

Decoding Disablism: A Dialogue on Disability and Covid-19 in India

Priyam Sinha

Volume II

**Perspectives - A Peer-Reviewed, Bilingual, Interdisciplinary E-Journal
Janki Devi Memorial College
University of Delhi**

Find us at - <http://perspectives-jdmc.in/>

About the Author:

Priyam Sinha is a Doctoral Candidate at the Department of South Asian Studies, National University of Singapore. Her doctoral thesis focuses on how gender, disability and sexual cultures are represented in Bollywood cinema. She delves into these understandings through metanarratives of people with visible physical disabilities in India. Her research interests include feminist-queer and disability theory in the Global South, Indian diaspora studies, Bollywood's masculine and feminine constructions and constructivism of stardom.

Abstract

Does ableism permeate into coping mechanisms for a pandemic struck world? Is universalisation and disability inclusion still an afterthought in India? India imposed a lockdown after the World Health Organisation declared Covid-19 a global pandemic that adversely affected healthcare and the economy. Along with the alarming rise in Covid-19 cases, there were economic and social vulnerabilities, rising mental health concerns, discrepancies in access to vaccinations, and inaccessible formats of information with sudden shifts to digital formats of schooling and employment. Multinational companies went to an unprecedented 'work from home' structure; education meant online classes, and the healthcare systems collapsed as the demand outnumbered the supply of medical amenities. Underlying social inequalities started drawing prominence, but inaccessibility worsened for all regardless of one's class, caste, region, religious, and communal affiliation. Among them people with disabilities were severely impacted during resource shortages. Metanarratives of the disabled during a pandemic highlight the underlying biopolitics and culture of disablism embedded in society. What challenges that people with disability faced due to the sudden shift to online forums of education, work, caregiving, and communication has been discussed here. Can inaccessibility, social distancing, isolation and work from home lead to empathy towards building a disability-inclusive infrastructural approach? Thus, I foray into discussing disablism through metanarratives of people with disabilities, primarily the visually challenged, those with hearing impairments and wheelchair users based in Indian cities. Hence, I foreground my analysis to theorise disablism, focusing on disability and personhood during Covid-19.

Keywords: Covid-19, accessibility, biopolitics, disablism, Global South, India

Introduction

Raewyn Connell highlights the importance of critical disability studies, informed from the Southern perspective, as it probes into the nuances of violence and neo-colonial supremacy in producing disability ethnographies. Within these ideological underpinnings of situatedness, he expresses the importance of lived experiences of disability, providing a contextual understanding of disabling social environments.¹ Therefore, contributing to forms of prevalent structural violence/social impediments that essentially limit experiences and curtail resources required to sustain a livelihood that shapes self-perception and capabilities. Covid-19, in a way, introduced another dimension to the narratives by highlighting inaccessibility, uncertainty and shortage of resources for all.

The Government of India has been compelled to impose stringent measures to curb the spread of Coronavirus in India across different rural and urban areas since the start of 2020. By May 18th, India reported over 1 lakh infected cases despite the Government imposing a lockdown by the 25th of March 2020. Due to a sudden upsurge of cases, the lockdown was extended for about two months more still the cases reached 8 lakhs. (Ghosh et al. 2020) Educational institutions shifted to online platforms, farmers and daily wage workers suffered substantial financial losses, and the non-essential services sector, including retail, beauty and hospitality services, was severely affected. Overall, every sector of the economy had to bear repercussions with no compensation for losses incurred in the process. The ramifications were most prominent and severe among all vulnerable categories, especially those reliant on caregivers. The dependence on caregiving and routine health check-ups is not a luxury in most cases for people with disability; instead, an essential requirement to perform everyday activities. I briefly discuss an overarching atmosphere of disablism and the social model of disability through narratives of people with disability in India, such as polio, cerebral palsy, spinal cord injury, blindness, deafness and arthrogyrosis. However, I highlight how

they contextualise their challenges of accessibility in India during a pandemic. Finally, I argue against the generalised bracketing of people with disability as each disability varies, and the degree of disability itself has different social support requirements.

To foreground and contextualise my analysis based on the narratives of people with disabilities about Covid-19 in India, the culture of disablism and the biopolitics of disability during a pandemic. I question the structural cleavages that positioned people with disability in India as the most vulnerable by excluding them from resources easily accessible to all. While it did underline the importance of accessibility and introduce work from home and online schooling culture, it also positioned how an ableist sense of space and spatiality has only now recognised the value of accessibility.

Ableist ideologies operate within a culture through legal, medical, political and literary discourses of exclusion that create the physically disabled body as an embodiment of corporeal insufficiency and a repository of social anxieties about control and identity. (Ghosh 2010: 58)

Even though Indian cities have tried to essentialise accessible and disability-inclusive infrastructures, a generalised conception of disability and its social model comes in the way of resource allocation. Also, these factors highlight how knowledge production of Disability Studies has been dominated by a select few developed countries, which overlooks intersectionality and positionality in developing countries, foregrounding the importance of theorising disability in the Global South within the Covid-19 context.

Background and Context

The world witnessed many epidemics such as the Spanish flu (1918-1920), Asian Flu (the late 1950s), AIDS Pandemic and Epidemic (1981- present-day), Mexico smallpox, H1N1 Swine Flu (2009-2010) and Ebola Epidemic (2014-16) which affected the Indian population over

different periods. The outbreak of each aggravated health risks and severely impacted the economy. However, we cannot generalise each of their impacts, as every pandemic had its own disrupted notion of everyday lives, which accentuated pre-existing inequalities and vulnerabilities in society. Covid-19 posed very different challenges that disrupted accessibility for all, indicating reduced mobility independent of one's social stature. The curtailment of the virus meant the imposition of social distancing norms, prolonged periods of self-isolation, work from home for an indefinite time, sudden closure of educational and recreational spaces, employment risks and restricted mobility within a bubble of uncertainties. It becomes imperative to look at the most marginalised sense of being at these times; disability forms one such category of vulnerability.

Over 21 million people, about 2.1 per cent of the Indian population, have a disability as per Census 2001. Most of the persons with disabilities reside in rural areas, which often their presence is not documented. Uttar Pradesh (3.6 million), Bihar (1.9 million), and West Bengal (1.8 million) outnumber other states with their disabled population. However, the culture of disablism, questions around accessible design and infrastructure, disability-inclusive policies, etc., remain debatable and, to some extent, prevalent across India. The pandemic, in a way, has outlined how it constructs resources within a paradigm of ableism, systematically side-lining the disabled.

This paper traces one such culture of contextualising the ideological construction of disability during a pandemic that is inferred as synonymous with individual pathology, excluding the disabled from the broader social framework.ⁱⁱ It is helpful for me to begin with what I mean by disablism. Disablism implies a culture that views people with disability as inferior and subjects them to discrimination which may be abusive, offensive and raises self-doubt. The systematic form of violence may not be physical/vocal but includes exclusion from public resources and social interactions and situating them at the lowest priority

level within an ableist structure that enables resource allocation and distribution. While the number of people infected by the virus kept increasing, additional concerns about mental health, embedded social inequalities, and global recession that severely hit every country were raised. The accentuated levels of vulnerability and socio-economic disparities outlined the severity of the cultural trends of disablism, which impacted the provision of healthcare, education, and economic infrastructures.

These factors draw attention towards disability, crip cultureⁱⁱⁱ and capabilities approach^{iv}, which signal the role of society in shaping a person's sense of being and critique the constructivism of normalcy. They questioned how normative standards create tensions about accessibility based on societal parameters, which is particularly applicable in understanding the lived experiences of people with disability during a pandemic. Similarly, McRuer's (2006) description of disability as a failure to 'fit in' within the norm adds to the dissonance about the disabled being viewed as social beings, which eventually excludes them from the societal framework. A dialogue on these factors leads me to the 'biopolitics of disability', which questions the representativeness of disability itself. David Mitchell and Sharon Snyder (2015) argue about the insights derived from disability subjectivities beyond social restrictions and contextualise biopolitics of the culture of disablism and embodiment. They built upon McRuer's (2006) work to describe how culture intersects in diverse ways such as disability aesthetics and art, disability literature, disability pedagogy and commercialised mainstream disability cinema, which essentialises a theorisation of disablism and its metanarratives during a pandemic.

Research Method and Limitations

Methodologically, I rely on the lived experiences of people with disabilities residing in Indian cities, inferences of which I draw from metanarratives, semi-structured interviews and

conversation analysis. A cross-sectional, purposive snowball sampling technique was adopted to reach out to students and working professionals. Data was collected through semi-structured interviews conducted online among people with visible physical or visual disabilities (men and women between the age group 21 - 45 years) due to imposed travel restrictions. The lack of assistive technology and structural barriers are predominant in developing nations where poverty, employment opportunities, class discrepancies and societal expectations impinge the quality of life, significantly impacting the lives of the disabled. I initiated a dialogue on how the pandemic impacted their lives and what have been the challenges they have been confronting. The right to the accessible format of instructions to prevent the spread of the virus, the absence of access to primary healthcare and rehabilitation facilities, limited accessible vaccination centres for wheelchair users, and denial of vaccination itself were put forth as some significant concerns during the study.

These factors highlighted the underlying themes of how the pandemic further marginalised the disabled in India. However, not all factors laid out in the narratives were negative, as the shift towards advocating the alternative model of work from home/online study culture also created a wheelchair accessible space for dialogue. I also state that one core limitation of my study is its online format of interaction which restricted the interaction and social engagement. Additional elements of narrative analysis that lie in non-verbal cues, gestures, silences and mannerisms are missed out, and online platforms also make rapport building difficult. Furthermore, these factors get hindered due to zoom fatigue in conducting interviews and limits outreach to theorise and contextualise a grounded knowledge of disablism during a pandemic.

Disablism and its Implications

According to the World Report on Disability (2011), more than one billion people have a disability. On that note, the World Health Organisation and World Bank vehemently argued for a systemic inclusion process to mandate a sense of belongingness and security as a human right for all. It aimed to provide universal human rights that look into equal opportunity, equal participation, and individual human rights regardless of differences. Hence, highlighting the importance of inclusive policies and how dominant societal perceptions shape ideas, beliefs, values, institutions and social systems.

A culmination of these factors make the voice of the disabled integral in producing scholarship about disability and disablism, especially during a pandemic.

Disablism is a set of assumptions (conscious or unconscious) and practices that promote people's differential or unequal treatment because of actual or presumed disabilities. (Campbell 2009: 4)

Disability also has a contextual understanding, and within Indian cultural ethos, a disabled person is bracketed as a misfit, or incomplete, as having a deficit or an anomaly in the dominant framework of the able-bodied. Historicising the cultural framing of disability within Hindu mythology reveals how disability was viewed as being a result of *karma*.^v (Ghai 2002a, 2009, Addlakha 2007, Mehrotra 2014) Drawing upon those lines, the incapable, dependent, evil, demonised and spiteful characterisation of disability was dominant in the *Mahabharata*, and the *Ramayana* too contributed to the negativity associated with it. For instance, *Dhritrashtra*, was considered incompetent to rule a kingdom despite his proficiency in administration and decision making, due to his visual impairment. Along similar lines, *Manthra* (a dwarf woman) and *Shakuni* (orthopaedically impaired) were characterised as malicious and cunning who contributed to the narrative discourse that perceived disability as the 'lowest form of being' and 'to be avoided.' These dominant social frameworks and literary conceptualisations situate disability as the least priority, reaffirming the culture of disablism.

It is a culmination of these factors which creates attitudinal differences towards perceiving and eventually treating people with disability as dependents with no agency. The paradoxical understanding of disability as inferior. The other interpretation of disablism focuses on the divine, otherworldly and *divyang*^{vi} categorisation. The belief towards viewing children with disability as ‘special’ or referred to them as ‘children of god’ stems from perceiving disability to be a test of suffering inflicted only on those who have the inner strength to live with it. Focussing on resilience to combat the disabling social environments reiterates how the disabled are dissociated from the constructs of normative/ideal. A culmination of these factors eventually produces a culture of only celebrating those people with disability who can be ‘inspiration’, which glorifies how they fight disabling social environments. The renowned Indian poet Surdas was visually impaired and always lauded for his credibility to be successful in fighting an oppressive environment.

Disability or disablism cannot be understood as a socio-cultural construct in isolation. The social model of disability, prejudices and stigma about disability and personhood raises self-doubts but denies opportunities quite easily accessible to the rest. (Shakespeare 2006, Barnes 2012) Eventually, these factors pit the disabled against an idolised norm due to the dominance of ableism as the ideal. On the other hand, ableism is described as a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) projected as the perfect, species-typical and therefore essential and fully human.’ (Campbell 2001: 44) Hence, those failing to ‘fit into’ those pre-decided parameters of normativity eventually get labelled as the anomaly, a constructed deviant which includes the disabled. Along a similar vein, ableism has been defined as ‘ideas, practices, institutions and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalised which largely invisibilised "others.”’ (Chouinard 1997: 380)

From where did these ideas emerge? The theoretical foundation and critical theories about the construction of bodies within medical anthropology reveal the role of the ‘social’ in determining the accessibility of spaces, opportunities, resources and experiences for the disabled. However, how do we define disability? What are the individual, social, medical, charity and rehabilitation models that closely interact to produce disabling social environments? Furthermore, how do those factors reflect during a global pandemic amidst a shortage of resources and become a lens to view situated inequalities, intersectional ties and embedded hypocrisies within hegemonic constructs of ableism?

Models shape ideas, practices, rituals, perceptions and everyday lives. Thomson (1997) argued that one could not overrule the role of the social and universalise the experience of disability which varies based on one’s positionality based on stigma and stereotypes about the disabled. Thereby the social, charity, rehabilitation and medical models become a mediated path that is not so individualistic and closely intertwined with accompanying ideas of industrialisation, urbanisation, medicalisation, eugenics and most importantly, the social typecasting of the norm.

The fundamental cultural appropriation of an able-bodied hegemony, accompanied by prejudices and framing of disability as an ‘anomaly’, eventually justify the allocation and stratification of resources. It is these factors that exclude the disabled community from the mainstream economic, social and sexual life contributing to the culture of disablism. Thus, the onus of moving beyond the oppressive and patronising model of exclusion and creating spaces for dialogue on civil rights, policies and proactiveness for disability inclusion lies with society. (Barnes 2012, Thomas 1999, Shakespeare 2006, Morris 2002)

Culture of Disablism in the Global South and Covid-19

Accessibility, affordability and availability of resources shape experiences made available to the disabled. There can be some overarching generalisations in understanding disability, but the integral aspects of disability, gender, caste, class and its intersectionality and positionality cannot be overlooked. The prominence of disability rights activism in the Global North has ignored the subjective realities of the disabled from the Global South. A grounded sense of subjectivities involved in disability studies provides ‘a prism through which one can gain a broader understanding of society and human experience.’ (Linton 1998: 118) Poverty, lack of access to foreign aid, financial and cultural barriers that hinder their access to political engagement, the internalised notion of ideal and ableism, hunger, malnutrition, and hazardous working conditions can be noted as the contributing factors of ghettoization based on disability. (Connell 2011, Chouinard 2015, Davis 2017) This constructed notion of disability scholarship seen through the lens of universalised Western cultural ideas can be critiqued as a ‘minoritising view.’^{vii}

With Covid-19 these questions around a minoritised view, disillusionment about personhood, inaccessibility, and lack of basic healthcare facilities have emerged in public dialogue. Historically, the reasonings of disability have been directed towards divine punishment, moral failings, labels as a ‘misfit’, ‘deficit’, ‘pathologised’ and ‘patronised’ and eventually subjected to stares and not the gaze. (Linton 1998, Buckingham 2011, Thomson 1997, 2011, Morris 2002, Ghai 2001) Thus, an overarching generalisation of the disability perspective overrules the multi-dimensional and socio-cultural contexts within Disability Studies. In other words, the overview of ethnocentrism dominates the representativeness of disability studies, its ethnographies and narrative analysis.

A culmination of these factors underlines a sense of intersectional invisibility, especially since those with multiple marginalised identities are subjected to severe forms of discrimination. (Vaughns & Eibach 2008, Chouinard 2015) Especially in the Global South,

disability has been described as an 'evil construct', 'punishment for committing sins in the past, *karma* or even moral failing. Hence, even in India's Hindu mythological tales, disability is associated with evil and spitefulness, which permeates into popular cinematic imagination and characterisation in literature. (Buckingham 2011)

Meekosha (2011) called it 'scholarly colonialism' and clarified that the North/South divide is not based solely on the geographical positioning of countries but a more complex web of structured inequalities and the impact of colonialism in producing research about what construes as disability and who is counted as the disabled. In 2011 the WHO also reported that around 80 per cent of the people with a disability reside in the Global South, but when it is materialised in the form of accountability and recognition, we see a stark disparity. The United Nations Convention on the Rights of Persons with Disabilities (2006) mandates the need for changing negative perceptions about disability by outlining the legislation and policy framework. However, the ambiguity about disability and the low priority to meet even the bare minimum for sustenance raises questions about disability in the Global South. (Miles 1995, 1996, 2006) 'For a government struggling to provide basics such as food and water, disability is a low priority.... the developing world continues to agonise over securing the fundamental elements that disabled people need to survive.' (Ghai 2009: 283) Covid-19 becomes a lens to view these forms of structural inequality, a space to witness the binaries of the non-disabled and the disabled, the developed and the developing countries, and the situated vulnerabilities of the already marginalised among them. It also indicates the urgency to address how every disability has its specificities for assistive technology, and caregiving uncertainties, and varies in terms of healthcare, counselling, and rehabilitation service requirements.

In the 'Disability-Inclusive Response to Covid-19' (May 2020), the United Nations pledged to leave no one behind, to be inclusive and recognise the differences in the needs of people with disabilities as they are one of the hardest hit by social, economic and

health factors which increased their vulnerability. However, to what extent can we see its implementation; and also vigilance towards establishing a disability-inclusive society remains questionable. Consideration of inclusive policies for the disabled is a recent and niche intervention. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act takes note of disability jurisprudence. A critical evaluation of disability experiences and culture of disablism in the society provides a lens to view how normalcy forms the crux of social structures and creates a binary between the able-bodied and disabled for accessing opportunities ranging from education, skill development and even work. Evidence has been discussed in disability ethnography, which centres on the gaps for ensuring inclusive education, the judiciary's role, and access to sustainable employment opportunities. (Addlakha & Mandal 2009, Addlakha 2009, 2013, 2019) With no prior experience in handling a global pandemic raised questions of inaccessibility for all, more so the disabled, who were anyway more susceptible to contracting the Covid-19 virus.

The Covid-19 pandemic first affected China in December 2019 and soon spread worldwide. The Government of India, in the first two months of 2020, was unaffected by it, but by March 2020, it was compelled to announce its first phase of the nationwide lockdown. Eateries and cinema halls were shut down, transport and travel were halted, shops, markets, schools, colleges, and offices were abruptly shut, and eventually, some sectors transitioned to work/study from home. Most importantly, provision to primary healthcare facilities was put on hold unless essential lifesaving situations needed immediate attention.

The transition to online platforms was not as smooth in developing countries as in the developed countries, which were better equipped and well-resourced with healthcare provisions and technological assistance, especially for the elderly, children and the disabled. The government strictly mandated the need for social distancing, restricted mobility, maintaining personal hygiene and wearing face masks at all times in public spaces, and strictly

imposed work from home for all. However, these measures did not bring down the alarming number of cases and increasing death rate due to the Covid-19 virus.

People with disability were severely hit as many needed timely medical assistance, physiotherapy sessions and the presence of caregivers for performing routine activities. Eventually, there were some relaxations, new rules and more open spaces to access public facilities, but there remained the impending fear of contracting the Covid-19 virus. So, how can we situate people with disability within the context of Covid-19 in India? Are the differential needs of the disabled gaining empathy and consideration?

Voices from the Disabled: Impact on the Blind and the Deaf

The sudden lockdown highlighted many challenges for people with visual disabilities, hearing impairments, polio and even wheelchair users with different locomotor difficulties. The threats posed to people with disabilities ranged from inaccessible healthcare, lack of accessible instructions about preventive measures to be adopted, and social distancing norms. Apart from an overarching generalisation of how Covid-19 impacted the lives of people with disability, the question of accessing information from emerging online forums of dialogue becomes a lot more prominent among the visually challenged and those with hearing difficulties.

The measures imposed to curb the spread of the virus wiped out the need for care services as non-essential and raised anxiety about the most efficient and supportive ways to facilitate everyday tasks for the visually challenged. The first sentiment shared as a collective was the vulnerability due to a pandemic. Additionally, the loss of sight, in general, adds to the need for touch to access as the visually challenged are restricted in multiple ways in the absence of assistive technologies. One of the visually challenged participants expressed her constant fear of contracting Covid-19 as 'touching' cannot be avoided, and she too would not be aware of others flouting social distancing norms or not wearing their masks properly. Similarly, touch

is integral as access is dependent on holding hands, getting the support of railings and the feeling of objects/people that may come in the way. These factors eventually would limit access to any public place.

Further, the absence of readable format of the information, reliance on caregivers, and their empathy to make information accessible during online classes also raised the question of inclusive education for all. Some undergraduate and postgraduate students who have been visually challenged since birth expressed how the transition to online classes was not a smooth process, and very often the absence of personal interactions made teachers unwilling to make accommodations that may be needed for just one student. Hence, the minority, in this case, the visually challenged would bear the brunt of not being able to learn from the 'share screen' in online classes. Although not entirely focussing on the Covid-19 situation, Hemachandran Karah (2021) discussed the assumed authority over knowledge structures that limit the opportunities and capabilities of blind people in special schools since childhood. He described his life in blindism^{viii}, and a cursory glance of his autoethnography also helps understand the assumed authority that glorified the need to rectify a disability as heroic. Therefore, it helps theorise how the pandemic, as described by Anuja,^{ix} could be called a 'double-edged sword' In other words, it might have reduced the physical dependence on caregivers, and simplified the process of submitting assignments via e-mails but did not help in the process of learning anything new as most teachers adopt visual methods to teach online without providing alternative models that may be viable to the blind students. Her views reflected how disablism continues to exclude people with disability by placing them at the periphery in terms of accessible education and affordable healthcare.

Ranjan^x, a visually challenged disability rights activist and lawyer, described how the agency, creative freedom and career choices of the disabled community are comprised of limited visual engagements, leaving only the social sciences as a viable option. He

acknowledged that coming from a privileged urban setting and having a supportive family enabled him to be ‘one of the few vigilant about his rights since high school.’ However, he commented that the generic attitude towards disability is ‘laid back’ In his words:

Digital spaces have not been very accessible for people with blindness, hearing impairments and speech impediments. It is just that the efforts are not given that much momentum, and the adversities of inaccessibility for the blind only worsened since the pandemic.

The deaf community too commented on such ‘systemic inequalities’, ‘loopholes in administration and provisions’ and ‘failure in providing accessible information’ to generate awareness about precautionary measures during a global pandemic. Although a generic level of collective consciousness was there, rising cases the Covid-19 left many ‘incapacitated’ and reliant on caregivers to provide information about the Covid-19 situation. The World Federation of the Deaf (WFD) requested accessible information in sign language for the deaf community. It was not restricted to just knowledge about basic healthcare facilities but also enabled forums for education and availing other public services during the pandemic. Hence, professional sign language interpreters for every space of dialogue and interaction were pitched as a necessity even before Covid-19. (United Nations 2006) Although many of these provisions remain on paper, the implications of lockdown, subsequent closure of schools and colleges, online teaching, and work from home underlined the question of accessibility. (Brennan 2003) Ms Sundari Sivasubbu^{xi} who also has a hearing impairment, stated:

I do not rely on sign language. People rarely learn it, so most of what I understand when someone speaks depends on noticing the movement of lips. Now, with the masks people wear, I cannot understand, which makes it very hard for me to even communicate in public places.

Therefore, the pandemic posed some questions about representativeness, the need for inclusivity and communication gaps. One of the many forms of inaccessibility would be the Arogya Setu app which is still not accessible for people with visual and hearing disabilities. Most importantly, the critical updates of Covid-19 related cases, contact tracing, and measures to be taken were not made available in an accessible format. A comprehensive evaluation of these factors highlights how disablism as a culture permeates into marginalising the disabled in diverse ways, even during a pandemic. However, in some ways, these experiences underline the social model of disability and socio-culture impetuses in the Global South, particularly in India.

Work from home is a leveller for wheelchair users.

While there cannot be an overarching generalisation of medical ableism and its impact during pandemics on people with disability, one factor that remains poignant is how inaccessibility and restrictions on social mobility were a question now raised unanimously. Nipun Malhotra,^{xii} born with arthrogryposis, described how disability rights activists in India had been requesting a work from home arrangement for the disabled for a decade. So, what makes these changes mandatory?

In his words:

It is a déjà vu moment for us because everybody has been forced to work from home. So that has become a great opportunity in that sense; as we were told before, it is impossible, but policies changed overnight. I am only talking about wheelchair-users in urban spaces and sectors where work from home is possible. Disclaimers apply for which sectors it is possible. Education still has a long way to go with challenges and the need for special educators on zoom for lessons that can be taught to all.

Taking this dialogue forward on the ‘disclaimers that apply’ about disability employment, there is still much scepticism about the representativeness and accountability of disability employment. There is a downside to employability and which sectors can function normally during a lockdown. The Executive Director of the National Centre for Promotion of Employment for Disabled People (NGO based in New Delhi, working towards disability rights) elaborately discussed Covid-19 and its impact on the job market for people with disabilities in India. With limited formats of educational and capacity building initiatives, the scope of careers to be eventually taken up is also limited for people with physical disabilities. The subsequent outcome is limited options in terms of career opportunities. Communication, attitudinal and infrastructural barriers left the disabled population vulnerable in terms of employability as well. He also commented on the massive unemployment, food shortages and financial losses incurred by people with disability during the pandemic. Also, only a niche sector of labour can be shifted to online work platforms. In his words:

It depends on the kind of job roles they have. For example, if one is working in the hospitality industry, IT company, or retail business, there is no work from home. However, the job market has been hit for people with disability as we are still not equipped with assistive technology, so many have lost jobs.

Social distancing measures and the likelihood of people with disability being dependent due to lack of accessible infrastructure and healthcare systems not being disability friendly makes it difficult for all with locomotor disabilities. Providing a very contrasting worldview, the pandemic was also described as a space that provided opportunities online. Similarly, Anamika,^{xiii} who was born with spinal muscular atrophy and has been a wheelchair user, elaborated on how conducive the online platform is for college education. She described, ‘For some people, especially with locomotor disabilities, it is easy. We now can work from home, study from home, attend conferences from home and do many things without feeling that we are

missing out on something due to a disability. So, I do not need to be worried about inaccessible spaces or professors not allowing me to study from home anymore.’

Rahul Rawal,^{xiv} a wheelchair user who had already been working from home before the pandemic, candidly described Covid-19 as creating a ‘level playing field.’ Adding to it: ‘Dependability for any mobility has been an issue all along. Now online forums have opened up opportunities for me even to interact, and people know the value of accessibility.’ Their views, in one way, highlight how the pandemic has also shown a bright side and bridged the gap between some disabled and the able-bodied. However, there are still other challenges that play a prominent role in terms of denial of caretakers who assist people to their interaction is Sundari Sivasubbu, who stated: ‘I am at home. I take care of all the protocols to avoid Covid, but then I need an assistant, and she uses a shared auto to commute from another place. So, she can pass on the infection to me, and that leaves me vulnerable. To avoid the health risk, we stopped her from coming, and now my mother, who is 63 years old, helps me with the washroom, which is very challenging at her age.’ In a way, her statement provided a snapshot view of family caregiving practices, the range of limitations and subsequent dependability on nuclear families in urban India needs closer attention during a pandemic.(Chakravarty 2008)

The functional limitations of cerebral palsy, which is reported to be one of the dominant causes for locomotor disability in India (NSSO 2002) and increasing nuclear family systems, essentializes the need for caregivers beyond ageing family members. While the question of caregiving has always loomed large within the context of disability in India, the pandemic raised the uncertainty of how despite being able to afford caregivers in urban spaces, the social distancing and quarantining norms significantly restricted the daily chores for all with disability.

The vaccination tussle: Who is left out?

To completely negate the role of the government to prioritise disability rights and policies would be incorrect. To some extent, alternative measures were adopted, healthcare needs and caregiving concerns were looked into and changes within the infrastructure to ensure vaccinations for wheelchair users while at home were implemented over time. However, these measures were looked into in hindsight and not prioritised in the initial months. The provisions for the elderly, disabled and those with limited mobility due to health risks which were to be administered began in May 2021 after much anticipation. Contrary to India's late reaction to disability inclusive policies, countries such as Singapore had provisions for the disabled to access dominant supermarket chains to procure groceries while also maintaining social distancing rules. It had a designated hour set aside on two days per week (8 am to 9 am for 24-hour stores) and a special check out and billing lane at all times to ensure the safety of the elderly (above 71 years), pregnant women and disabled population who were categorised as the 'vulnerable population.' While one may give examples of developed countries, the entire question of accessibility and provision of services for the disabled becomes even more prominent during a pandemic in a developing country. Prateek Khandelwal,^{xv} extensively advocated accessibility concerns while working for infrastructure solutions and universal designs that can be disability-friendly. He emphasised how Covid-19 reflected the prevailing forms of 'inequality' and 'inaccessibility.' He stated:

The system is not mentally tuned to have people with disability as a priority which got exposed during Covid. For example, the vaccination centres were not even accessible and had steep ramps for entering, and one could not see which centre would even be wheelchair friendly initially.

Another common reason for resistance and apprehension towards vaccination was unawareness of the side effects. The neglect and ghettoisation of people with disability (which included men and women) from being vaccinated was the fear of caregiving, restricted

external support, apprehension towards quarantining, presumed dependence and infantilisation and ableist labelling as ‘burdens.’ Only recently, by September 2021, the Government of India addressed the matter and announced that the vaccines for the elderly, those with special needs and the disabled would be provided at home. Moreover, they were assured that trained medical professionals would make arrangements to ensure that the mobile vaccination systems would benefit those who previously could not access public vaccination centres. Nevertheless, the afterthought of vaccination intervention tells how ableism is systematically ingrained in society and becomes prominent in policies, law, order, and most importantly, during a pandemic when there is a paucity of resources.

Can we combat the Culture of Disablism?

The culture of disablism cannot change overnight, but a systematic intervention process of inclusion of the disabled into the mainstream would allow their challenges to be taken into account during critical care decisions. The reasoning for exclusion and questions about caregiving must be taken into account seriously for a more cohesive understanding of special needs, considerations and provisions for the disabled. Detailed mapping of medical history and individual accounts of assistive mechanisms that enable disability inclusion must be taken into consideration. Also, the culture of disablism must be refuted by first and foremost viewing the disabled as equal, with capabilities that must be nurtured through alternative provisions even during a pandemic. The unfair disadvantages, neglect of their representation while coming up with solutions to combat a pandemic and absence of systematic interventions to make all resources accessible, affordable and available to the disabled population despite its shortage, highlights that the culture of disablism is primarily attitudinal, a lot more than what appears on the outside. An approach that equalises the value of life of all, recognises human rights, is considered worthy of opportunities to work and educate themselves even through online forums

would enable the creation of a disability-inclusive society. A dialogue on disability ethnographies in the Global South provides a reflexive journey of theorising the structured inequalities in developing countries.

The metanarratives reflect how the underlying structures of disablism disadvantage people with disabilities during a pandemic. The pandemic in a way provided a lens to view how structural forms of inequality, the lack of thought, absolute invisibility, or even an afterthought of the disabled excludes them from the larger periphery of the society. It is for these reasons that accessible information; the importance of caregivers to enable the performance of everyday chores like eating, drinking, and using a washroom; the need for vaccination; and the provision of healthcare or online education/work platforms have taken place after concerted efforts within disability rights activism. These problems reflect the urgency to mandate stringent measures that view the disabled population as equal and worthy of human rights. The fundamental concerns about the culture of disablism have become more prominent with Covid-19, but they also highlighted how there still is a long way to go for building a disability-inclusive environment.

Disablism also forays to recognize, acknowledge and narrate the experiences of people with disabilities beyond a myopic view of the Global North. Also, stressing on the need to address how disabling social environments curbs opportunities, basic amenities and creates an environment of inaccessibility to enhance capabilities. These are the layers of understanding inaccessibility that need critical evaluation. It will foreground how caregiving for the disabled is not necessarily a luxury but a necessity for performing mundane activities. Criticism of the 'deficit-oriented framing' (O'Sullivan & Phillips 2019) highlights that the disabled are seen as misfits, which accentuates the minority experience of the disabled. It also underlines how the world is based on ableist ideologies and only views disability as an

afterthought. These models of disability permeate into theorising how the impact of Covid-19 on disability cannot be clubbed as a universal category.

A comprehensive study of the voices of the disabled and the challenges they face provides a lens to theorise this culture of disablism. More specifically, it addresses the impact of Covid-19 on the deaf, visually challenged and wheelchair-users in Indian cities. These factors answer how they define inaccessibility during a pandemic and what kind of infrastructure, assistive technology and services, rehabilitation and counselling would create a disability-inclusive society. Most importantly, legitimise a systematic policy intervention and amendment within the disability rights framework can ensure breaking down the culture of disablism. Hence, disability consciousness is the only way forward in building infrastructure and refashioning attitude to be inclusive of people with disability in India.

Conclusion

Disability and its challenges also imply how a generalised overview of disablism and the impact of Covid-19 cannot be theorised. Discussions have begun on how proactive measures of disability inclusivity and accessibility need to be investigated by the Government of India. However, it also raises doubts on how the post-pandemic world would be for the disabled and if societal attitudes per se would change to think of disability even during a shortage of resources. The restrictions on mobility were regardless of one's caste, class, region, religion, disability, or any other identity and in a way modelled how inaccessibility can be experienced, but can it make people more empathetic towards the disabled? Most people with disability hopelessly expressed that this innate sense of consciousness and empathy for the disabled is temporary and may fade away with time in the post-Covid world. Some are optimistic about imagining emancipatory transformations and a progressive society accessible, affordable, and inclusive for all.

Although the downside and challenges faced by the visually challenged community significantly outnumber this criterion, one cannot refute how the constructivism of disablism is not novel; instead, it is deeply ingrained in the psyche, making it almost impossible to be inclusive of people with disability. Article 25 of The UN Convention on the Rights of Person with Disabilities addressed the need for providing efficient and affordable healthcare facilities to the disabled. Hence, the vulnerability of the disability should prioritise them, especially during the pandemic, through collaborative efforts of the government, the family and the society at large by recognising the need for inclusive education and interactive spaces for dialogue, rehabilitation services and the creation of a disability-friendly work from home environment. The culture of disablism can only be removed through establishing an enabling environment, provision of assistive resources and dissemination of information in an accessible format, such as the use of sign language to clearly communicate about Covid-19.

The arguments centred around the 'biopolitics of disability and crip culture and the narratives of people with disability in India reiterate the impact of the social model of disability, particularly during a pandemic. It also highlights the pre-existing culture of disablism in India. Some of these are explicit forms of exclusion, while the others might be implicit or salient, strongly rooted in history, culture and policies which shape opportunities and accessibility. The diversity of disability experience tells of biopolitics that creates inequality and reasonings about who would be prioritised and why. Therefore, the pandemic becomes a lens to view pre-existing forms of structural inequalities, crip culture, vulnerabilities, positionalities and prejudices. Overall, providing a perception of whose life is given precedence over the other and the fundamentals that shape the society and compartmentalises its resources based on a hierarchical structure of ableism.

Notes

ⁱConnell, R. (2011). Southern bodies and disability: Re-thinking concepts. *Third World Quarterly: Disability in the Global South*, 32(8), 1369-70.

ⁱⁱMike Oliver (1990) stated that the exclusion of people with disability from the larger society is due to it being viewed as a personal issue, not to be taken into consideration while formulating policy frameworks and making accommodations as it is the minority, 47.

ⁱⁱⁱRobert McRuer (2006) coined the term crip theory to describe how disability and sexuality are perceived as incongruent. So, the absence of dialogue on disability and sexuality often produces disillusionment about sexual cultures itself. Media too can contribute towards reiterating such prejudices and stigma towards sexuality of the disabled.

^{iv}Capabilities Approach (1993) was a theory researched upon extensively by Amartya Sen. He outlined that human capabilities are shaped based on the quality of life and opportunities made available to him/her. Martha Nussbaum (1999) added the gendered element to it and reiterated that freedom, choice and violence shape the experiences and agency of women to nurture their capabilities, which is also reliant on social, political, economic and cultural factors.

^v Karma is associated to be a form of punishment for sins/misdeeds in the previous birth and a way to compensate for them is to bear the repercussions by living with the disability.

^{vi}The word *divyang* in Hindi translates as 'someone with a divine body part.' It has been contested by disability rights activists and eventually the Prime Minister also expressed that the term must no longer be used to refer to people with disability.

^{vii}Eve Kosofsky Sedgwick (1990) proposed a dominant queer theory which questioned gendered binaries. His theorisation critiqued how overarching generalisations of a desirable state of being often leads to an 'othering' culture. Similar framework can be adopted to understanding the constructivism of an ideal type/the able-bodied, or even theorising disability experiences from the Global North by overlooking the intersectionality and subjective realities of the Global South.

^{viii}Blindism is a terminology used to describe a pattern of repetitive behavior by blind children such as rubbing the eyes, constantly swaying, body rocking tendencies, fingers flickering or any distinguishing behaviours which do not specifically serve any purpose. Hemachandran Karah (2021) commented on it stating how these stereotyped behaviours are drawn as assumptions/normal ways of being considering their inability to see. Assimilation of these factors create a culture of viewing blindness with such mannerisms which are not innate but also a result of the social environments which did not persuasively look into it.

^{ix}Pseudonym has been used to avoid disclosing identity.

^xPseudonym has been used to avoid disclosing identity.

^{xi}Sundari Sivasubbu is a communications professional, writer and editor with over twelve years of work experience in the newspaper, banking and IT industries. For 7+ years, she was with a top IT company as a CSR & Sustainability Communications Specialist. Born with Cerebral Palsy Ataxia. She decided to be a motivational speaker, storyteller, and author of 'A Bumblebee's Balcony', a collection of personal anecdotes on rising above personal and societal barriers, significantly rising above obsession with 'being normal.'

^{xii}Nipun Malhotra, born with arthrogryposis, established a disability rights advocacy organization in Delhi called Nipman Foundation,. He is also the Founder Chair of the Federation of Indian Chambers of Commerce & Industry (FICCI) and a disability rights activist.

^{xiii}Pseudonym has been used to avoid disclosing identity.

^{xiv}Rahul Rawal is a wheelchair user and author of a book titled 'Blue Crayons: tales from life and beyond' and has been working in a US-based firm.

^{xv} Prateek Khandelwal, founder of 'Ramp my City' and 'I Break the Barrier', had a spinal cord injury due to an accident at a construction site a few years back and has been a wheelchair user since then.

Acknowledgements

I am extremely grateful to all the participants for sharing their lived experiences for this study and advocating the need for more awareness generation about their communities.

Works cited

- Addlakha, R. (2009). *Disability and Society: A Reader*, Orient Blackswan, New Delhi.
- Addlakha, R. (2019). The Sociology of Disability: Conceptual Ethnography of an Analytical Category in India. In *Critical themes in Indian sociology* (1st ed.). Srivastava, S., Arif, Y., & Abraham, J. Los Angeles, CA: SAGE Publications, Inc., 313-329.
- Addlakha, R., & Mandal, S. (2009). Disability law in India: Paradigm shift or evolving discourse? *Economic and Political Weekly*, 44(41/42), 62-68.
- Brennan, M. (2003). Deafness, disability and inclusion: The gap between rhetoric and practice. *Policy Futures in Education*, 1(4), 668-685.
- Buckingham, J. (2011). Writing histories of disability in India: Strategies of inclusion. *Disability & Society*, 26(4), 419-431.
- Chakravarti, U. (2008). Burden of caring: Families of the disabled in urban India. *Indian Journal of Gender Studies*, 15(2), 341-363.
- Chappell, P., & De Beer, M. (Eds.). (2019). *Diverse Voices of Disabled Sexualities in the Global South*. Palgrave Macmillan.
- Chouinard, V. (1997). Making space for disabling differences: challenging ableist geographies. *Environment and Planning D: Society and Space*, 15, 379-387.
- Chouinard, V. (2015). Contesting disabling conditions of life in the Global South: disability activists' and service providers' experiences in Guyana. *Disability & Society*, 30(1), 1-14.
- Connell, R. (2011). Southern bodies and disability: Re-thinking concepts. *Third World Quarterly: Disability in the Global South*, 32(8), 1369-1381.

- Davis, L. J. (2017). The Ghettoization of Disability. Paradoxes of Visibility and Invisibility in Cinema. *Culture–Theory–Disability. Encounters between Disability Studies and Cultural Studies*, 39-49.
- Garland-Thomson, R. (1997). Theorizing disability. *Extraordinary bodies: Figuring physical disability in American culture and literature*. 19-54.
- Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, 26(3), 591-609.
- Ghai, A (2002). ‘Disabled women: an excluded agenda of Indian feminism’, *Hypatia*, 49-66.
- Ghai, A. (2020). Ignorance of Disability: Some Epistemological Questions. In *Disability Studies in India*. Springer, Singapore., 75-91.
- Ghosh, N. (2010). Embodied experiences: Being female and disabled. *Economic and Political Weekly*, 45(17), 58-63.
- Ghosh, A., Nundy, S., & Mallick, T. K. (2020). How India is dealing with COVID-19 pandemic. *Sensors International*, 1, 100021.
- Kosofsky, E. S. (1990). *Epistemology of the Closet*. University of California Press.
- Karah, H. (2021). The metanarrative of blindness in India: Special education and assumed knowledge cultures. In *Metanarratives of Disability*. Routledge., 30-44.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. NYU Press.
- McRuer, R. (2006). *Crip Theory: Cultural signs of queerness and disability*. New York University Press.
- Meekosha, H. (2011). Decolonizing disability: Thinking and acting globally. *Disability & Society*, 26(6), 667-682.
- Miles, M. (1995). Disability in an Eastern Religious Context: historical perspectives. *Disability and Society*, 10(1), 21.

- Minkowitz, T. (2006). The United Nations Convention on the Rights of Persons with Disabilities and the right to be free from nonconsensual psychiatric interventions. *Syracuse J. Int'l L. & Com.*, 34, 405.
- Mitchell, D. T., & Snyder, S. L. (2015). *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*. University of Michigan Press.
- Morris, J. (1993). Feminism and disability. *Feminist Review*, 43(1), 57-70.
- Morris, J. (2002). Untitled conference presentation. *GLAD, Reclaiming the Social Model of Disability Report, London: Greater London Action on Disability*, 1-3.
- Sen, A., & Nussbaum, M. (1993). Capability and well-being. The quality of life. *Nussbaum, Sen, A.(Eds.), Oxford, Clarendon*.
- O'Sullivan, T. L., & Phillips, K. P. (2019). From SARS to pandemic influenza: the framing of high-risk populations. *Natural Hazards*, 98(1), 103-117.
- Oliver, M. (1990). *Politics of disablement*. Macmillan International Higher Education.
- Purdie-Vaughns, V., & Eibach, R. P. (2008). Intersectional invisibility: The distinctive advantages and disadvantages of multiple subordinate-group identities. *Sex Roles*, 59(5-6), 377-391.
- Scully, J. L. (2020). Disability, disablism, and COVID-19 pandemic triage. *Journal of bioethical inquiry*, 17(4), 601-605.
- Sedgwick, E. K. (2008). *Epistemology of the Closet*. University of California Press.
- Senjam, S. S. (2020). Impact of COVID-19 pandemic on people living with visual disability. *Indian journal of ophthalmology*, 68(7), 1367.
- Shakespeare, T. (2000). Disabled sexuality: Toward rights and recognition. *Sexuality and disability*, 18(3), 159-166.
- Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2, 197-204.

Swartz, L. (2018). Representing disability and development in the global south. *Medical Humanities*, 44(4), 281-284.

Thomas, C. (2001). *Feminism and disability: the theoretical and political significance of the personal and the experiential*.

Thomson, R. G. (1997). *Extraordinary Bodies: Figuring Physical Disability in American Literature and Culture*. New York: Columbia University Press.

United Nations. (2006). *Convention on the rights of persons with disabilities*. New York: United Nations.

WHO & World Bank. (2011). *World report on disability*. Geneva.