Disability during COVID-19
Increasing Vulnerability and Neglect

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COVID-19 and the resultant lockdowns have severely curtailed the mobility of persons with disabilities, restricted their ability to seek basic necessities, healthcare, and assistance. Uncertainty on the disbursement of financial protection schemes meant for persons with disabilities have exacerbated their existing financial precarity. At this juncture, obstacles in accessing healthcare should be identified, facilities should be made affordable, and financial support should be exclusively planned for persons with disabilities to save them from the dreadful risk of the coronavirus and its aftermath.

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The COVID-19 pandemic is an unprecedented public health crisis, and the attendant infections and fatality are concentrated in the lower strata of society in developing countries. It has also devastated developed countries, including the United States, Italy and United Kingdom. Poor health and socio-economic conditions widen the spread and susceptibility of COVID-19 in India. Increasingly, public medical facilities are getting overcrowded and failing to meet the massive demands of intensive care. Persons with disabilities (PWDs) is one of the segments of the population who face compounded vulnerability to contagious diseases and lack of access to necessary facilities. Globally, it is estimated that a billion people have one or more types of disability (WHO 2011). In India, 26.8 million people have one or more forms of disability (GOI 2011). The difficulties faced by PWDs in India are multidimensional in nature and their poor socio-economic conditions increase the risk and vulnerability from the pandemic and prolonged lockdowns.

COVID-19 is intensifying the inequalities experienced by PWDs around the world. Often, information on disability is gathered remotely, rarely highlighting emergency preparedness during a disaster. Despite provisions made to ensure equal rights and responsibilities towards PWDs, they are neglected. Looking at their conditions amid COVID-19, the United Nations (UN) and the World Health Organization (WHO) have come up with a framework, and guidelines for protecting PWDs by ensuring possible measures to protect them from distressful economic conditions (WHO 2020; UN 2020a). The guidelines mention the role of healthcare institutions and healthcare professionals in maintaining compliance for the inclusive development of PWDs (Armitage and Nellums 2020). Detection, assessment, treatment, escalation and recovery are the main steps that have been evoked to tackle COVID-19, and during the assessment phase, the strategy of test, isolate and treat has been followed in the current approach to mitigate COVID-19 in the West (Watkins 2020). The role of local governments to cater to the needs of PWDs has been emphasised in view of the pandemic by the UN (2020b). An online survey undertaken on PWDs across India by the National Centre for Promotion of Employment for Disabled People (NCPEDP) highlights the difficulties faced during the COVID-19 crisis, including problems in accessing essential items, medicines and pension.

The daily updates by the government on infections and fatality from COVID-19 rarely list out infected PWDs. The chronic underlying conditions of PWDs are a significant threat in addressing their health problems. It is often difficult for them to self-report health problems. The situation gets aggravated for those having disabilities in mental or intellectual categories, as they are unable to understand and express physiological requirement by themselves. Neglect and discrimination experienced by PWDs often remain unaddressed and unnoticed when countries face mass infections or other health burdens. The multidimensionality of suffering often faced by them is interlinked with persistent discrimination, deprivation, atrocities, and exclusion.

In order to portray the magnitude and conditions of PWDs, especially against the backdrop of COVID-19, we have reviewed data from Census 2011 and the National Sample Survey (NSS) (76th Round, 2019—Persons with Disabilities).

Health Conditions

According to Census 2011, 2.68 crore people—2.2% of India's population—has disabilities (Table 1). The NSS also

Table 1: PWDs in India by Age and Sex Categories

Age Groups	PWDs in India (%)		
	Total	Males	Females
0–14	20.9	20.6	21.2
15–59	59.0	61.2	56.1
60+	20.1	18.2	22.7
Number	2,68,14,994	1,49,88,593	1,18,26,401

Source: Census 2011.

estimates that 2.2% of India's population has disabilities as of 2018–19. According to Census 2011, disability in movement (20.3%), in seeing (18.8%) and in hearing (18.9%) contribute a sizeable share of total disability (Table 2). Disability in seeing, locomotion and multiple disabilities show that more than 25% of the disability is among the elderly (60 years and above). Disability in locomotion has significantly high prevalence among males (62%) than females (38%). Disparities in the prevalence of disabilities across geographies, gender, social and economic groups orient us to understand the differentials in the risk experienced by PWDs during COVID-19 induced lockdowns.

Table 2: Types of Disability by Age and Sex

Categories	Total	Seeing	Hearing	Speech	Movement	Mental Retardation	Mental Illness	Others	Multiple Disability
Number	2,68,14,994	50,33,431	50,72,914	19,98,692	54,36,826	15,05,964	7,22,880	49,27,589	21,16,698
Percentages	100.0	18.8	18.9	7.4	20.3	5.6	2.7	18.4	7.9
Age group									
0–14	20.9	20.9	23.3	24.0	11.6	26.4	11.1	26.3	22.9
15–59	59.0	52.0	56.4	65.7	63.3	67.6	76.2	61.1	46.9
60+	20.1	27.1	20.3	10.3	25.1	6.0	12.7	12.6	30.2
Gender									
Male	55.9	52.4	52.8	56.2	62.0	57.8	57.5	55.4	54.9
Female	44.1	47.6	47.2	43.8	38.0	42.2	42.5	44.6	45.1

Source: Same as Table 1.

The highest share among PWDs is locomotor disability (52%) and multiple disabilities (10.36%). Seeing and hearing (9% each), and speech, mental retardation,[1] and mental illness (5% each) were the other major forms of disabilities. The pattern of disabilities observed across age groups reveals that a larger share of disabilities is contributed by the elderly having disabilities in locomotor, seeing, hearing, and mental illness. Disabilities in speech and mental retardation display an opposite pattern and have a higher percentage among the younger ages. Prevalence of disabilities among males (2.4%) is higher than females (1.9%), and slightly higher in urban areas (2.3%) compared to rural areas (2%).

Addressing the healthcare needs of PWDs in India reveals two issues. First, the treatment-seeking and caregiving situation of PWDs needs to be comprehended in a better manner. The NSSO data on PWDs (2019) shows that more than 30% of PWDs in India are undergoing treatment with or without consulting a doctor, and about 7% cannot undergo any treatment as it is either unaffordable or facilities are absent in their areas. The personal assistance required for doing daily activities varies from 90% for disability in hearing to 60% for locomotor disability. Data on living arrangements show that most PWDs are staying with their families and only 3% are living alone. About 63% of PWDs are required to have some form of regular caregiving from others (GoI 2019).

Second, the availability of assistive devices for the mobility and communication of PWDs in India is poor. The NSSO data provides information regarding the use of assistive devices for three specific types of disabilities—locomotor, vision, and hearing. PWDs who have acquired an assistive device is 24% among those with locomotor disability, 33% among those with visual disability, and 21% among those with hearing disability. Around 11% to 19% of PWDs under these categories could not acquire an assistive device, owing to unaffordability or non-availability. However, not all of them regularly use an assistive device due to the lack of repairing facilities, steep terrain and lack of awareness regarding the usage of assistive devices. The NSSO data also indicates that only 30% of PWDs in India have a certificate of disability issued by a competent authority, and around 60% of those who received these certificates have significant disability.

Lockdown and PWDs

During lockdown, the support system for PWDs is considerably affected, which demands an active response from the government and society at large. A majority of PWDs in India do not use any assistive devices and thus are dependent on others for performing their daily tasks. Availing transportation is a significant issue at this time as access to medicines and basic needs, like going to the market or ration shops, are a concern for the PWDs who are staying alone. According to NCPEDP (2020), 67% of PWDs did not get essential items delivered at their doorstep. Repairing or replacing assistive devices (prosthesis, orthosis, hearing aids, spectacles and wheelchairs) is difficult during lockdowns, which worsens the disability by restricting movement.

Additionally, the language of communication for PWDs varies. For instance, persons with visual impairment employ and understand Braille, PWDs in hearing and speech understand lip readings or sign languages. Our conventional information-dissemination systems, like daily news reports and announcements from governmental organisations/departments on electronic or hard copies of news or information, usually do not use any mode of sign language. Covering of face with a mask or avoiding touching a surface due to a probable chance of infection adds another barrier in accessing information by PWDs. These problems are compounded in rural areas where a significant share of PWDs reside. Also, since the already few rehabilitation centres that provide services like prosthetics, orthotics, therapeutics, individual schools, and rehabilitation centres are located in faraway places, healthcare for PWDs during the lockdown remains a major challenge. Only 325 district disability rehabilitation centres (DDRC) and few active non-governmental organisations (NGOs) are available to serve 27 million PWDs (Ministry of Social Justice and Empowerment nd). Many DDRCs are not functional due to shortage of staff and supply during the lockdown. Confusion regarding the immediate contact to repair, replace, or purchase an assistive device can cause further anxiety among the users during the pandemic. Transport for PWDs in reaching these resource centres is practically absent, and additional expenditure to hire a vehicle or an escort to reach the clinics or rehabilitation centres add economic burden. People with limited mobility or persons who cannot avoid coming into close contact with support providers and caregivers are more likely to be affected. Many caregivers are also

reluctant to work or assist due to the fear of being exposed to the coronavirus.

Neglect, isolation and deprivation during COVID-19 can be minimised if the disability rights prioritised in programmes are oriented for pandemic mitigation. Maternal and reproductive rights are needed to be ensured for this specialised group. Health rights must be promoted and delivered with every possible support without delays in availing basic health demands. Limited accessibility to communication concerning COVID-19 and further restrictions in social connectedness due to the lockdown can result in trauma for PWDs. Those with severe disabilities as well as those who are living alone have an extra cost of living due to higher medical expenses, assistance for caregiving, transportation and overall disability cost. They are more dependent on private caregivers as they cannot always count on informal caregiving support from their families (Mitra et al 2007). Because of the fear of infection, many PWDs would not be able to perform necessary activities without help from a caregiver. Based on the data on the requirement of daily assistance, it can be comprehended that due to lockdowns and restrictions in supportive services, the situation has grown miserable for PWDs. Family members and friends are not allowed to travel to visit them, and as assistance is not always available, it restricts their daily activities. Limited number of caregivers at homes for PWDs stretches the already scarce amenities such as sanitation, medical supplies and therapeutic exercises.

PWDs suffering from health conditions like cerebral palsy, stroke, paralysis and upper limb amputation are far away from particular protocols and safety precautions that heighten the risk of infectious diseases (Watkins 2020). For example, regular cleaning of hand, wearing a mask all by themselves and maintaining physical distance is difficult for the dependant PWDs. PWDs have more healthcare needs and higher healthcare expenditure than others and usually report higher unmet needs in accessing healthcare services due to long waiting lists, lack of accessible transportation, costs of medicines and inadequate primary care benefits (Sakellariou and Rotarou 2017). Behavioural risk factors lead to lesser functions and a higher chance of growth of chronic conditions like cardiovascular diseases, diabetes and respiratory diseases. There is a higher possibility of increase in the risk of infections from COVID-19 among PWDs due to their multimorbid conditions and disadvantaged living conditions. Besides the social and economic factors, demographic factors like age become crucial as elderly PWDs are more helpless in terms of seeking care.

Old age marks a higher prevalence of comorbidities along with the increasing burden of disability. PWDs often suffer from underlying health conditions like cardiovascular, respiratory, neurological, malnutrition and orthopaedic issues (Nas et al 2015). Underlying comorbid conditions increase the likelihood of getting infected from COVID-19 (Guan et al 2020; Wang et al 2020). Lack of exercise reduces physiological activities as well as cognitive performance, especially among the elderly (Paterson and Warburton 2010). Poor sanitation at the inhabiting places increases the chance of common illnesses. In India, almost 10% of the elderly reported having multi-morbid conditions (two or more chronic diseases), and 12% of the elderly have restrictions in at least one activity of daily living (Arokiasamy et al 2015) and are dependent on assistance for daily activities.

According to Census 2011, 78,314 institutions are accommodating 2.40 lakh PWDs. People living in shelter homes or institutions are known to have a poor quality of life due to inadequate physical infrastructure, and thus run a higher risk of aggravating chronic conditions, especially if these places have more than their designated share of inmates. Caregiving activities for the elderly among them, who require added medical support and physical assistance, could escalate their risk of infection. Western countries have already suffered the heightened risk of infections and subsequent higher mortality among the elderly living in institutional setups.

The management of the infection is another dimension that raises serious concerns for the PWDs. Quarantine or isolation can be a cause for concern without assistive services and specialised medical care. Individuals who have disabilities in mental retardation or illness require external support or caregiving at this critical time. Lack of expression could lead to physical, emotional, sexual, or domestic violence, which can have long-term effects. Furthermore, the notion of stigma attached to disability can be multiplied with a perception of unhygienic stay, fear of contamination, spreading of infection due to barriers in accessing basic sanitation and menstrual hygiene. Besides, family members of PWDs are afraid of the social stigma attached to COVID-19. Hence, social distancing actually results in more deprivation at multiple levels in the present context.

Financial Inclusion

Socio-economic conditions highlight the deprivation among PWDs in terms of human development. Almost 50% of PWDs are not educated, suggesting structural discrimination in accessing schools and other educational facilities. The "selection effect" hypothesis suggests that those in poor socio-economic conditions are prone to suffer from disability (Jenkins and Rigg 2004). Strengthening this argument, the average monthly per-capita expenditure of households having PWDs is lower than the households with non-disabled members in India (Menon et al 2014). The work participation ratio for PWDs (number of workers with disabilities per 100 PWDs) in India is 23%, despite many provisions by the government. The limited social safety net for PWDs is not enough to meet their basic requirements even in normal times. The NSSO data suggests that around 77% of PWDs do not receive any kind of financial assistance. Although there are multiple central and state financial support schemes for PWDs, only 14% receive disability pension and 10% get assistance from multiple sources. Prolonged lockdowns have only aggravated their financial distress as savings have depleted.

Disability pension is one of the financial assistance schemes that helps individuals and households in the absence of a sustained income. The Indira Gandhi National Disability Pension Scheme (IGNDPS), funded by both the central and state governments, provides support to the economically marginalised among PWDs. However, the money given under the

pension scheme varies considerably across states. Bihar offers ₹300 whereas Arunachal Pradesh offers ₹2,000 per month under the same scheme. In 2017–18, 7.12 lakh PWDs belonging to below poverty line (BPL) households benefited from IGNDPS (Indiastat nd). Even though many more adults with disabilities are eligible, lack of disability certificates and a cut-off of 80% and above in the disability level, restrict their actual eligibility. Few states who use their own funds for disability pensions have made a lower cut-off (40%) for identifying disabilities.

In March 2020, the central government announced the disbursal of three months pension in advance under the National Social Assistance Programme (NSAP), and ex-gratia payment of ₹1,000 to the poor PWDs. However, 63% of PWD respondents are yet to receive any pension or grant (NCPEDP 2020). The meagre amount in the form of pension is not enough to cater to the daily needs of PWDs. As food and other essential items are often not readily available, a price hike and extra transportation cost to avail those benefits can be stressful to those who are fully dependent on the disability pension. At present, the biggest concern is how regularly these financial assistance are reaching beneficiaries.

Widespread unemployment, even among family members of PWDs, can lead to material deprivation and subsequently, result in anxiety and depression. Uncertainty on the disbursement of financial protection schemes result in miserable living conditions. Given this scenario, PWDs may be forced to spend much less, which is likely to further expose them to health and economic vulnerability.

Integrating PWDs

Although we have many important legislations to protect the rights of PWDs, including the Rights of Persons with Disabilities Bill, 2016, very little is done for its implementation. This needs to change, given that COVID-19 exacerbates the precarity of PWDs. Urgent measures can ensure that pandemic mitigation remains inclusive. At this juncture, obstacles in accessing healthcare should be identified and facilities should be made affordable. An affordable shelter at the community level with disability-friendly facilities is required for the large number of PWDs who are beggars and are also homeless. Treatment regimens for PWDs must be designed with extreme sensitivity, should be conducive to present physical conditions, and additional protective measures must be taken for people with certain types of impairment. Medical and paramedical staff need to be trained and sensitised on the requirements of PWDs. We must ensure adherence of safe and sustainable protocols for the services towards PWDs and augment community support, generate awareness and maintain the standard norms set by international bodies. Also, educational facilities, access to study materials, and careful supervision to contain the spread of the virus among children with disabilities are essential to ameliorate the situation. Financial support exclusively planned for PWDs and their reintegration into the labour market could save thousands of PWDs from the dreadful risk of a pandemic and its aftermath.

NOTE

1 This term has been used due to the categorisation in Census 2011, based on the Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participations) Act, 1995, whereby it was defined as "a condition of arrested or incomplete development of mind of a person which is specially characterised by subnormality of intelligence." According to the Rights of Persons with Disabilities Act, 2016, the nomenclature mental retardation is replaced by intellectual disability, which is defined as "a condition characterized by significant limitation both in intellectual functioning [reasoning, learning, problem-solving] and in adaptive behavior which covers a range of every day social and practical skills including specific learning disabilities and autism spectrum disorders."

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