

Pandemic, Persons with Disabilities and Resurgent Networks

Nandini Ghosh

Abstract

COVID-19 pandemic destabilized lives in multifarious ways. For persons with disabilities, both the lockdown and the pandemic were experienced in varied ways by people from different impairment categories, rural-urban contexts and socio-economic groups. With an almost absent state, NGOs and disability networks stepped in to collaborate to provide food and other support, especially in rural areas. This paper explores the social solidarity and collective building efforts during the pandemic with reference to disability. The first section focuses on the larger issues of concern for disabled people and their families during the pandemic and lockdown phases. The second section uses the case study of the COVID Crisis Support Network (CCSN) in West Bengal which worked towards providing relief and medical support during the pandemic. The CCSN led by disability activists and parents of disabled people continuously networked with people in positions of power to ensure disabled people in the remotest rural areas were able to access food, shelter, medicine and later vaccines.

Author Profile

Nandini Ghosh is Faculty at the Institute of Development Studies, Kolkata. Her areas of interest are qualitative research methodology, sociology of gender, marginalisation and social exclusion and social movements. She has published a monograph *Impaired Bodies Gendered Lives: Everyday Realities of Disabled Women* (Primus Books, 2016) and co-authored a book on domestic violence titled *The Violent Domestic: Law, its Practice, and Strategies of Survival* (Zubaan, 2022). She has edited a volume titled *Interrogating Disability in India: Theory and Practice* (Springer 2016). She also has co-edited two books, *Pratyaha Everyday Lifeworlds: Dilemmas, Contestations and Negotiations* (Primus 2015) and *Caste and Gender in Contemporary India: Power, Privilege and Politics* (Routledge 2018). She has published widely on issues around gender, disability, law and politics in peer reviewed journals.

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Introduction

COVID-19 pandemic has destabilized lives in multifarious ways, with illness and death juxtaposed with the sudden lockdowns to prevent the spread of the virus resulting in widespread poverty, immense distress and anxiety. One of the strictest lockdowns in the world was imposed in India. For persons with disabilities, both the lockdown and the pandemic were experienced in varied ways across different impairment categories, rural-urban contexts and socio-economic groups. Inadequate access to food, medicines, sanitizers and care stemmed from poor access to documents and government systems. Cramped living spaces, concerns over sanitization and masking, and social distancing destabilized routines, created pressure on disabled people and their families. The continuous anxiety of contracting COVID-19, lack of accessible services in medical institutions or complete absence of care provision of disabled family members, caused immense stress and mental health issues. The social isolation of persons with disabilities and their families in India was exacerbated during pandemic induced social distancing, with families and their disabled members being cocooned from immediate communities. This paper highlights the experiences of disabled people and their families during the pandemic lockdowns—isolated from larger networks, with poor access to essential services—and the ways in which social solidarity amongst disability groups led to collective building efforts in the state of West Bengal, India. The paper rests on the insider view of a community that struggled and strived to survive. While the data for the first part of the paper comes primarily from media reports and social media (emails, Facebook and other platforms) content, the second part of the argument rests squarely on the personal experiences of collective building of which the author was a part.

Disabled people, their families and the Pandemic

Historically, disabled people in India have been marginalized within families and communities and labeled as being dependent or in need of support (Ghai 2003, Vaidya 2016). While the COVID-19 pandemic threatened all members of the society, persons with disabilities were disproportionately impacted due to attitudinal, environmental and institutional barriers that were additionally reproduced in the COVID-19 response. During the pandemic and lockdown, fear and suspicion regulated everyday social relations constructed and negotiated within specific structural conditions, laying bare the vulnerabilities of the population marginalized due to poverty, caste, class, religious, ethnic, gender and ability divides. While social isolation is a privilege for some, it became a nightmare for most during the pandemic. For the first time that the larger community experienced what disabled people do in their everyday lives – excluded, restricted to homes and powerless in a situation of constrained family and social contact. The differential access to social and cultural capital, couched within instrumental social relations¹ is the effect not just of the status

¹ Cultural and social capital is enhanced by social relations that individuals and families have, which are essentially instrumental in nature as they help them to access different social and community resources. Several studies (Kerr

of the family and its resources but also of the way in which disability is understood and interpreted, resulting in lack of trust and reciprocity within the social structures in which they are embedded.

The disabled emerged as one of the most vulnerable groups, with a greater risk of contracting COVID-19, primarily due to the poverty, lack of proper information on safety measures, poor access to hygiene measures like safe and clean water, soaps and sanitizers, etc. (NCPEDP 2020, Indiaspend 2020). While the state in India issued advisories to all citizens about COVID-19 and related information, the lack of accessible information about the spread of the disease, protocols to be followed and specific pathways to accessing help, in case a person with disability or a family member gets diagnosed with the virus, meant that the specific vulnerabilities, of persons with physical, sensory and cognitive disabilities fueled fear among families. The lack of sensitive directives and user protocols made disabled people and their families anxious and fearful regarding quarantine and management of COVID-19. Moreover, the lockdowns meant that disabled people fell through the food security net, due to limited digital skills, and inability to move out in search of everyday supplies and medicines, often resulting in starvation (Agarwal 2020; NCPEDP 2020). For people with high support needs, getting medicines and access to caregivers became extremely difficult, as reported by helplines run by civil society organizations, central and state governments (NCPEDP 2020; Indiaspend 2020).

The pandemic and lockdown presented different kinds of barriers to accessibility in healthcare facilities. In a pandemic situation when only emergency health services were operating, the vulnerability of disabled people increased due to poor quality or inaccessible healthcare services and the unavailability of impairment-specific requirements and additional vulnerabilities (Sampath 2020). Persons with chronic medical conditions requiring blood transfusion, dialysis and medicines, either went without these services or queued up at hospitals but were denied their life-saving interventions (Salve 2020; *Indian Express* May 6, 2020). People with disability who are at greater risk of developing into severe cases of COVID-19 due to underlying health conditions, like poor respiratory function, immune system function, heart disease or diabetes, were left in the lurch, as the management of the pandemic was through established medical care institutions. Almost no effort was made to reach out to people within communities for testing and to ensure protection for the most vulnerable groups, or even sensitization of healthcare personnel on disability inclusion to improve service delivery. For people with different disabilities, physical distancing, isolation and sanitization are difficult, for example, people needing hands-on help for basic everyday self-care tasks, having physical difficulty in rubbing hands together thoroughly, having to touch things to obtain information from the environment or for physical support or mobility. Further, social distancing is often daunting for persons with intellectual disabilities and persons on the Autism Spectrum, as continuous reminders to sanitize make them uneasy and anxious. The financial burden of frequently disinfecting assistive devices, including wheelchairs, walking canes, walkers, transfer boards, white canes, etc., becomes prohibitive for many persons with disabilities, most of whom are living in poverty and dependence (Prasad et al 2020). The social isolation imposed on disabled people within communities is further aggravated by the issues around touch, contamination as well as problems of imposing social distancing for disabled people. During the pandemic when individual responsibility for hygiene was projected as a virtue, the type of

and McIntosh 1999, Chenoweth and Stehlik 2004) have pointed to the social isolation of parents and families of children with disabilities with reduced capacity to access social networks.

impairment, social class, caste, gender and other identities complicated the situation further for the disabled.

The welfare state in India has seldom assumed responsibility for the elderly, disabled, marginal and vulnerable groups, preferring to pass it on to families, mostly unpaid provision of support. With little role of the state in the provision of care in India, the family has been the site of care and protection in urban cities. Within nuclear families, often it is the elderly providing bulk of care for the elderly and disabled in their families (Vaidya 2016). During the lockdown, the state remained notoriously absent, even abdicating responsibility for disabled citizens in state-run residential institutions. All residents of state-run institutions, with intellectual and psychosocial disabilities were sent home, thereby shifting the responsibility for their care and protection to parents and families, where there are limited health facilities, caregivers and other support. The COVID-19 pandemic brought to the fore, the anxieties and stress around contagion, of combating the disease and providing the care required, the worry about money and medical facilities, in both people with disabilities, their immediate caregivers and/or people with chronic illnesses.

Solidarities in the Time of the Pandemic

The genesis of the pandemic reflected not only the pain and anguish of disabled lives, but also the resistance to the oppression inherent in living with a label, which evokes and attaches a negative value to lack, deficit as well as difference (Ghai 2020). As mentioned before, the social capital of persons with disabilities and their families has been weak and tenuous in India. Social capital is the effective functioning of social groups through interpersonal relationships, a shared sense of identity, a collective understanding, shared norms, shared values, trust, cooperation, and mutuality. In neo-liberal times, individualism does not build kinship and inclusive community, specifically in COVID-19 (Ghai 2020). In the wake of the COVID-19 pandemic, social distancing as a necessary mitigation strategy has reduced interaction between people. Social distancing refers to a conscious effort to reduce close contact between people and suspected cases that may be capable of transmitting the disease (Tiffany 2020). COVID-19 pandemic, with its stress on social distancing and individual responsibility, served to push to the margins people who are represented as dependent and incapable of assuming responsibility. While the term ‘social distancing’ was used for the need to maintain physical distance between people during the pandemic, it has been used differently in the past. Social distance refers to the degree of ‘intimacy and understanding’ (Huges et al. 1950) or closeness that an individual or a group feels towards another individual or group and is often influenced by the prejudices manifested in the form of social stereotypes (Natraj 1965). Social and physical distances make it difficult for people to sympathize with others (Paskov & Dewilde 2012).

Social solidarity is the cementing force that binds individuals based on normative obligations that facilitate collective action and social order (Hechter 2001). It underlines the interdependence between people in a society, which makes them feel that they can improve the lives of others (Durkheim 1933). Social solidarity not only involves collective responsibility for the promotion of well-being of members of the group and community at large (Paskov & Dewilde 2012) but also emphasizes taking care of the needs and interests of the underprivileged members of the group (Reichlin 2011; Stjerno 2004). From the beginning of the COVID-19 crisis, the United Nations repeatedly underscored the importance of solidarity and global cooperation in dealing with the

pandemic (Modeer & Ryott 2020; United Nations University 2020). The failure to recognize the difference between social distance and social distancing by the global community and state parties meant that the increase in affective and normative social distance affected solidarity. Social distancing measures heightened the social distance that already existed in our society and has challenged the basis of solidarity. In situations where people were isolated from one another, because of fear fomented by the messaging around the virus and pandemic, disabled people and their families found themselves at the point where social solidarities were the weakest within communities and they were cut off from other communities from which they could access support.

Coming Together

In India, the disability movement has flowed along two parallel streams – that of the disabled activists and that of the parents of persons with disability. While one group argues for the upholding of rights of persons with disabilities – contesting ‘dependence’, the other has largely been focused on care and protection for persons with intellectual and multiple disabilities. The two groups have been positioned on either side of the debate on autonomy and care, with little dialogue between them, leading to each representing their concerns in different forums (Ghosh 2022). However, at this moment of panic and extreme crisis, two West Bengal based networks working for and with persons with disabilities convened an emergency online meeting in April 2020, within days of a stringent lockdown being announced across India – Parivaar Bengal and Disability Activists Forum West Bengal (DAF WB). While Parivaar Bengal is a state level network of parents of persons with intellectual and developmental disabilities that federates into a national network, DAF WB works for establishing the rights of persons with disabilities in the state, through awareness and advocacy programs. The two forums had previously worked together on the issue of safety in schools and institutions for children with disabilities. With the announcement of lockdown and the looming pandemic, these two forums convened an emergency meeting to find ways of responding to the imminent crises. This meeting led to the formation of a joint platform titled COVID Crisis Support Network (CCSN) with 11 members, 5 from DAF WB, 5 from Parivaar WB and 1 member belonging to both networks. The small group decided that the purpose of the network would be to support persons with disabilities and their families during the pandemic, in a time bound and focused manner. Two conveners from the 2 organizations were nominated from within the small group to take lead on coordination. There was also a larger platform where 104 members across the state were inducted, with their permission, to reach out for support to a range of players. Details of members were secured to create a database, with information about diverse needs of parents and people with disabilities, along with resources they could garner (both financial and skills) and their ability to provide support as and when required. Some of the members were people without any prior experience of working on disability but with a genuine concern about different issues of PWD's during the lockdown period. This gave the network access to medical and other professionals, linking it to an entire range of service providers and facilitating financial support. The CCSN was sustained primarily by the efforts of the small coordinating group and the conveners ensured a constant flow of information from the small group to the larger group, to keep up the morale and get others to become involved in the different activities being taken up, volunteer with this platform and get back to CCSN, if any family with a disabled member needed help. The small group recognized that the, “Big group is needed as number (sic) and also to understand that (sic) what are the primary concerns expressed and practical suggestions coming.” The larger group was constantly widened to include activists known to the members to mobilize a

larger support base, keeping in mind that the CCSN would have to be operational for a long period of time.

While the major objective was to reach out to and support disabled people and their families, the CCSN from the outset had decided not to replicate the work of the state, rather to ensure that the state agencies took responsibility for persons with disabilities at par with all other marginalized groups. Thus, there was an impetus on garnering support from state agencies in various ways. From the initial days of the lockdown, CCSN contacted the state government officials in the Disability Commissioner's Office and in the Department of Social Justice and Empowerment for all kinds of support ranging from passes for caregivers to medical support to food for families living below the poverty line. As the Disability Commissioner's Office was initially reluctant to respond to requests for help, the platform decided to use pressure tactics. The department was bombarded with letters from all members of the platform requesting varied kinds of help. It was hoped that the flurry of letters requesting help for persons with disabilities and their families in the pandemic situation would create pressure on the government to act. Along with the Disability Commissioner and the Minister for Social Justice and Empowerment, CCSN and its members wrote letters of appeal to the Minister for Health in West Bengal, Chief Secretary of West Bengal and to the Director General of Police, West Bengal and Kolkata, and local police stations for support and specific directives. There was a clear understanding that these people in positions of authority should facilitate access of disabled people to an entire range of goods and services at par with others. However, the absent state machinery and the delayed response to disability issues were evident from the non-response from both the Disability Commissioner's Office as well as other state departments working for and with persons with disabilities. The Conveners of the CCSN platform regularly networked with the Disability Commissioner's Office often through multiple phone calls, where the Disability Commissioner expressed his inability to meet requests even as simple as furnishing a comprehensive list of all persons with disabilities in West Bengal using their database of disability identity cards issued by the state. Till May 2020, there was no official report of disabled people contracting COVID-19 with the state Disability Commissioner, who had organized distribution of food and medicine for those disabled people and their family members who had contacted them.

Working in Tandem

Sensing that the state was unwilling to take responsibility for disabled people, CCSN decided to reach out, through NGOs and its other members, to persons with disabilities and their families. For this they recruited volunteers, to be operational whenever need arose. A 5-member Volunteer Co-ordination committee was formed in the second week of its existence, which took responsibility for building a database of volunteers with their name, contact details, organizational affiliation, location details so that tasks could be assigned accordingly. They were also asked to list contacts, if any, with the local police, councilor or local club that could be mobilized if there were any families of persons with disabilities in need in that area. While CCSN began with 41 volunteers, at the end of 6 months there were 95 volunteers listed with CCSN to help disabled people and their families in getting medicine and food. The small group of CCSN also compiled a list of contacts of important people from different districts to approach if required for support as "they will be able to mobilize people in their districts. If other supports are needed, then the members of this group will intervene, as during quarantine /hospital stay." It was envisaged that the local volunteers

would be able to connect disabled people to existing schemes, through local administration to procure food stuff or other items, failing which he/she ultimately may seek help from the members of the group, who will take a decision to resolve the issue by mobilizing the common fund.

However, soon it was revealed that disabled people and their families had access to very poor resources – lack of relevant documents to claim relief, poor access to information and means of accessing support, state apathy etc. culminated in the CCSN being flooded with requests for food and medicines through its members and organizations during the lockdown period. These requests were primarily from rural areas for food and medical support, where families of disabled people were starving because of lockdown. NGOs that were part of CCSN found the disabled people and their families in dire condition within local communities and approached the CCSN with lists of people with disabilities in distress. Members of CCSN themselves took responsibility to ensure that relief reached families in all parts of the state. The food committee was given the responsibility for deciding what kind of dry food rations will be distributed to which area as they were in charge of the verification of the process or ‘Know Your Customers’ (KYC), and also, they had a complete picture of volunteers, resources available and need. The food committee enlisted volunteers to get the KYC done of all families for whom rations were being sought. Once the KYC of an area was completed, the arrangement to buy provisions and reach them to the identified and verified beneficiaries would be carried out with the help of volunteers. Throughout the distribution process the reach of CCSN was mapped and accounts maintained. Food distributed by different member organizations of CCSN was also done under the CCSN banner. There was great collaboration and coordination among the different member NGOs through sharing the resources across different sites. There came reports from the districts about the alarming situation. For example, in Midnapur town one elderly gentleman was providing cooked food to many people, nearly half of them being disabled people. So, it was decided to provide a "one time aid" of dry ration to these people from Midnapur, and the local volunteer was requested to make a field visit to confirm the authenticity of the recipients and arrange for the provisions from a local shop and make the payment directly to the shop owner. After the rations were distributed the volunteers had the responsibility to call the beneficiaries to verify if they had actually received the listed provisions. NGOs distributing in remote rural areas were asked to post photos of the recipients with the rations. This ensured transparency and accountability in use of public funds.

Medicines were one of the major demands of the families of persons with disabilities, especially from those who require regular medication for chronic conditions. Due to lockdown, families were unable to access medicines both due to poor access to medicine shops but also because of loss of income. The CCSN platform recognized this need immediately and constituted a small committee to whom all requests for medicine were directed. This group created a team of volunteers and requested for prescriptions to be sent to them, verified the dates of last doctor visit, the requirement and the capacity to fulfill the requirement. The group framed criteria for extending support and linked up with the medical representatives to access free samples. They also created a list of essential and life-saving medicines with the idea of creating a medicine stock sourced from donors. There was a doctor on this team who took responsibility for identifying the gaps in prescriptions and advised families and organizations to seek advice from the doctors before CCSN supported their medical needs. Families received supplies across the state of West Bengal by linking up through volunteers with medical representatives and medical stores for discounted prices, with organizations taking responsibility for collecting and reaching the medicines to different families

in remote rural areas. Parents' groups and DPOs were mobilized for different kinds of support in this process. While requirement of medicines was different for different people, CCSN sought to ensure that almost all requests for medical support were met, even ensuring that people were taken to doctors to renew their prescriptions and dosage decided adequately.

As requests for different kinds of support came up to the CCSN, the two main partners Parivaar Bengal and DAF WB also decided to look for financial support through other channels. However, as the CCSN was an ephemeral entity primarily for a short-term purpose, it was decided that each forum would receive money into their account and maintain distinct accounts to be presented to the large group at periodic intervals. At the same time, facing the need of the disabled people and their families, each entity took a decision to contribute an amount of 25000/- for a common fund, while promising to also look for funds and support from other sources. Most of this fund was used to provide food, medicine and other support. Many queries also came from Corporate Social Responsibility (CSR) agencies for providing rations and volunteers. There was an offer from Cognizant Technologies to fund some of the relief and they requested for a proposal and budget from the CCSN. However, it was, at that point of time, difficult to furnish an exact list of beneficiaries from specific areas.

The CCSN also worked in different ways to allay the fears of individual parents of persons with disabilities when they were affected or infected by COVID-19. Parents especially of persons with intellectual impairments were unsettled by the pandemic as they feared their children were more vulnerable not just because of their precarious health status but also as they would not be able to comprehend the complicated preventive and quarantine measures. One parent living in a housing complex was scared of contamination and infection as many families in the same complex had tested positive for COVID-19. Panicked she requested the CCSN for support, but it was not clear what exactly she wanted. After intense conversations with the CCSN lead members, it was understood that she wanted help in case they contracted the virus and also in the dire circumstances of either hospitalization or death. The CCSN assured her of interventions in such a situation and promised that immediate plans would be made in such a scenario. These long conversations with the mother resulted in calming her down and allaying fears, rather like a counseling situation. However, incidents like this brought to the fore the apprehensions of many families, the fear of quarantine and hospitalization with the care of the disabled person either at home or in the institution being the most worrisome. What is also revealed is the precarious fate of many families where parents are the sole carers and there are no alternative care arrangements. In the CCSN it was also decided to send an advisory through the different networks for families to list out next of kin to call in case of emergencies and store the information in multiple places. During discussions about facilities for disabled people affected by COVID-19, there were also requests for either home isolation or particular hotels being designated for disabled people and their families to ensure that those who required care could be together. However, many parents of people with intellectual disabilities requested for home isolation and concomitant medical support as they did not want to disrupt the lives of their offspring.

In May 2020, West Bengal was devastated by the Cyclone Amphan amidst the pandemic lockdown. Amphan brought in new needs and concerns, not only for the disabled people and their families but for others too. The CCSN started getting urgent distress calls from the coastal districts across the south of Bengal, where dams were damaged, and entire villages were submerged and

hundreds of homeless people were forced to take shelter in school buildings, where physical distancing was impossible. There was a fierce debate within the group about whether to support everyone who approached the organization for help or to continue to support only disabled families in this moment of a natural disaster. With limited resources was it possible to extend support to non-disabled people and families? As one member put it, “the situation is such (sic) grave that [it is] not only impossible but also inhumane to just give [support] to PWDs and not others.” It was resolved in the meetings that CCSN would try to rally around and garner support for non-disabled people while focusing on attending to the requirements of disabled people and their families. People were seeking different kinds of support – food, drinking water, utensils, mosquito repellents, tarpaulin and even snake repellents. Even families of persons with disabilities were affected badly, as CCSN partners and allies started reporting. CCSN linked these NGOs to a group of government volunteers to ensure that they were adequately served.

After the initial lockdown and Amphan related relief work, the CCSN shifted its attention to emerging issues of education and vocational training for children and young people with disabilities. While the government, both at state and central level, had started issuing directives about re-opening of institutions and online modes of education and training for general students, there were hardly any directives for education of disabled students and trainees. Parents were concerned that their disabled children and young adults were out of the routine and discipline of institutions and the impact it was having on them. “Can we send a request to our Sarva Siksha Mission's State Project Director that...the special educators of SSM must keep contacts with the Children with Special Needs (CWSN) they work with and try to support them or mobilise food and medicine...or through SSM they support CWSN.” A leading partner within CCSN took the lead to discuss issues of common concern regarding opening of services by service providers, post lockdown. Though different organizations and institutes serving the disability sector started online support systems soon after the announcement of lockdown (which included online classes for students and young adults with disabilities, therapy sessions, counseling sessions for the children and their families), many families were unable to access these alternative support systems for genuine reasons such as not having continuous electricity, access to a smart phone, network issues, unable to recharge for paucity of money, lack of adequate supervision during online activities. A letter was sent to the Minister of State for Women and Child Development and Social Welfare, and Minister of Social Justice & Empowerment, Government of West Bengal, requesting to develop necessary protocols and guidelines for effective functioning of organizations working with people and families of those with disabilities. There was a demand for developing an action plan for persons with disabilities, as per RPWD Act 2016, in terms of their treatment, therapeutic support, assistive devices, education, skilling and livelihood. Despite repeated advocacy with the state government departments, this issue was not adequately addressed and these organizations remained in a state of limbo for a prolonged period.

Emerging Issues of the Pandemic

In the second phase of the pandemic, CCSN was confronted by the issue of guardianship of persons with intellectual disabilities as mandated by the law in case of death of parents. One case that came to CCSN was of a person who was a member of the network and had 2 young adult offspring with intellectual disabilities. When he passed away suddenly because of COVID, he was cremated by the state agencies and there was a delay in accessing his death certificate. His children were shifted

to a residential institution as per his will, but there was an issue of legal guardianship. Members of CCSN guided the lead person from the residential institution to approach the relevant authorities for guardianship, but his petition was rejected as the death certificate was not available. Getting the death certificate proved to be a cumbersome issue, and the Local Level Committee that is entrusted with the task of conferring guardianship under the Chairmanship of the State Disability Commissioner, kept the matter in abeyance for over a period of 6 months, which meant the two children were unable to access the funds left for them in trust by their parents. The CCSN tried to coordinate between the three players here and ensured that the decision to approve the Legal Guardianship of these two young people was processed as soon as possible and also linked up with the life insurance provider to ensure that the transfer of funds happens as soon as the guardianship issue is resolved.

Another issue that the CCSN took up was the vaccination of persons with disabilities across the state with the Disability Commissioner. This was soon after the notification on vaccines for all was circulated in May 2021 to ensure a prioritized, accessible and sensitive process for all. There was a fear among the members of the CCSN that persons with disabilities may be the last group to be considered for vaccination along with the issues around taking disabled people to vaccination centers, and producing relevant documents for accessing the vaccines. As the Aadhar or UDID (Unique Disability Identity) card was a mandatory requirement for vaccine, many disabled people complained that the biometric parameters for the documents made it difficult for them to access such documents, since UDID cards had not been rolled out in West Bengal. While a series of letters were sent by CCSN to all concerned including the State Disability Commissioner, Director Health Services, and the Minister of Social Justice and Empowerment for adopting specific steps for ensuring vaccination for all persons with disabilities, the lack of response from them and the absence of public announcements to this effect worried the CCSN and its members. When approached, the state Health department asked the CCSN to provide the list of persons with disabilities across the state, which was preposterous as such data is maintained by the state and it was the responsibility of the state both to furnish data and to plan vaccination programs for all vulnerable groups. While all members agreed that the issue of vaccination of disabled people and their families was a policy issue relevant both at state as well as central level, there was also impatience and worry about the delay in accessing vaccines. The panic was further fueled by the deaths of many people, including parents and relatives of disabled people. CCSN then decided to file a Public Interest Litigation at Calcutta High Court, regarding priority vaccination of vulnerable and marginalized groups and other entitlements with support from Human Rights Law Network (HRLN). From the CCSN platform, it was a unanimous decision to be a part of this petition and press for a quick resolution in the form of a directive from the court. However, there was a substantial delay that demoralized the entire group of CCSN as the virus loomed over families. After three months the court announced that disabled people would be included within the different marginalized groups for priority in vaccination.

Conclusion

Solidarity involves concerns for the well-being of others (Davies & Savulescu 2019) and an understanding that one can maximize one's well-being by improving others' conditions (Stjerno

2004). The pandemic and the lockdowns exposed the vulnerabilities of all the marginalized groups in society, where physical and social distancing led to collapse of solidarities and resulted in differential access to social and cultural capital. While on one hand there were impairment specific issues like sanitization and access to health services, there were structural concerns around poverty and food security for disabled people and their families. In the complete absence of state mechanisms to provide care, protection and support to such vulnerable groups, new social solidarities had to emerge in order to address the concerns of people who were considered to be sharing the same identity markers. When the idea of the CCSN first germinated, it was the coming together of two disparate networks, one promoting rights of disabled people and the other working for care and protection of persons with severe disabilities. In India and across the globe, parents' groups have often found themselves left out of the disability discourse, as emphasis on rights (with a firm grounding in individual autonomy) is often projected as antithetical to care and protection, which are mostly seen as leading to loss of autonomy. The two networks in West Bengal - Parivaar Bengal and Disability Activists Forum West Bengal, however, worked together building on their previous work on developing safety guidelines for institutions for persons with disabilities to establish CCSN.

The relevance of such a network has been demonstrated by their ability to successfully connect across the state with Organizations of Persons with Disabilities, Disabled People's Organizations, parents' groups, civil society organizations and NGOs to reach out to and support, as required, disabled people and their families across the state. The efficacy of the CCSN can be measured by the real time support it provided to people and families at the community level, during complete lockdown and when the state administration was in a limbo. The spirit of collaboration among the members and the concerted effort to deliberate on and find adequate solutions to issues brought to their notice was another reason for the success of the CCSN. Finally, the thrust on state level advocacy (putting pressure on the state and seeking legal directives) and the ability to look beyond the immediate survival needs (thrust on vaccination and guardianship issues), also lent credibility to the network. The CCSN was recognized by all India networks of and for persons with disabilities and their families like PARIVAAR National Coalition of Parents' Organisations, National Centre for Promotion of Employment of Disabled Persons etc. The social solidarity generated between the two forums buttressed by the impact of their efforts has ensured that the two significantly distinct forums will collaborate in the future for the strengthening of the rights of persons with disabilities in West Bengal.

In conclusion, during the pandemic when suspicion, fear psychosis, and trust deficit were rampant, where the state huddled in a corner unable to support any of its vulnerable citizens, when disability groups felt pushed into a dark corner, the social solidarity demonstrated by the CCSN emerged from and further strengthened the "we feeling" in the larger disability community revealing a pressing concern for the well-being of others (Davies & Savulescu 2019). While disability groups and parents associations of the disabled in India have always been distinct in their concerns and the ways in which they project their rights. It was at this moment of crises that the two streams – the disabled activists and parents of the disabled came together to strive for collective benefit – when individuals with disabilities and their families needed support to survive, to weather the storm together to allay the fears of one another and to emerge stronger to claim their rights. While the pandemic called for individual responsibility and physical distancing, fear of the virus led to social distancing yet this social solidarity among members of cross disability groups demonstrated

the power of collectives, despite marginalization. Not all of CCSN's initiatives were successful but they reflect the will to strive, thrive and take responsibility for all.

References

- Agrawal, S. 2020. "Relying on Kindness of People" – India's Disabled Bear the Brunt of Covid-19 Lockdown." *The Print*, 29 March 2020. <https://theprint.in/india/relying-on-kindness-of-people-indias-disabled-bear-the-brunt-of-covid-19-lockdown/390631/>
- Davies, B., J. Savulescu. 2019. "Solidarity and Responsibility in Health Care." *Public Health Ethics* 12 (2): 133-144.
- Durkheim, Emile. 1933. *The Division of Labor in Society*. New York: Free Press.
- Ghai, Anita. 2003. *(Dis)Embodied Form is an Engagement with the Issues of Disabled Women*. New Delhi: Har-Anand Publications.
- Ghai, Anita. 2021. A Rendering of Disability and Gender in the COVID-19 Era. *Economic and Political Weekly Engage* Vol. 56 (11). <https://www.epw.in/node/158131/pdf>.
- Ghosh, Nandini. 2022. Citizenship, Rights and Persons with Disabilities in India, *South Asia Multidisciplinary Academic Journal* [Online], 28 | 2022. DOI: <https://doi.org/10.4000/samaj.7924>
- Hechter M. 2001. "Sociology of Solidarity." In *International Encyclopaedia of the Social and Behavioural Sciences* Vol. 21, edited by N.J. Smelser & P.B. Baltes. Oxford, UK: Elsevier.
- Huges, E.C., C.S. Johnson, J. Masuoka, R. Redfield, and L. Wirth. 1950. *The Collected Papers of Robert E. Park: Race and Culture*, Vol. 1. Glencoe, IL: The Free Press.
- India Spend*. 2020. "Too little, Too few: An Initial Analysis of the Social Protection Response to COVID-19 Crisis for Persons with Disabilities in India." May 2020. https://www.indiaspend.com/uploads/2021/01/04/file_upload-374250.pdf
- National Centre for Promotion of Employment for Disabled People (NCPEDP). 2020. *Locked Down and Left Behind: A Report on the Status of Persons with Disabilities in India During the COVID – 19 Crisis*. National Centre for Promotion of Employment for Disabled People (NCPEDP). https://ncpedp.org/reports/Report-locked_down_left_behind.pdf
- Modeer U., and A.Ryott. 2020. "COVID-19: A Reminder of the Power of Hope and Solidarity." <https://www.undp.org/content/undp/en/home/blog/2020/covid-19--a-reminder-of-the-power-of-hope-and-solidarity.html>
- Nataraj P. 1965. "Social Distance Within and Between Castes and Religious Groups of College Girls." *The Journal of Social Psychology* 65 (1): 135-140.
- Paskov M., and C. Dewilde. 2012. "Income Inequality and Solidarity in Europe." *Research in Social Stratification and Mobility*, 30 (4): 415-432.

- Prasad, Rajendra, Anandita Lidhoo, Tarun Lala, Prateek Sharma, Anjali Lodwal, Manish Jaiswal, Shagufta Nayar, Charu Khatri, Surbhi Vyas, Surbhi; Umaid Singh Deora, and Shikha Vaswani. September 2020. "COVID-19 Pandemic-related Lockdown: Effects on Persons with Disabilities in India." *Apollo Medicine* 17 (Suppl 1): S44-S49. DOI: 10.4103/am.am_81_20
- Reichlin M. 2011. "The Role of Solidarity in Social Responsibility for Health." *Medicine, Healthcare & Philosophy* 14 (4): 365-370.
- Salve, P. 2020. "COVID-19 Lockdown Causing Further Shortage at Blood Banks." *IndiaSpend*, 1 April 2020. www.indiaspend.com/covid-19-lockdown-causing-further-shortage-at-blood-banks/
- Sampath, J. 2020. "Persons with Disabilities Bear the Brunt of Coronavirus Lockdown." *The Federal*. 5 April 2020. <https://thefederal.com/states/south/tamil-nadu/persons-with-disabilities-bear-the-brunt-of-coronavirus-lockdown/>
- Stjernø, S. 2004. *Solidarity in Europe: The History of an Idea*. Cambridge: Cambridge University Press.
- The Indian Express*. 2020. "Amid COVID-19, Thalassemia Patients face Challenges with Blood Transfusion." 6 May 2020. <https://indianexpress.com/article/lifestyle/health/covid-19-thalassemia-patients-are-being-denied-blood-transfusion-services-6396475/>
- Tiffany, K. 2020. "The dos and don'ts of 'social distancing'." *The Atlantic* 12 March 2020.
- United Nations University. 2020. "UN Secretary-General: COVID-19 Pandemic Calls for Coordinated Action, Solidarity, and Hope." 19 March 2020. <https://unu.edu/news/news/un-secretary-general-covid-19-pandemic-calls-for-coordinated-action-solidarity-and-hope.html>
- Vaidya, S. 2016. *Autism and the Family in Urban India*. New Delhi: Springer.