interactions as they tend to become more introverted because of they cannot hear and many of them cannot speak. So, they develop their own social world. This also has much to do with their single disability-specific schooling, like blind schools or deaf and speech impaired schools, which create a kind of solidarity which is very difficult to break when they try to become a part of the larger cross-disability movement. Hemachandran Karah has recently wonderfully written about what blind schools actually do, if they empower students, what kinds of barriers they have created, and all that.⁵² That is why I find that these are disability-specific barriers within the movements.

But then there are intersectionalities like class and caste. I remember one of the conferences I attended at the Council for Social Development in Hyderabad. It was also on law and disability or something like that. There I found that there were some activists from rural areas and there was hardly a way in which communication was happening between “us” and “them”. Their experiences were very different, our

⁴⁸ ‘About Val Resh’ (Valresh.com). <https://www.valresh.com/>. Accessed 25 October 2021.

⁴⁹ ‘Bhargavi Davar’ (International Growth Centre). <https://www.theigc.org/person/bhargavi-davar/>. Accessed 25 October 2021.

⁵⁰ The Department of Comparative Human Development, ‘Michele Friedner’ (The University of Chicago). <https://humdev.uchicago.edu/directory/michele-friedner>. Accessed 25 October 2021.

⁵¹ Ritika Gulyani, ‘Examining the Question of Deaf Education within Disability Studies in Delhi, India’ in Mehrotra (ed), *Disability Studies in India* (n 12).

⁵² Hemachandran Karah, *The Metanarrative of Blindness in India: Special Education and Assumed Knowledge Cultures* (Routledge 2021).

experiences were different. Our experiences were largely based on our research, they were thorough grassroots activists.

That is why I say in my title also in the 2011 article, that I wrote about movements, not just a movement.⁵³ This is the main mistake we committed in the women's movements also, that we thought that there was a women's movement; no, there are movements. Because they cater to differential categories of people, they have specific requirements, they have different aspirations and goals and visions of what kind of society they want to live in. They sometimes come together for strategic purposes but most of the time they are working in their own small niches. That is what I see and that is not changing much. I do not see that changing much.

7. **AG:** *Continuing our conversation on divisions within movements, these divisions do make the cross-movements much richer, but do you think they affect the ability of the disability rights movements to negotiate with the state?*

NM: Yeah, like we have seen in the case of the RPwD Act, before it was passed, I think just before that, it was put in a lull for a year or two. This was, I think, in 2014. There was so much of dissension in the movements. I think the government wanted to pass it in a huff, which led a lot of activists to be divided. There was a division between the blind activists and those who were representing the interest of the intellectual and psychosocial disabilities. The blind activists were in a hurry to push it because they said that they had waited for a very long time, whereas others wanted their concerns to be properly contained in the new draft. This was also a very important moment of crisis in the movements. I do not know whether both of you are a part of the disability studies Google group which Shilpaa Anand runs.⁵⁴ There was a whole thread over this, with people writing and people responding.

Secondly, on one question recently, there was a major point [of departure]. This is again a very small fraction of what we are seeing of the disability rights movements. What happens on the ground, we really do not know; this is only for us who can read and who can engage on social media. Another thing which happened recently during the 'Me Too' movement when one prominent activist died, and one survivor claimed that this particular activist had tried to molest her some years earlier. She raised this issue and the whole community got divided very badly, saying that on death we should forget about all that. She said this is how accusations, especially gender-based accusations, are completely brushed aside.

Every movement, and the disability rights movements are no exception, will have contradictions and contradictions bring in dynamism and change. Without that, unless people air out their differences, unless people have dissensions, how democratic a movement then can it be? These are new social movements without very clearly assigned leaders and, therefore, I think the movements will have to be imagined in terms of patches or scattered groups who would definitely come together. And this not just, as I said, disability rights groups. In the women's movements, I

⁵³ Mehrotra, 'Disability Rights Movements in India' (n 31) 65.

⁵⁴ 'Disability Studies India' (Google Groups). <http://disability-studies-india@googlegroups.com>. Accessed 28 October 2021.

saw the same thing in the late 80s. They hardly saw each other, hardly agreed on anything. They had very different views on things, so you cannot have people agreeing on everything.

8. **AG:** *In the Preface to Disability, Gender and State Policy,*⁵⁵ you note that legislation of the rights of the disabled was a product of international pressure. This was accompanied by increased participation of international NGOs, making access to funds easier for disability rights movements. Since a lot of work on rights and social justice is funding dependent, there is always a risk of funding agencies (especially international ones) imposing a neoliberal agenda on movements.⁵⁶ So, although funding has opened up several rehabilitation avenues for PWDs, it has also depoliticised and homogenised disability rights. In what way can this paradox be navigated?

NM: This is the crisis of the development process. You look at the World Bank in 1998 or 1999, I am forgetting. They, for the first time, spoke about disability besides gender and how it should be at the heart of development discourse.⁵⁷ Now you see almost all international organisations talking about disability, which is a great thing. Even I would say that I would owe my interest in disability studies to that particular small fellowship that I got from the state for doing research. I think that you cannot reduce the role of funding organisations, you cannot ignore that.

But as we have seen in the case of the women's movements, a lot of NGO-isation happened from the early 90s onwards.⁵⁸ In the case of the disability rights movements, I think many of the disability rights only came because of these funding organisations. When I was working in 2002, we worked with an NGO at a village named Khorī in Haryana. When we asked about whether they had any agenda regarding disability, they said that they did not. Out of the two-three other NGOs in Haryana that we spoke to, none had disability as an agenda in their discourse. They will start thinking about these issues only if the money is available. That always has a limiting role.

Since I worked with tribal development also in the past, in the 90s, I found at that point—and this was in Odisha—that nobody was talking about public health. All the NGOs were putting in money for education. I am not saying that education is not important, but everybody was putting in money for that. Those were the areas where malaria is endemic and when we were doing fieldwork in 1995, the District Magistrate had died of brain malaria. Imagine how people must be surviving in those areas and none of these international NGOs thought about putting in money for health. Today, after COVID-19, everybody is saying that we should put in money for public

⁵⁵ Nilika Mehrotra, *Disability, Gender and State Policy: Exploring Margins* (Rawat Publications 2013) 16.

⁵⁶ See Srila Roy, 'The Indian Women's Movement: Within and Beyond NGOization' (2015) 10(1) *Journal of South Asian Development* 96.

⁵⁷ Ann Elwan, *Poverty and Disability: A Survey of the Literature* (World Bank 1999). <https://documents1.worldbank.org/curated/en/488521468764667300/pdf/multi-page.pdf>. Accessed 25 October 2021.

⁵⁸ Roy, quoting Ashley Tellis, 'The Indian Women's Movement' (n 56) 97.

health. That is the problem, that you do not ask people what they want, you do not see what the priority of the people could be.

I think that initially when NGOs were formed in the 80s and 90s, the activists were very clear about what they wanted to do. Today, because of the professionalism, so much of professionalism—social workers are also being professionalised, it is a paid job—you take up a project because there is money and then you close it and then you move on to another project.⁵⁹ That is also going to happen to this field.

I think that brings a question of the state. The nature of the state has changed. This neoliberal state, though it is very compromised to constantly deal with the market and NGOs etc., it nevertheless is also bound by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).⁶⁰ If you do not follow it, you will have problems. I will just give you an example of a university. Universities go in for NAAC accreditation and one of the things it mandates is that you have to provide disability accessible infrastructure.⁶¹ Whether you want it or not, you will have to have that structure; only then will you get points. So, it's a vicious circle that demand is created, the resources are accessed because there is a global discourse at work, but global discourse also limits your work because you can work for, say, assisted devices and not for say health.

9. **SS:** *In your field work-based research on rural women in Haryana,⁶² you have found that there are inbuilt cultural mechanisms available to disabled women within family, kin, caste, and community. A similar theme is also found in your chapter in the book Disability Studies in India,⁶³ where you have written about how mental disabilities are often managed within the ambit of family and social networks. Yet, for disabled women, these social structures of kin, caste, family are very often also patriarchal sites of gender-based oppression. In your opinion, can these ideas be reconciled? If yes, how?*

NM: If you look carefully at these narratives of women, and the case studies, you find the negotiations and manoeuvring of the women and their family members. You cannot see a person statically; you have to take the rhythm of life into consideration. You cannot pre-decide that all women are oppressed, or that they all face violence. Because often this is thrown at me, 'Do women with disabilities essentially face violence at home?', I answer that by asking—do women face violence? And are women with disabilities women or not? This othering process, which goes on even within

⁵⁹ Ibid. 106–109.

⁶⁰ Convention on the Rights of Persons with Disabilities (adopted on 24 January 2007, entered into force on 3 May 2008) UN Document A/RES/61/106 (CRPD).

⁶¹ NAAC Assessment Update, *Gender Sensitive Quality Indicators and Disabled Friendly Environment at Education Campus* (Published by NAAC Bangalore). <http://www.naac.gov.in/docs/Books/NAAC%20Assessment%20Update.pdf>. Accessed 25 October 2021.

⁶² Nilika Mehrotra 'Women, Disability and Social Support in Rural Haryana' (2004) 39(52) *Economic and Political Weekly* 5640.

⁶³ Nilika Mehrotra and Shubhangi Vaidya, 'Exploring Constructs of Intellectual Disability and Personhood in Haryana and Delhi' in Renu Addlakha (ed), *Disability Studies in India: Global Discourses, Local Realities* (Routledge 2013).

the movements, that you are constantly othering people, we want to normalise [questioning] this. We want to say that look, women with disabilities are like anyone and as women, we are all in it together. Yes, many times they have specific issues. Like my friend and student, who I was previously talking about. I remember when we started working on her thesis, she said to me that her family has problems. She was a single mother. Her husband had unfortunately passed away at a very young age. She had two young children and one of them had autism. And I remember that she also said, ‘This is my problem. Another family would have another problem.’

At one level, when we think about PWDs, they want to be accepted as any members of society. And in my work, especially in rural areas, I have found disability being normalised. In urban settings, often I have seen parents become overprotective. In the rural areas, I did not find this overprotection, but saw more of normalisation. But this normalisation is also oppressive because life is oppressive.

During my study in Haryana, I found that one man with a disability had committed suicide because, as you know, Haryana has a skewed sex ratio and often men are forced to marry outside the state. This has so far not appeared in my work, and I do want to write a paper on masculinity and disability in rural areas, but somehow it has not begun. This man that I mentioned was suffering on an account of a crisis of masculinity—he did not have a job, he came from a poor family, he had a disability, no prospects of marriage, and there was a lot of ridicule thrown at him. He was very sensitive, and he could not take it. In contrast to that, I found girls from the same parts much more at peace with their disability because they are made useful in some way or the other. They are working and there is also an attempt of the family to marry them off. So, there is normalisation of disability.

Another one of my students is a person with cerebral palsy. He is working on looking at disabled youth and their perceptions of sexuality, their marriage prospects, etc. And he always says that the more he talks to his informants, he finds how disability is constantly normalised within households. Practically speaking, in the beginning, for a person with disability, people will worry. But over time, you cannot keep worrying about things and you must devise your own ways to deal with things.

There are patriarchal setups which hamper women. For example, we see girls in the Indian society with a dark complexion getting rejected for marriage. This is just a small example, but there are so many other ways in which the dynamics of marriage and relationships go on. A student of mine, who has a disability, constantly tells me that because of his disability, he is not able to find a girlfriend, someone he can be in a permanent relationship with. It is happening because people think he is a disabled person. And I said to him that in relationships, it is not necessary that disability is the only consideration. It could be a very important consideration, but it’s not the only one. He does not have a job currently and he is still studying, which are also things that matter in a relationship. Maybe the girls that he comes across want to marry somebody who’s a civil servant or somebody else with some other criteria.

I would say that negotiating with patriarchal setups can become very difficult for most women with disabilities, but then we must understand what kind of, I do not want to say support, but what kind of negotiating mediating structures one has, through which one will manage life, and everybody else manages lives too. Am I not dealing with patriarchy or is another person not dealing with patriarchy? For a

disabled woman, sometimes this patriarchy can create many more barriers than in other cases, but they can find means to negotiate. A friend and colleague of mine, who had very frail health, needed constant assistance and was a wheelchair user, used to say that she was where she was because of her class. She said to me, ‘My parents thought that investment in an education is the best thing for me. And so, they did not think about my marriage, and I also did not think about my marriage.’ So, I am just saying that when you live life, your life is situated in a context. And that gives you options and choices. That also gives you barriers and support structures, and you choose. You pick and you choose. Sometimes your parents choose for you in the Indian context. In fact, often parents choose for you. And in rural areas, people go by largely what the parents have chosen for them. And so that is how life is lived.

10. **SS:** *Your study on women in rural Haryana⁶⁴ found that women with disabilities, often due to conditioning of patriarchal ideology, neglect their own health. As an academic and scholar of anthropology, have you found such gendered behaviour to have undergone any significant change in the last few years?*

NM: Much has changed, I would say, at least from what I see around me. Not necessarily in the same field as the study you are talking about, because I have not taken a longitudinal study, and so it is very difficult for me to say what has happened there or how my informants are living their life. But what I see is in the current middle-class situation—the girls with disabilities in like JNU, for instance, are extremely self-assured. They are confident and many of them are abreast with the ideas of the disability rights movements. At least those who are educated know what their rights are. But that may not be the case in all sections of society, and especially in working classes. But generally, life is always changing. For example, a PhD thesis that I examined, from the University of Hyderabad by Vandana Chaudhary, is about rural Andhra Pradesh. Again there, I found that the intervention of NGOs has actually brought in a lot of self-confidence in women with disabilities in rural areas, villages, etc. I do feel that education has a very big role. And if you are employed, that also, I think, creates capacities. Law, legal changes, public discourse, all these are enabling situations, enabling structures, which I am sure were not the same two decades back.

Also, I think our popular culture, media has a role. There have been some films recently which figure PWDs. I feel more film makers should have PWDs as characters because it works much more than anything else. People may not have legal awareness, but you know, people have some idea about how to deal with people who have disabilities. I think these attitudinal changes are very much required and people are changing. It is not that people are not changing. Some deep-seated biases and prejudices will be there always. For instance, caste prejudices are there. Have we been able to erase them? It is very difficult to do that. So, it is a slow process.

⁶⁴ Mehrotra, ‘Women, Disability and Social Support in Rural Haryana’ (n 62) 25–31.

11. **AG:** *The relationship between law and disability is an uneasy one. On the one hand, legal mechanisms construct the disabled body as a rights-bearing entity while on the other, they limit the multiplicity of disabled identities to fixed medico-juridical terms, disempowering those they had set out to empower. How do you assess this duality?*

NM: Possibly for activists, it is a duality. I am not sure who is talking; mainly activists would talk about this. Obviously, they are analysts of law but for millions of people, I would still think that it is true that medical certification is required. The RPwD Act has used not only the medical but also the social model. It has expanded the definition of disability, while examining the way we look at discrimination, the way we look at exclusion. We have many more expansive definitions today, which I think would work in favour of PWDs.

Secondly, I feel that it is true that you fix people; you create those kinds of identities, but law is a very evidence-based discipline and I think that is why it is very important to have factual reality. If you look at the Americans with Disabilities Act (ADA) 1990, they have not had a clear definition of disability.⁶⁵ Anybody who can actually produce a certificate, say I have a backache and I can produce a certificate saying that I am not able to function or work, then I would be entitled to social security. They too utilise some kind of a medicalisation.

I have always had problems with people who say that the medical model is not important; they are not right. Because in a country like ours, even a case of simple spectacles is a matter of enabling a person to go about with their normal functioning in a rural area. Let us not think from a particular class perspective. Though law does cater to the middle classes and the rich, it is nevertheless an instrument of social change. So, I feel that you cannot just rule out the importance of law in the lives of people.

On the other hand, I have problems with just the idea of legal capacity. There I ask a question and say that true, you have created legal capacity of an individual, but we are still a very collective-based society. Family is very important. A lot of people who have commented on the mental healthcare aspects of the RPwD Act 2016 find the focus on family problematic. In my work, I found that not just in case of say people with mental disabilities, but even with all kinds of benchmark disabilities,⁶⁶ the family does remain very important.

That very small quip which I have put in my 2011 paper, ‘What is independent living for PWDs in India?’,⁶⁷ led this activist, who is very prominent, to tell me, ‘I want to live independently and support my family with the family.’ And just think about independent living in the west. That is a very different kind of independent living. You are totally dependent on state support. You do not want to live with the

⁶⁵ 42 USC s 12102.

⁶⁶ Rights of Persons with Disabilities Act 2016 s 2(r), a ‘person with a benchmark disability’ refers to ‘a person with not less than forty per cent. of a specified disability where specified disability has not been defined in measurable terms and includes a person with disability where specified disability has been defined in measurable terms, as certified by the certifying authority.’

⁶⁷ Mehrotra, ‘Disability Rights Movements in India’ (n 31) 70.

family because that is not the culture to live with the family. There, the individualism is very aggressive. Our individualism is, ‘Okay I should have education, I should have a job, I should be able to do things on my own, meet a partner, maybe marry a person of my choice.’ Because I deal with young people all the time, when I ask them what they want, they do not want to exclude the family because that is the way in which most of the people live in Indian communities. So, family does remain a very important part of our lives and you see that more clearly in the laws relating to the aged people, the elderly. Even penalties can be imposed on children who do not take care of their parents. So, family remains so central in one law and the other law is more individual-centric. Why? I may ask this question. I am not saying that family is all good. Family has all kinds of problems. It is altruistic but oppressive too. But you deal with people of different kinds all the time.

My problem with the RPwD Act is that it gives very little room for family and any kind of family; it could be biological, it could be social, and it could also be a grouping which you live with. Where is the place for others? Veena Das and Renu Addlakha have written about ‘connected selves,’ that we are not individual selves, we are connected selves.⁶⁸ We are connected with each other in some way or the other and that is very telling about the way we look at the situation of individuals with disabilities situations vis-a-vis the law.

On the family aspect, I have differed with my friends with disabilities. I said, ‘Why do you forget the family?’ I said that they were taking family for granted. That is the value of objectivity in research, that you are able to see how family and community support are so essential in the absence of state support in India. And do not take it for granted. Today, in discussions on the care economy, we are saying that women should also be paid.⁶⁹ So, are they a part of the family or not? Disability and family is one field which we require more literature. One of my students is looking at disability care and family for her MPhil and I want her to do fieldwork that is more family-centred and more family-focused, because when I started to do my work, I found literature which looked at families essentially as oppressors. I thought to myself, ‘Where are these families, where are these abusive families?’ I did see these abusive families in my fieldwork. There will always be some abuse, some violence in the family but you have to have a very clear interpretation of what family is in giving a broader perspective.

12. **AG:** *In the midst of the COVID-19 pandemic, PWDs have found themselves at the receiving end of ‘triple jeopardy.’⁷⁰ First, some PWDs with underlying health conditions or chronic diseases are at a greater risk because of physiological reasons and the nature of the disease. Second, PWDs have greater*

⁶⁸ Veena Das and Renu Addlakha, ‘Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject’ (2001) 13(3) *Public Culture* 511, 520.

⁶⁹ See Shreya Khaitan, ‘Will Payment for Housework Discourage Women from Paid Work?’ (*Indiaspend*, 7 April 2021). <https://www.indiaspend.com/women/paying-women-for-housework-pragmatic-or-retrogressive-740368>. Accessed 25 October 2021.

⁷⁰ Tom Shakespeare, Florence Ndagire, and Queen E Seketi, ‘Triple Jeopardy: Disabled People and the COVID-19 Pandemic’ (2021) 397(10282) *The Lancet* 1331.

healthcare needs than the non-disabled but their access to quality healthcare has become more constrained than before because of medical rationing, where most resources are cornered by the privileged. Third, draconian lockdowns have been imposed in different parts of the world without due consideration for the supply of essentials for the disabled. What could the state have done differently? In the interest of social justice and equitable distribution of resources, could PWDs have been given certain concessions from policies that were meant to break the chain of disease transmission?

NM: I do not know whether you have seen it yet, I have edited a special volume of DGS—Disability and the Global South journal, where I have written the Introduction and I also have an article on social media activism.⁷¹ Basically, in the article on social media activism, I talk about how some groups and individuals were making special demands during the COVID-19 pandemic about access to healthcare, access to food, access to cash, and general monetary resources. Other papers that I have worked on also deal with some of these aspects. In another paper which is under publication, I specifically look at PWDs and access to food during the pandemic, since food has been one major area of distress.

I think we should do as we did in the case of gender. I think some kind of gender budgeting or disability budgeting is required currently because you cannot take away the resources that are meant for certain vulnerable categories of people and move it to other heads. So, I think funds for those with disability and disability budgeting are very, very important.

Secondly, on part of the civil society organisations, it is almost mandatory to keep asking for more—more facilities and access. In the case of the National Platform for the Rights of the Disabled (NPRD),⁷² I think they have been very consistent in demanding resources. But the NPRD is just one of the voices. We need more voices coming from other parts of the country also speaking about what they require. There are some people like RTI activists and others like Dr Satendra Singh and Nipun Malhotra who have been writing popular articles in the journals on these issues.⁷³ I think pressure on the state, pressure on development organisations to make special provisions is required. For instance, in the case of income generation schemes, we must have some special provision for PWDs to be employed. Under the Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA), the state has

⁷¹ See Nilika Mehrotra and Karen Soldatic, 'COVID-19 in South Asia: State Practices, Responses and the Experiences of Persons with Disability within the Region' (2021) 8(1) *Disability and the Global South* 1873; Nilika Mehrotra, 'Emergent Disability Voices on Social Media During COVID-19 Times' (2021) 8(1) *Disability and the Global South* 1993.

⁷² The NPRD is a pan-India cross-disability rights organisation. See Shampa Sengupta, 'National Platform for the Rights of the Disabled (NPRD) Turns 10 This Year' (*Feminism in India*, 20 February 2020). <https://feminisminindia.com/2020/02/20/national-platform-rights-disabled-nprd-turns-10/>. Accessed 25 October 2021.

⁷³ See e.g., Nipun Malhotra, 'How India's Disabled Community Fought to Halt a Legislative Change Amid the Lockdown—and Won' (*Scroll.in*, 10 July 2020). <https://scroll.in/article/967018/how-indias-disabled-community-fought-to-halt-a-legislative-change-amid-the-lockdown-and-won>. Accessed 25 October 2021.

been asked to create more room for PWDs.⁷⁴ For instance, in the whole debate on the migrants who were returning home,⁷⁵ there was no discussion about disability. I was really surprised by that and kept wondering how many people with disabilities must have been a part of the migrant population and that there is no conversation about them. Many persons must have suffered much more than others. So where is the data on them? Data segregation is so important—and data must be demanded from the state. The state does not give data for anything, leave aside disability. And I really get angry at times thinking when will we start getting data to make sense of what is happening to people around us? So yes, I think the state must be more active in identification of and in provisions to PWD, especially from poorer communities.

13. **AG:** *We would like to end the interview by asking you a question about Paralympic sports, since the Tokyo Paralympics 2020 have just concluded. They have been subjected to several kinds of criticism by scholars. First, there has been some controversy after Indian discus thrower Vinod Kumar was stripped of his bronze medal.⁷⁶ Many have criticised the classification of athletes based on the nature and extent of impairment.⁷⁷ Most importantly, academics see sport as an inherently ableist institution that locates ability solely in the body.⁷⁸ In the Paralympics and Special Olympics, we give medals to those who are more able than others who are similarly disabled/impaired. The “celebration” of disabled athletes is thus inscribed in a profoundly ableist paradigm. What are your thoughts on this?*

NM: I feel I may be generalising too much, but I think society and many social structures, institutions are ableist; sports are no exception. To me, this whole thing about “inspiration porn”⁷⁹ as they say, that let’s not “glorify” people with disability, this idea of super-crip, I have had some issues with. Everybody needs role models. If we have competition within our society, that competition is based on role models. Why do we have celebrities? Why do we say that disabled people should be protagonists in films? So why not in sports? The most important thing is, those who say that

⁷⁴ See Girija Shivakumar, ‘MGNREGA for the Differently-abled’ (*The Hindu*, 23 August 2013). <https://www.thehindu.com/news/national/mgnrega-for-the-differentlyabled/article5052339.ece>. Accessed 25 October 2021.

⁷⁵ See S Irudaya Rajan, ‘COVID-19-led Migrant Crisis: A Critique of Policies’ (2020) 55(48) *Economic and Political Weekly* 13.

⁷⁶ Mihir Vasavda, ‘Tokyo Paralympics: Why Discus Thrower Vinod Kumar Was Denied a Bronze Medal’ (*The Indian Express*, 07 September 2021). <https://indianexpress.com/article/explained/vinod-kumar-tokyo-paralympics-bronze-medal-7479523/>. Accessed 25 October 2021.

⁷⁷ See e.g., Carwyn Jones, and P David Howe, ‘The Conceptual Boundaries of Sport for the Disabled: Classification and Athletic Performance’ (2005) 32(2) *Journal of the Philosophy of Sport* 133.

⁷⁸ See e.g., James L. Cherney, ‘Sport as Ableist Institution’ in *Ableist Rhetoric: How We Know, Value, and See Disability* (Penn State University Press 2019).

⁷⁹ ‘Inspiration porn’ is an informal term coined by Australian disability rights activist Stella Young to criticise the objectification of PWDs to inspire the so-called non-disabled. See Gwen Knapp, ‘Inspiration Porn: Paralympians Know it When They See it’ (*The New York Times*, 05 September 2021). <https://www.nytimes.com/2021/09/05/sports/olympics/inspiration-porn-paralympians-know-it-when-they-see-it.html>. Accessed 25 October 2021.

this kind of glorification is bad, they are stripping away the agency of the people who want to be in sports, who want to have recreation in life, who want to have pleasure in life.

Once a woman joined the JNU Disabled Persons Association, who is paraplegic and does yoga. She gave so many yoga lessons to people. And she spoke of how only through yoga and meditation, she has been able to overcome her bodily and mental blocks. I thought she was an amazing motivator. Do we not need motivators in our lives? Everybody needs motivators.

I have another story about George Abraham.⁸⁰ He's a blind activist and is obsessed with cricket. One could ask him why he is obsessed with cricket, why he is talking about cricket. Whenever there is a cricket match, his Facebook posts are full of that. I think this is stretching the boundaries of normality. In the field of sports particularly, I also see it as breaking stereotypes. If, as an interviewer, I see a wheelchair user and the other so-called able-bodied person standing on their feet—the immediate assumption is that the former is less competent, while the latter is more competent. I think what Paralympic athletes are doing is stretching all boundaries, even within sports. The so-called able bodied have not been able to get so many medals as the disabled athletes have gotten for India. And this is another strange situation because on the one hand, you say that the disabled are a burden. They are not contributors to the GDP and so on. But the discourse must change somewhere. It should not be just inspiration porn. But I would see it as stretching the imagination that a person with limb deformity can throw a javelin, can be an athlete. Why cannot we stretch that imagination? I think sports are changing the representation of PWDs.

Let us also remember that they are doing it without the state's support. These victories have also reminded the state to make provisions for the PWDs who would want to attend the Paralympics. I was listening to BBC News every night when the Paralympics were going on. And every day they would bring one athlete or sportsperson, and that person would talk about how with great difficulties, without any support from the state, they were able to come to that level. So, is it not the responsibility of the state to see to it that PWDs get funding or support?

We keep thinking about sports as an activity for the non-disabled. But I think sports also have to be an imagination where people with diverse abilities participate and enjoy and I think live to the fullest. This yoga teacher that I was talking to you about, I found her such a motivating person that at that point, although I was not doing any yoga, I felt that yoga is good, and I should also start practicing it. I think we need people to just stretch their imagination, visions of disability, and that is good. I do not see any problem with it.

⁸⁰ IANS, 'Meet George Abraham, the Visually Impaired Cricketer Who Has Bowled Us Over' (*The News Minute*, 28 January 2018). <https://www.thenewsminute.com/article/meet-george-abraham-visually-impaired-cricketer-who-has-bowled-us-over-75517>. Accessed 25 October 2021.

Declaration

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