

COVID-19 in South Asia: State practices, responses and the experiences of persons with disability within the region.

Nilika Mehrotra^{a*} and Karen Soldatic^b

^a*Centre for the Study of Social Systems, School of Social Sciences, Jawaharlal Nehru University, New Delhi, India;* ^b*School of Social Sciences, Institute for Culture & Society, Western Sydney University, Parramatta, Australia. Corresponding Author- Email: nilikam@gmail.com*

Introduction

This idea for this special volume on Disability and COVID-19 in South Asia came up at a time when all of us, globally and locally, were struggling with the pandemic for the majority of 2020. Bringing out this volume under the aegis of journal *Disability and the Global South* (DGS) is significant. DGS has aimed to first identify and acknowledge the diversity of disability experiences in the Global South and, second, make these experiences readily available and accessible to disabled people and their communities in the regions where the contributors themselves are from. In fact, in undertaking this special issue as editors, we would like to recognize the incredible persistence of our contributors to continue to work with us throughout the development of the papers, alongside acknowledging the many original contributors who were also unable to accept our invitation to participate because of the covid-19 pandemic impacts upon every aspect of their lives.

The focus on South Asia in this special issue shares many patterns of similarities and differences with other regions within the Global South such as Africa, South East & Central Asia and Central and South America. The national landscape with the resultant longstanding outcomes of (neo)colonisation such as underdevelopment, poverty and at times, ineffective political governance processes is well documented as a shared experience across the Global South. Yet, the locally specific and unique complexities of social life, conceptions of personhood and personal autonomy, community and family relations differ significantly. Through examining the nation state, responses to COVID-19 via the lens of disability, this volume takes a step forward in not only countering the global dominance of Northern representations, but also contributes to understanding and engaging with lives of persons with disabilities in their historical context of colonization. The papers offered in this volume, therefore, represent, both continuity and contrast, the increased consolidation of the global-local nexus of power (glocalisation), and the very specific situated political economic contexts of each nation state of the South Asian region.

Disability Studies (DS) in the Global South has made some impressive interventions in the last two decades or so through highlighting the implications of structural barriers in the lives of persons with disability in these contexts. Moving away from narrow representational and cultural approaches to structural and postcolonial approaches, DS opens up the field to create spaces for examining the structural bases of discrimination and oppression against persons with disabilities as well as policies both at national and international levels in looking for solutions that seek to engender social justice in varied multi-cultural contexts and landscapes. In times of globalisation, the circularity in the flow of capital, technology and discursive logics make it impossible to merely think in terms of isolated social and political contexts and practices. Disability rights, social justice and disabled subjectivities represent a process of hybridisation of local, regional and global currents, vocabularies and sites of political action. Any discussion on disability within the Global South thus acknowledges the complex layering and intermeshing of ideas, debates, institutional practices and activist mobilisations.

Given these long-standing relations of global power, the focus on South Asia within this special issue was seen to be urgent, especially during this particular pandemic. It reminded all of us of how connected we are, wherever we are. The COVID 19 virus smoothly moved around the globe through the vehicles of neoliberal materialities *viz* intensified air travel alongside labour and educational mobility, affecting almost everyone. Taking a devastating toll on the world's most powerful nations China, Europe and United States, the predicated devastating impacts upon south Asian countries have now been realized. The high density of populations, low human development index, weak governance structures all merge and combine with the poor, underdeveloped health infrastructure of the region.

South Asia is an interesting region due to the long-standing historical relationships across the region between India, Pakistan, Sri Lanka, Nepal, Afghanistan, Bangladesh, Maldives, Myanmar and Bhutan. It is seen as a geopolitical entity sharing significant land mass, demarcated by tenuous political boundaries of national territoriality. Shared complex and fraught colonial histories continue to mark the relationships between India, Pakistan and Bangladesh marking little friendship, more of mistrust and animosity. This is despite countries within the region coming together to facilitate cooperation. For example, in 1985, the development of South Asian Association of Regional Cooperation (SAARC) was a clear expression of the region's collective decision to evolve a cooperative framework. Presently, with eight-member states, Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan and Sri Lanka (Ministry of External Affairs, 2011), SAARC represents the region's attempt to build and assert greater economic autonomy from prior colonial rulers. The focus on economic cooperation through promoting regional trade was coupled with the promotion of social resources for the benefit of the region, including education, health and development assets.

What appears as newly formed economic regional alliances however, are also premised upon culture commonalities that often were in play through vast trade networks long established

prior to the arrival of the European colonizer. Familiar languages, customs, food, family and marriage practices, and social divisions involving constructions of caste, religion, ethnicity and economic stratification and hierarchies are, often shared. Theories like *karma* and similar fate-based cosmologies are practiced by numerous communities in this region (Mehrotra, 2013). Further, social practices of community, kinship and familial relations, are also similarly shaped with the family central to the orientation of social lives (Mehrotra, 2013). Experiments with democracy and authoritarianism, toxic patriarchies and militant nationalism, are also some of the features shared by people in this region.

Sociologically, there are many common structural inequalities manifesting in large scale poverty, underdevelopment, lack of distribution and access to resources for people on the margins. The patterns of exclusion, discrimination and marginalization of women, ethno-religious minorities, people with disabilities, queer communities are best exemplified by their limited access to education, healthcare, employment and democratic institutions. Given this, it should not be surprising that South Asia has been one of the important focus areas of international aid donors and organisations and, persons with disabilities have become highly targeted in these development interventions. As a result, the late 1990s and the new millennium has seen a mushrooming of Disabled People's Organisations with the mobilization of disabled people demanding the right to be fully included within political, social, material and cultural institutions (Mehrotra, 2013).

People with disabilities constitute around 15 percent of the total global population and a large number of this global population live in South Asia. Globally, COVID-19 has exacerbated existing inequalities. It is now well documented that the most marginalized have been the most susceptible to the worst outcomes of the COVID-19 pandemic. From the start, it was evident that people with disabilities and the elderly were going to be affected significantly. Not necessarily due to disabled people's impairments and/or chronic conditions, but due to the structural factors of living in poverty, lack of readily available and/or accessible healthcare alongside ableist state responses that either disregarded or were not conscious of disabled people's expressed needs to remain safe and well. All the countries that we could include in this volume on South Asia have disability-specific state legislation, but have, as documented by disability groups, been tardy in both the execution and implementation of disability rights policies, programs and responses. As signatories to the UNCRPD and many other international UN conventions on human rights, many of the governments in South Asia are under obligation to take specific measures to safeguard the interests and rights of people with disabilities.

When we began to work on this project, the relationship between the structural inequalities experienced by persons with disabilities and state responses to the pandemic within the South Asian region, thus dominated our discussions. In turn, as the contributors to this special issue attest, a number of questions took centre stage, including: How will people with disabilities negotiate their livelihoods, food security, access to appropriate supports with sudden

lockdowns be resolved and recognized?; what kinds of social infrastructure will be put in place to enable disabled people to have continued access to health care?; and what potential risks will they face, including the psychological distress as experienced more broadly across the rest of the global community? Additionally, as part of these dialogues with the contributors, discussions surrounded the active practices to sustain and protect themselves throughout the pandemic. This focus is particularly important, as it illustrates how despite public imaginings, disabled people engaged in active practices of negotiation, to ensure that their expressed needs are appropriately addressed. Therefore, contributors, where possible, also responded to questions such as: how did people with disabilities respond given their local context?; how can disabled people's expressed actions inform future policy learnings for forthcoming disasters, emergencies and pandemics across the region?; and finally, how can the knowledge generated by and for disabled people and their lived experiences of the pandemic be shared across South Asia to inform future collaborations beyond national territorial boundaries and ensure justice for disabled people and their communities?.

The first paper of the special issue, contributed by Sharin Shahjahan Naomi, discusses the unfortunate context of war-torn Afghan society, where women with disabilities, particularly those from highly marginalized sections face severe problems with state implemented COVID-19 restrictions. Drawing upon intersectionality, Dr Sharin illustrates the ways in which the COVID-19 crisis made the lives of women from lower socio-economic class and ethnic minority groups extremely difficult. Living with poverty alongside the severe lack of regional and economic development, intensifies the stigma and shame that they experience in their communities. Unemployment, lack of mobility, COVID-19 protocols awareness, insufficient institutional support and infrastructure coupled with widespread feelings of insecurity resulting from conflict and terrorist attacks, render them more vulnerable.

The second paper in the special issue focuses on Bangladesh. Arpeeta Shams Mizan and Nusrat Jahan examine the role of the law in shaping access to the necessary resources to sustain and maintain disability wellbeing. Drawing on theories of legal consciousness, the aim of the paper, through the use of narrative studies, is to demonstrate the disconnect between the written law even with judicial oversight and the implementation of COVID-19 state laws and responses for Bangladeshi's living with disability. In fact, through their local level work, they illustrate the ways in which COVID-19 further marginalizes disabled people and their local level organisations, further entrenching longstanding disability inequality and poverty.

In the third paper, Pratima Gurung maps out the adverse impact of the pandemic in the lives of Indigenous peoples and persons with disabilities in Nepal with a special intersectional focus on girl children and women. Gurung outlines how insufficient attention to health care for Indigenous girls and women with disabilities is a core area in need of radical policy reform. This is especially the case for those rural and remote regions where the environment can be particularly harsh. Gurung also documents the impact of the lack of access to state information,

employment and livelihoods, and rigorous social protection systems are critical and necessary, yet are severely lacking in their availability and widespread accessibility for Indigenous women and girls with disability.

The fourth paper by Niroshini Kandasamy, Binendri Perera and Karen Soldatic sketches the manifestation of vulnerability for women with disabilities from Sri Lanka's minority communities given the protracted backdrop of active discriminatory state policy. Economic and social insecurity is further heightened for those living in the former conflict zones. They argue that the longer-term impacts of COVID-19 will not become immediately visible and will require concerted effort by the disability movement to ensure that appropriate state responses are implemented over the long term.

Saira Bano Orakzai's paper on the other hand examines the Pakistan government's response to the COVID-19 crisis through tracking both the historical and contemporary developments of local disability law and policy. Importantly, Orakzai illustrates that with the absence of any substantive policy measures prior to the pandemic, people with disabilities will remain neglected and treated with apathy. As Orakzai argues, this has meant that in Pakistan, that a large majority of persons with disabilities have been left to deal with the situation on their own with little, if any, state support.

The next set of papers focus on India, encompassing different regions across the sub-continent alongside elucidating the differentiated impact for disabled people from difficult socio-cultural, ethno-religious communities and often, self-define as belonging to a particular impairment group. Looking at experiences of persons with specific disabilities, Ritika Gulyani's paper examines the lack of access to information as one of the most important barriers for deaf youth in the Indian context. She discusses the role of sign language in communication during the lockdown and further community building among the deaf mainly due to the intervention of technology. Access to basic resources became difficult for them but the deaf activists tried to reach to people who were left disconnected in the absence of communication about social protocols.

Mahima Nayar, Srilatha Juvva and Chitra Lakshman explore the psychosocial consequences of the COVID pandemic through the experiences of young people living with vision impairments residing in an urban low-income community in India. The study discusses how they took to new challenges with regard to access to health care and educational facilities and how they had to build new schedules to cope with the changed circumstances. By locating their strategies, the paper focuses on how policy needs to be cognizant of and also respond to new types of challenges that people with visual impairments in urban slums face.

One of the most urgent consequences of the COVID-19 pandemic and the associated containment measures has been a mental health crisis globally. The mental health implications

for marginalized populations emerge from existent structural inequalities. Suchaita Tenneti examines its consequences for the LGBTIQ+ population whose lives were rendered even more precarious due to loss of livelihoods unemployment and loss of mobility. The paper highlights the risk areas for the mental health of LGBTIQ+ people in India, the advice being given to them by mental health professionals and activists, and need for queer revisionings of uncertainty, the concept of a future and individualism.

Disabled populations are divided by class dimensions in the South Asian region. Looking at how the otherwise well-off middle-class sections live, Vaijyanti Bezbaruah examines the uncertainty, crumbling of support structures and fear of the disease as the implications of COVID 19 on the elderly population in the eastern part of India, and how they are trying to cope with new disabling challenges.

The final paper by Nilika Mehrotra looks at the class, gender and disability intersections to elucidate how technology has been utilised as an enabling tool by young persons with disabilities to talk about and discuss their problems and challenges. A consolidation of virtual Indian disability community occurred during the initial months of COVID related restrictions. The disability community has found new voice and different modes of awareness building and resistance to the state authoritarianism are emergent on the social media.

On the whole the volume tries to bring different facets of the intersectional realities of persons with disabilities living and navigating their lives through the COVID-19 pandemic in the South Asian region. Written as stand-alone papers, each of the papers talk to each other as the structural barriers, challenges and strategies to combat a combination of state neglect, poor infrastructure and community exclusion, appear as a familiar and shared experience for people with disabilities from across the region. As each of our contributors demonstrate, there are important lessons to be learnt for policy building and community making for the full realisation of rights of persons with disabilities. Many of these learnings can be shared not just within the South Asian region, but also more broadly across the Global South. It is hoped that this volume will pave the way for many more regional collaborations in the future for strengthening and enriching disability studies and activism to facilitate South-South exchange and knowledge transfer.

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