

POLICY BRIEF



INDIAN
INSTITUTE OF
PUBLIC HEALTH
HYDERABAD



A STRATEGIC ANALYSIS OF IMPACT OF COVID-19 ON PERSONS WITH DISABILITIES IN INDIA

COLLABORATIVE RESEARCH STUDY
SACDIR - IIPH HYDERABAD CBM INDIA TRUST AND HUMANITY & INCLUSION

KEY RECOMMENDATIONS

- Special assistance and disabled-friendly COVID-19 protocols must be available and accessible to persons with disabilities.
- Medicines, disinfectants, masks etc. for Persons with disability and their families must be provided.
- Information on rehabilitation, therapy support and other specific services must be made available in accessible formats.
- Enable tele-rehabilitation, especially for children who were receiving services through the RBSK programmes.
- Online counselling must be started for managing stress, fear and anxiety.
- Respective State Governments must ensure relief measures, special financial assistance, subsidies, furlough schemes, access to interest free loans for improving / maintaining current livelihoods.
- Loans from cooperatives, and the obstacles to availing such loans must be quickly cleared.
- Universal healthcare must be provided, to avoid catastrophic expenditure
- Best practices such as organic farming and dairy and the income from these initiatives must be promoted rapidly.
- The government should ensure that pensions are protected.
- Online education for children in schools must be provided in accessible formats. To avoid the pressure of buying smart phones by parents, education must be provided in formats that are easy for parents to receive, both cost and technology wise. Special educators could prepare individualised education plans for children and train the parents through phone or a school website podcast.
- Provision of free internet services for Persons with disabilities who require access to internet for education must be sincerely explored.
- Prioritise Persons with disability when developing a program or strategy to combat future emergencies.
- Include Persons with disability in the development of and implementation of any plan, policies, strategies and programmes.

SUPPORT AND FUNDING:

This study was funded by CBM India Trust, and Humanity & Inclusion (HI).

BACKGROUND

The COVID-19 pandemic is proving to be a challenge for achieving the SDGs. How far this will impact on the deliverables especially those that are time-bound is difficult to state at the moment. The challenge is of Herculean proportions for many low and middle-income countries like India where the health system is fragmented with inconsistent quality and inadequate coverage, and meagre wages compromise the situation even more. Within countries like India, the steep differentials between regions, sex and disadvantaged populations including Persons with disability can be further detrimental to their well-being if not recognized and managed in a timely manner.

STUDY OBJECTIVES

- (i) To assess the level of disruption on the living conditions of Persons with disability due to COVID-19 and related restrictions
- (ii) To generate evidence to inform actions for future pandemics or emergency preparedness

METHODS

A cross-sectional mixed methods study design using a purposive snowballing technique was adopted. Data was collected through telephonic semi structured interviews and focus group discussions facilitated through the network of NGO partners providing care and support for Persons with disability. NGO leadership, government program officers, caregivers of, and Persons with disability were included. The cross sectional survey was repeated 6 weeks after the first interview on a randomly identified 25% sub sample to discern trends over this period.

LOCKDOWN PHASE - QUANTITATIVE FINDINGS

403 respondents were included in the study, from 14 states. The median age of Persons with disability was 28 years (interquartile range 19. 36.5 years) and 60% were males. 51.6% had physical impairments, 16.1% had visual impairments, 10.9% had intellectual impairments and 9.2% had speech and hearing impairment.

HEALTHCARE

- Overall 42.5% respondents reported that lock-down had made it difficult for them to access routine medical care.
- Among those with a pre-existing medical condition (which was 12.7%), 58% stated facing difficulty in accessing routine medical care.
- Nearly a quarter reported difficulty in getting their medications
- 28% reported postponing their scheduled medical appointments.
- More than half perceived that continuous lock-down would have a deleterious effect on their health
- 35% needed out-patient services during lock-down but 55.6% had difficulty accessing the same.
- 16.6% needed emergency medical care of whom 45% had difficulty in accessing.
- 35.7% needed medicines during the lock-down, but 46% stated that they faced problems in getting them.
- 58% of those who needed regular blood pressure monitoring and a third needing sugar monitoring could not get it done.
- Of the respondents needing a surgical procedure, 47.6% could not get access services due to the lock-down.

SOCIAL PARTICIPATION

- 54.2% of the respondents felt that working or participation at community level and Panchayati Raj Institutions (PRI) activities will be affected even after the pandemic.

REHABILITATION SERVICES

- Among the 17% needing rehabilitation services, 59.4% could not access the same. Reported difficulties in access were similar across types of disability, thereby highlighting that concerns of persons with disabilities are similar across disabilities.

ACTIVITIES OF DAILY LIVING

- About 81.6% respondents needed assistance for daily living and most were supported by family carers and 55.8% felt that they can manage if lock-down is imposed again.

LIVELIHOODS

- About 84.2% stated that their daily lives had been impacted.
- The lack of mobility both in rural and urban areas led to distress.
- For 34.3%, even drinking water supplies were affected.
- Pensions were affected for 33.1%.
- Almost all (98.4%) had to borrow money during lock-down and 61.9% had to borrow or request for support for food.
- 18.2% reported that loans were advanced by inclusive cooperative societies.

EDUCATION

- 73.3% stated that children were distressed with school closures and it had affected learning.
- These not only impact academics but also have profound effects on school-meal programs, special-education, therapy, counselling and peer-support and kinship.

MENTAL HEALTH

- Fear of getting infected with novel corona virus and loss of income were frequently reported.
- 81.6% reported experiencing moderate to high levels of stress.
- Stigma, discrimination and effect on family relationships were the leading psycho-social problems reported, with fear of isolation, abandonment and violence
- Only 25.9% had access to information on mental health issues (among 34.5% of the sample who needed services)
- Only 20% were able to get regular mental health counselling or therapy and 11.4% faced problems getting their regular psychiatric medicines.
- Half of the caregivers felt moderately stressed caring for children/ family member with disability.
- 58.2% were unhappy that therapy sessions had stopped during lockdown

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TO CITE THIS REPORT:

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LOCKDOWN PHASE - QUALITATIVE FINDINGS

We conducted 11 in-depth interviews (IDIs) and 2 focus group discussions (FGDs) in the lock-down period and 2 FGDs after easing of lock-down. People with disabilities, carers and relevant stakeholders expressed in their own words, the impact of lock-downs on their lives:

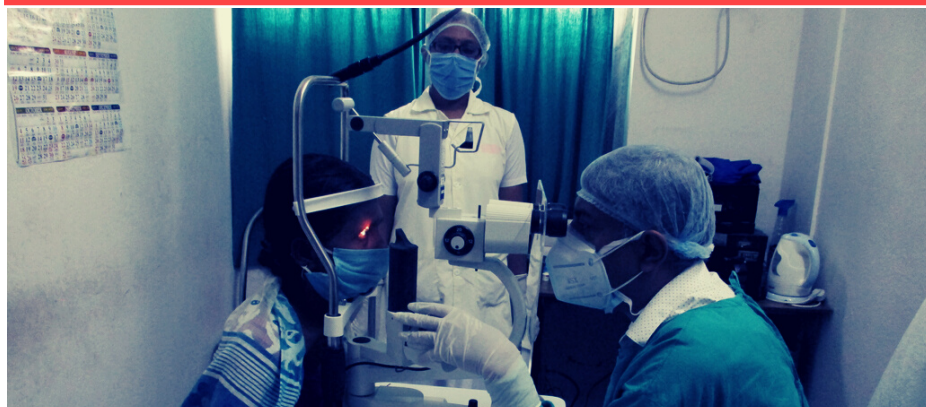
- COVID-19 had broken their confidence and resolve, with difficulty in accessing food, mainly vegetables and pulses, although rice was provided by the government.
- Access to medicines was difficult mainly due to travel restrictions in their region.
- Lack of information in accessible formats was highlighted by most interviewees
- Communication was badly affected-NGOs were unable to reach Persons with disability needing health services or consultations.
- Lack of an inclusive response needs of Persons with disability not given adequate attention where guidelines on COVID-19 response were released.
- Financial impact of COVID-19 was glaring- incomes were compromised and withdrawing money from their bank accounts was a challenge.
- Adverse financial situation led to using family savings earmarked for other purposes for feeding themselves and keeping themselves alive. If anyone falls sick, it can lead to catastrophic expenditure, thereby reinforcing the need for universal, inclusive health care.
- Respondents felt governments may not be prepared for another wave of COVID-19 or a similar health emergency.
- Adequate time for preparing for lockdown and consequences should have been given.

POST LOCKDOWN PHASE - KEY FINDINGS

- After strict lock-down restrictions were withdrawn, the difficulty in accessing emergency medical care and rehabilitation services reduced significantly.
- Online consultation was not very attractive both during the lock-down or later and this should enable planning response services accordingly.
- Stigma and discrimination reduced significantly after easing started. Stress however persisted. There was no significant difference in caregiver's mental health even after easing of lock-down. This aspect needs targeted attention for the future.
- With regards to education, livelihood, and social empowerment, there was no statistically significant difference in proportions before and after easing of lock-down. This could be because of continued restrictions in many regions.
- 73% still hesitated to go to hospital because of fear of contracting COVID. 86% feared going out to meet others.
- Some program managers opined that the public health system was concentrating only on COVID-19, to the detriment of other health conditions, and raised concerns on the exorbitant costs being charged by hospitals.

CONCLUSION

Lock-down has had a profound impact on Persons with disability. The findings of this study have highlighted the concerns of Persons with disability, and their care givers due to COVID-19. These observations should be used to prepare protocols and guidelines to tackle such emergencies in the future. Advocacy with the governments is critical, with inclusive plans to mitigate the adverse impact quickly rather than losing a lot of time in the response cycle.



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