

*Neglected &  
Forgotten:  
Women With  
Disabilities  
during the  
Covid Crisis  
in India*



## Neglected and Forgotten by Rising Flame and Sightsavers

Image description of cover page:

On the right hand top: Rising Flame and Sightsavers logos. On the left top in blue lettering is the title of the report - Neglected and Forgotten: Women with disabilities during the COVID crisis in India. On the remaining space on the page are six figures. Below the text is a woman dressed in a yellow saree in a wheelchair. Walking away from her - with their backs to her - are five people. One is dressed in white and a blue overcoat; one is dressed in a salwar with a small bag; another two in pants and shirt and one person in a lungi. There are all wearing face masks and are at a distance from each other.

This report is a collaborative initiative of Rising Flame and Sightsavers to respond to the urgent needs of women with disabilities in India during the COVID-19 pandemic. This project was undertaken with the aim to amplify voices and narratives of women with disabilities and in an effort to ensure that they are not left behind in policy, systemic and societal responses in the current times.

Rising Flame is a nonprofit organisation based in India, working for recognition, protection, and promotion of human rights of People with Disabilities, particularly women and youth with disabilities. Rising Flame's vision is to build an inclusive world in which diverse bodies, minds, and voices thrive with dignity; live free of discrimination, abuse, and violence; and enjoy equal opportunities and access. Since its establishment in 2017 as a self-led organisation, it aims to enable persons with disabilities standing at multiple intersections to have a voice, have a space, be heard and lead from the front. It is the Recipient for the National Award for Empowerment of Persons with Disabilities 2019. (Website: [www.risingflame.org](http://www.risingflame.org))

Sightsavers is an international organisation that works with partners in more than 30 countries to eliminate avoidable blindness, and fight for the rights and needs of people with disability. Sightsavers have been working in India since 1966 to eliminate avoidable blindness and to ensure that people who are irreversibly blind are supported adequately to lead lives of independence and dignity. They work in 13 states, extending eye services to the least served areas. Sightsavers focusses on collaborating with various departments of the state governments to scale up operations for Social Inclusion, Inclusive Education and Eye Health — its three core areas of work. In the last five decades, Sightsavers has supported treatment for over 36.5 MILLION patients having potential eye problems and performed more than 5 MILLION SIGHT RESTORATION OPERATIONS. In little over than the last decade, more than 25,000 visually impaired and blind primary school children have been supported under Sightsavers' Inclusive Education programme, and over 15,000 people with disabilities have received livelihood or vocational training. (Website: <https://www.sightsaversindia.in/>)

This research was led by disabled people themselves. Nidhi Goyal (Founder and Executive Director, Rising Flame) and Srinidhi Raghavan (Senior programs consultant, Rising Flame) both women with disabilities and Ketan Kothari (Advocacy manager, Sightsavers) person with disability led the research.

our heartfelt gratitude to all women with disabilities across India who participated in this research with honesty and trusted us with their issues. Thanks to all other experts who participated in our research call on education. The research calls were inclusive with the support of sign language interpreters Mansi Shah and Kinjal Shah from ISH (India Signing Hands) and live captioners Teesta Rawal, Kunjika Pathak, Fizza Juddy, and Roshni Srimany and transcriptionist Bhavya Gupta. The cover image is designed by Kruttika Susarla. Thanks to Chayanika Iyer (Program associate, Rising Flame) for coordinating the research project, Namrata Mehta (Programme Manager, Sightsavers) and Nalini Vaz (Global Advocacy Adviser-South Asia, Sightsavers International) for their engagement on the project, and Amba Salelkar, Priyangee Guha and Pooja Menon for their support on this report.

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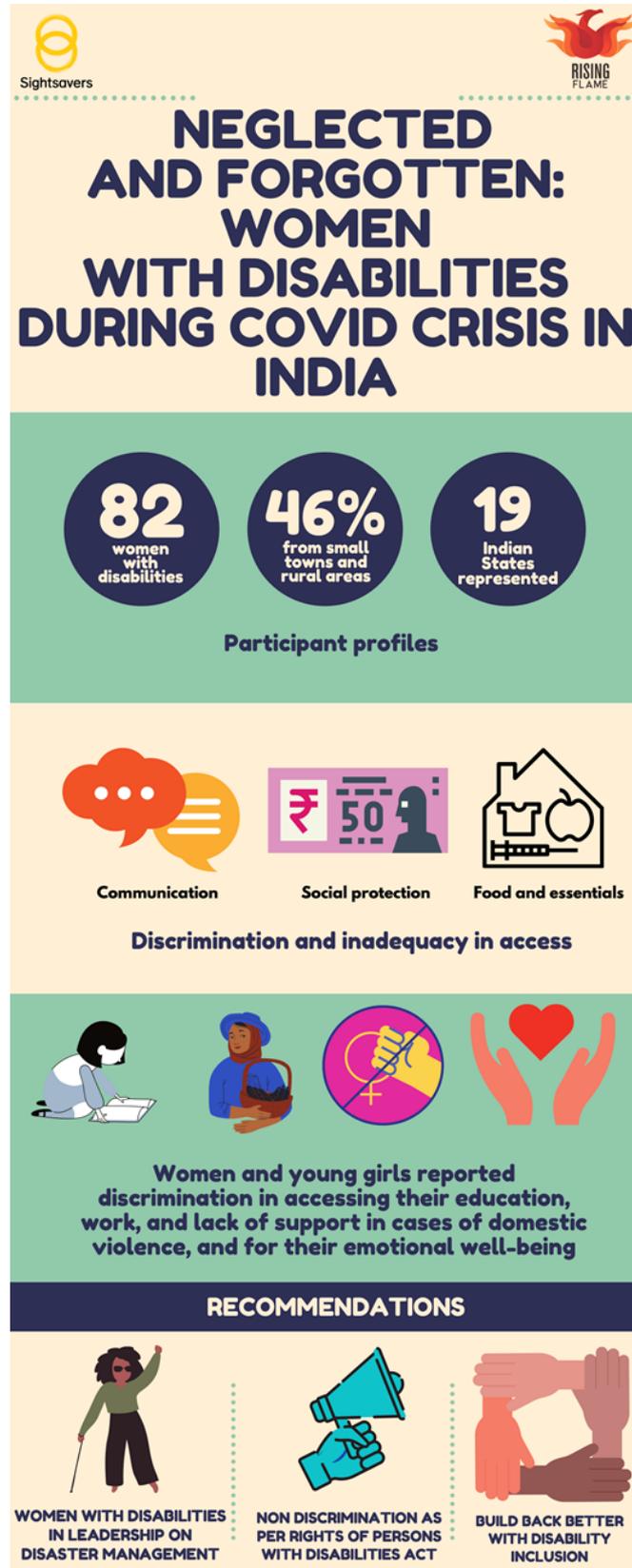
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# Executive Summary



## Neglected and Forgotten by Rising Flame and Sightsavers

Image Description: Sightsavers logo in the top left corner and the Rising Flame logo in the top right.

1st horizontal stripe- (beige with dark blue lettering) Neglected and Forgotten: Women with disabilities during the COVID crisis in India

2nd horizontal stripe-(teal green with three navy blue circles with white lettering)

Circle 1: 82 women with disabilities

Circle 2: 46% small towns and rural areas

Circle 3: 19 Indian states represented

Below the circles: participant profiles

3rd stripe-(beige background, 3 images, black Text)

Discrimination and inadequacy in access

Image 1: thought and speech bubbles

Text below: communication

Image 2: 50 rupee note

Text below: social protection

Image 3: House depiction with a shirt, syringe, and apple inside

Text below: food and essentials

4th horizontal stripe- (teal green with 4 images and dark blue lettering)

Women and young girls reported discrimination in accessing their education, work and lack of support in cases of domestic violence and for their emotional well being

4 images above text

Girl studying, black and white, she is sitting on her knees (denoting education)

Women dressed in a hat and scarf holding a basket (denoting employment)

Pink circle with the symbol for woman and a fist, and the circle has been crossed out (denoting gender violence)

Picture of a heart between two open palms (for emotional wellbeing)

5th horizontal stripe-(navy blue, beige wording)

Recommendations

6th stripe-( beige background, 3 images, black text)

3 pictures each with text below

Image 1: picture of a coloured woman with curly hair, dark glasses, and a cane, holding her hand up in an empowering pose

Text: Women with disabilities in leadership on disaster management

Image 2: Hand holding a loudspeaker, in blue

text: Nondiscrimination as per rights of persons with disabilities act

Image 3: 4 different hands holding each other, each reflecting a different skin tone

text: Build back better with disability inclusion

On the 24<sup>th</sup> of March 2020, India announced a strict lockdown allowing only four hours to the country's 1.3 billion plus population to prepare for a lockdown to combat a possible COVID-19 outbreak. The news quickly trickled down via social media and television but many people, particularly persons with disabilities, continued to struggle for clarity on the situation and access independent information that was accessible to them. The barriers to information were even more pronounced in the case of women with disabilities and worsened with every additional layer of marginalization. In May 2020, between the Phases 3 and 4 of the lockdowns, Rising Flame and Sightsavers India undertook a study focusing on the experience and situation of women with disabilities in the COVID-19 pandemic in India.

The study leveraged the best means of enabling focus group discussions and consultations given the circumstances and the barriers faced or accommodations needed by participants, including access to internet, the need for sign language interpretation and the establishment of a safe space. A total of **82 women with disabilities** and **12 experts** across **19 states** and **nine self-identified disability groups** participated in the research. The experts were involved in specific discussions around the inclusion of students and teaching staff with disabilities as education was going online.

From the discussions, thematics were identified around several issues, many of which were interlinked. These are some of the findings:

## Access

- Accessibility is a precondition to the enjoyment of rights, and in a world, which is already quite inaccessible, the experience of women with disabilities in accessing information and services, particularly online, has been fraught with discrimination.
- 75 out of 82 participants and all participants who identified as deaf, deafblind and hard of hearing faced access barriers with regard to information, physical spaces, to communication, to digital spaces, to health services, to food and essentials, to remote/digital education etc.

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"Few of my friends told me everything is shut. I did not know what was the problem but later on I learnt from ISH news - which is a news channel for the deaf community...in the starting I was told to stay back at home, that's it. They just said, if you got out, you will die."  
A 35-year-old Deaf woman, Delhi

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- Participants reliant on lip reading reported that extensive and necessary use of masks has created barriers for them in independently accessing of services.
- With regards to digital access, blind participants reported that not all applications and websites followed the Web Content Accessibility Guidelines making digital spaces inaccessible.

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The Aarogya Setu app is not accessible for people with disability. This is one of the most important apps. There are guidelines being circulated which is not accessible for blind people. It is a scanned document in pdf document. This is not readable by screen-readers. They should be following the web content accessibility guidelines.  
A 31-year-old blind woman, Trivandrum, Kerala

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- The personal mobility of many participants relied on interdependence with the community, which was complicated by enforcing norms on social distancing.

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"I had gone to buy some ration, and there my crutches slipped. I fell down. In normal times, someone definitely used to come to pick me up if this sort of a thing happened. But that day, no one came. Then I took out my sanitizer from my purse, and gave it to the shopkeeper, and then he came to help me get up."  
A 39-year-old woman with locomotor disability, Ahmednagar, Maharashtra

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## Food and Essentials

- Despite the notification of Disability Inclusive Guidelines for the lockdown emphasizing on enabling door delivery of food and essentials for persons with disabilities, myriad barriers to accessing food were reported across urban, small town and rural participants.

- Online delivery services were not complete solutions for many women requiring additional support to effect delivery of food and essentials to their homes

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"If online store people have dropped the groceries at my society gate, they don't offer to help. I am not able to pick up the 5 kgs and request them to carry this product. They refuse ... I am forced to pick that grocery up from the gate to my home and then the whole night I spend in pain."

A 54-year-old woman with locomotor disability, Ghaziabad, Uttar Pradesh

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- Seven DPO activists from Bihar, Rajasthan, Madhya Pradesh, Chhattisgarh, Orissa, and Maharashtra stated they knew of people in their communities that had no access to food. 12 participants reported that they themselves had insufficient access to food. 10 participants said they had trouble procuring supplies from the public distribution system due to issues of access. DPO activists were stepping in to bridge the gaps, often at great risk to their own health

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"Disabled women are getting weaker because of lack of food. They barely have rice to eat in their houses. Considering this condition, their health is going down even more. And women with kids are facing more health issues. If they are not facing now, then they will for sure face more issues in the coming times."

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## Social Protection

- Social protection schemes often had their own in-built barriers to access for women with disabilities who participated in the research, for example, requiring disability certificates and ration cards. Without either document, women were ineligible for benefits.

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"...in Bihar women with disabilities, unmarried persons with disabilities, and single women are struggling to get their ration cards made... And till how many days will NGOs or social workers be able to make these arrangements?"

A DPO leader with locomotor disability from Patna, Bihar

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- Participants across several states reported that despite announcement of adapted schemes they experienced delays in receiving pensions, reduced amounts of pensions, or were unable to receive the pensions as it had to be obtained in person or through visiting banks that were far away.
- None of the 28 women who identified to have been eligible for the PM Garib Kalyan Yojana Scheme ex gratia payment of Rs. 1000 said that they had received this amount.

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"I get Rs. 700 per month as pension. What can I do with so little? I need to buy medicines, food, clothes. It is not enough. I have to buy things on credit. I have spent all my pension."

A 29-year-old blind woman, from Orissa

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## Health, Sanitation, and Hygiene

- Among all participants there was fear, anxiety and worry around exposure to coronavirus, both for themselves and for their care givers and family members. Their anxieties are worsened by the inaccessibility of quarantine centres and the use of PPE that creates barriers for lip reading for those who rely on that.

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"I worry that if I were to get hospitalized in this situation, I wouldn't be able to hear the doctors and the nurses."

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

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- Participants from Mumbai, Gurgaon, Hyderabad, Bhubaneswar and villages in Jharkhand, Rajasthan highlighted the lack of access to necessities such as medicines, products required for menstrual hygiene, sanitizers, assistive devices such as hearing aid, batteries for hearing aid, gloves for arthritis, and adult diapers.
- Many women with disabilities found that they had an access gap in accessing emergency and essential health services not related to COVID-19

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"We do not have enough money to take the car and drive to the doctor. My back is in pain... the doctor in our village has switched off his phone. If we visit them personally, then he does not check us. The government should make arrangements for some conveyance, because even the ambulance was not ready to take... They are only attending to Corona patients."

A 38-year-old woman with locomotor disability, Bikaner, Rajasthan

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- Participants spoke of the fallout of the failure to notify menstrual products as 'essential services' and the closing of avenues of accessing them independently on the dignity of women with disabilities. Women with disabilities were forced to use cloth which often they could not adequately clean by themselves, placing them at high risk. The emphasis on hygiene was further complicated by factors like the unavailability of clean running water and accessible toilets.

## Education

- Participants across stakeholder groups in education expressed their anxieties regarding shifting classrooms online with little consideration of the access needs of students with disabilities. The role of the school for students with disabilities as more than just imparting education is lost in this transition.

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"...if there was any abuse, children shared it with teachers as trusted adults but in these times, they are inhibited since parents are around. Even where counselling is required, it became impossible to do it using virtual medium and also there is no confidentiality."

A 37-year-old who is a special educator working in Chennai, Tamil Nadu

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- Parents are unable to support the online education of their children as often they themselves have limited education or exposure and in many cases they cannot

provide a child with a smart phone or other device, nor are they aware of the accessibility features.

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"No special assistance, no captions or text are shared. Most of the assignments are PDFs scanned and sent which mean someone needs to read out to me."

A 20-year-old deafblind college student, Delhi

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- Teaching staff with disabilities were also greatly disadvantaged with the shift online, as they have not been given any training for these platforms and in many cases, they are not fully accessible.

## Employment and Livelihood

- While the majority of the women with disabilities who participated in the discussions had a job or some form of livelihood, 50% of them expressed issues and challenges on account of their access to work and livelihood during this time. Losing their livelihoods and jobs was observed to be the most common concern that all these women had.
- While a few respondents clearly benefitted from being given the ability to work from home, for others the shift to remote working appeared to just enable isolation and segregation on yet another forum.

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"For those of us who depend on lip reading, it's exhausting. We spent so much time reading the room, by the time we have grasped the conversation we are exhausted. There are so many calls I must attend...No one turns on the video. When they talk fast, I totally lose track of the conversation. At the end when they say "we decided this" - I just agree. Later I call a colleague to find out what I actually signed up for."

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

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- In the rural areas, self-help groups were mobilizing but others were losing their means of livelihood or facing barriers to accessing it.

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". mask making... work is available, but we are expected to come collect the cloth to make it, and go deliver the masks also on our own. How will that happen in lockdown? Also, about the work under NREGA is a couple of kilometers away. So disabled people, those walking with one leg – how will they go work?"

A 45-year-old woman with locomotor disability, Sirohi district Rajasthan

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- Women with disabilities also reported having to cook and maintain the home, with no support along with the challenges of remote working.

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"I asked [my husband] about meal planning since I had a two-hour meeting. He shouted, "I don't know! You take care of it!". So, I had to take a break in the middle of the meeting and make something quickly."

A 54-year-old woman with locomotor disability, Ghaziabad, Uttar Pradesh

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## Domestic Violence

- The 'shadow pandemic' was a reality for women and girls with disabilities. Participants who worked in DPOs and were helping women with disabilities through these issues reported a lack of privacy and accessibility for women with disabilities to seek peer support or redressal.

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"We do not have a streamlined process on how to reach out for help and subsequent steps. Where will they take shelter? What is the strategy? We need to work this out urgently. No woman will risk their safety by making a call if there is no follow up. There needs to be a fool proof system in place. There should be trust in the system that works."

A Deaf woman, Delhi

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- Even familial support for those who faced domestic violence was difficult due to the financial strains of the lockdown.

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"They [maternal family] told me that they could not support me physically or my expenses anymore and asked me to return to my husband's house with my small daughter."

A 42-year-old woman with locomotor disability (Scoliosis), Thane, Maharashtra. She had moved out of her husband's house because of domestic violence.

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## Emotional Wellbeing

- From DPO activists to homemakers to students with disabilities, all participants expressed grave threats to their emotional wellbeing during this lockdown.
- Respondents all across the board reported a sense of loneliness and isolation. More than 50% of the participants stated that they missed their friends or colleagues, were bored of not being able to work/ study/ have fun, and were frustrated of being confined to their homes only with their families – something they weren't used to, and this created tensions at home.
- For others involved in activism, and who had taken on the burden of the Government in terms of last mile delivery of services, the lockdown has been stressful, and no respite seems possible. The same applies for caregivers.

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"There are people who want to talk to me, but I am not able to meet them personally. One of the patients wanted to meet me and talk to me, but I couldn't go, and she died in two weeks, so I felt so guilty."

A 38-year-old woman with a spinal cord injury, Trivandrum, Kerala

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- The uncertainty and stress and disruptions of routine have also impacted mental health.

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"I used to plan and prepare accordingly because things had their own timings. Now everything is in a frenzy. There is no routine, no time left."

Now the kid is with me the whole time, and my husband is busy with his own work. In this situation, I feel depressed. And then there is no help available for me, so I do not know when I will be able to get out from this stress. Many times, due to this, I feel that I am not a good mother.”

A 32-year-old Autistic woman, Hyderabad, Telangana

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The apathy of duty bearers to women with disabilities is also leading to feelings of despondency and isolation.

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“The government is not at all paying attention towards us, which makes us feel that we are not the citizens of this country. Even after living between 10 people, I feel alone.”

A 29-year-old DPO leader, Bikaner district, Rajasthan

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## Key Recommendations

The recommendations cover immediate needs, recommendations over the thematic areas, and also towards a disability and gender inclusive disaster management policy. Overall, women across disabilities, including those from underrepresented groups such as Deaf women, deafblind women, women with intellectual and psychosocial disabilities, across age groups, those living in remote and rural areas as well as those experiencing multiple or intersectional discrimination must be included in leadership and decision-making capacities, in policy, planning and execution of COVID-19 responses. Recommendations include:

- Revisiting the Disability Inclusive Guidelines issued by the Department of Empowerment of Persons with Disabilities towards a **gender inclusive response** for ensuring access for persons with disabilities to food, essentials (including menstrual care products), quality healthcare and rehabilitation services, in urban and rural areas, with clear budgetary allocations and accountability mechanisms.
- Ensuring that authorities providing relief services and schemes during this period including under the Disability Inclusive Guidelines must collect **disaggregated data** on the number of persons with disabilities who have been reached.
- Implementing the RPD Act, appointing all authorities and strengthening the role of the State Disability Commissioners to take suo moto action on discrimination against persons with disabilities in accessing services and essentials during the pandemic.
- Ensuring accessibility of **all communications/ information/ announcements/helplines** regarding COVID-19, the lockdowns and the unlocking processes in a range of accessible formats including sign languages, braille, audio versions, easy to read versions and in local languages at the same time as it is available to the general population and access should be ensured to underrepresented groups among the disabled as well as those who continue to remain in group homes and institutions. Caregivers, personal assistants, and interpreters should be categorically exempted from norms of physical distancing.

- Ensuring doorstep delivery **of food and other essentials including menstrual hygiene products to the doorstep of women with disabilities;** especially for those who may be unable to leave their homes due to social distancing and communication challenges or experience difficulty with leaving home as they are immunocompromised or more vulnerable, even beyond the period of lockdown. For this purpose, **officials should not insist on production of disability certificates and/or ration cards.** This service should extend beyond the lockdown period. Assistive devices and their upkeep services should also be considered as essential.
- Ensuring the **disability pension and ex gratia payments under the Pradhan Mantri Garib Kalyan Yojana Scheme** are responsive to the added costs incurred by persons with disabilities in overcoming barriers to participation particularly during the lockdown. It should be uniform across States and linked to consumer price index and rate of inflation. These schemes should cover children with disabilities. Documentation requirements like disability certificates and ration cards should be streamlined with specific consideration of women with disabilities and the barriers they face in obtaining documentation.
- Children and youth with disabilities must have equal access to quality and ongoing education and allied activities and the risk of falling out of the school system, especially for girls with disabilities, must be taken seriously. The National Commission for Protection of Child Rights should frame **mandatory directives to schools on the inclusion of children with disabilities in all online education proposals at all levels of school education in public or private educational institutions.** This includes the provision of accessible teaching and learning material to ensure uninterrupted education at the earliest.
- Persons with disabilities should be able to access, **without discrimination, the same level of healthcare** including telemedicine and rehabilitation on an equal basis with others. Persons with disabilities should be able to access **emergency healthcare services** whether related to COVID-19 or not and access to healthcare should not be hampered by the availability of public transport services.
- Persons with disabilities **must not be discriminated against at the workplace,** particularly in the evolving scenario post lockdown. Online tools for remote working should comply with web accessibility guidelines The Chief Commissioner of Disabilities must frame additional guidelines under the RPD Act to ensure this protection and direct organizations to implement **equal opportunity policies** as mandated under the Act.
- All guidelines and policies developed around prevention and interventions in cases of domestic violence experienced during the lockdown and its aftermath **must be inclusive of and accessible to women and girls with disabilities** and designed to address barriers to reporting.
- **Strategies around domestic violence should consult with and actively involve women with disabilities** by the ministries and departments relation to women and children, the national and state's women commissions, the child protection commissions and other relevant authorities. Accessible information for

women with disabilities on their legal rights in the case of domestic violence should be disseminated.

- **Helplines, websites, and other complaint mechanisms** regarding gender-based violence should be **operational and accessible** for women with disabilities facing domestic violence. Helplines should also be available at the local levels to ensure that information is available in local languages and in the regional sign language. Women with disabilities facing domestic violence must have **access to safe and accessible shelter** particularly during this pandemic to move to, in order to avoid prolonging contact with the abuser at home, and that they receive reasonable accommodation towards accessing their requirements including assistive devices and personal assistance, interpretation etc.
- All persons, including those experiencing mental or emotional distress during the COVID-19 outbreak, must have equal access **to call-in, in person and online psychosocial support and peer support, based on respect for individual will and preferences**. All counselling and psychosocial support services should be deemed to be essential services. **Mental health responses** need to be embedded in the COVID-19 recovery for persons with disabilities with specific focus on women with disabilities. This includes **development and availability of a wide range of community-based services** that respond to the needs of persons with disabilities and respect people's autonomy, choices, dignity, and privacy.
- Involving organizations of persons with disabilities in the development of **training of members of disaster management task force** on issues related to the inclusion of persons with disabilities and their requirements including the requirements of women with disabilities. The understanding of disability should be beyond the list of disabilities under the RPD Act and should adopt an approach in line with the wider understanding of persons with disabilities under the CRPD to prevent discrimination.

It is hoped that stakeholders heed this call made by and for women with disabilities to not leave us behind in the fight against COVID-19 or in the efforts to build back a better and more resilient future. If this virus has shown how deep inequalities run in our societies, it is the best and only opportunity we have to set things right and ensure that the most marginalized in our societies, many of whom are women with disabilities, can come back stronger and better supported in law, policy and practice.

# Background

The COVID 19 pandemic that began in December 2019 and rapidly spread from January 2020 across the world has impacted health systems, economies, and societies at large. It is true that the virus can infect anyone irrespective of their geography, demography, identity, class etc. However, the impact of COVID 19 and the subsequent lockdown has in fact further widened social inequalities such as those between the rich and the poor, between the urban and rural, and between the disabled and non-disabled.<sup>1</sup> Preventive measures to curb the spread of infections involved widespread lockdowns, which meant a hit to economies across the world. In India, a nation-wide lockdown was announced on 24 March 2020 in response to a steady increase in the number of cases.<sup>2</sup> At the time of publication of this paper, this lockdown is in the process of being lifted, though lockdowns have been reinstated in several cities because of more reported cases.

The impact of the pandemic and subsequent actions on persons with disabilities has had myriad consequences.<sup>3</sup> The general population has found it difficult to process the ever-changing information around COVID-19 regarding preventive measures and potential treatments, and evolving government regulations at the national, state and local levels. For persons with disabilities this information was as good as not available, since they were not provided information by government, media or medical experts in accessible formats such as sign language or easy-to-read.<sup>4</sup> In addition to information alienation, many persons with disabilities live with a compromised immune system which means that potential infection could be fatal. Many persons with disabilities rely on tactile support or communications or physical support by caregivers. This means that they are vulnerable to an increased exposure to the virus.<sup>5</sup> The inaccessibility of public infrastructure has meant that persons with disabilities require support to access essentials but social distancing norms have re-

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<sup>1</sup> Guterres António (2020) "We have a unique opportunity to design and implement more inclusive and accessible societies" Retrieved from <https://www.un.org/en/coronavirus/we-have-unique-opportunity-design-and-implement-more-inclusive-and-accessible-societies>

<sup>2</sup> Economic Times. (2020). Full speech: PM Modi announces nationwide lockdown to fight coronavirus pandemic. Retrieved from <https://economictimes.indiatimes.com/news/politics-and-nation/full-speech-pm-modi-announces-nationwide-lockdown-to-fight-coronavirus-pandemic/videoshow/74798169.cms>

<sup>3</sup> Meenakshi B (2020 May) Too little, Too Few

<sup>4</sup> National Centre for Promotion of Employment for Disabled People (NCPEDP) 2020. Locked down and left behind. Retrieved from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked\\_down\\_left\\_behind.pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked_down_left_behind.pdf)

<sup>5</sup> Kumar A, Priyadarshi M, Mehta S, Mehta B.S, Singh I.P, Kumar R, Gupta R, Mehta A , Kamaal K, Roy B , Kumari P, Impact and Policy Research Institute (IMPRI) Team (2020, April 22) COVID19: Implications for People with Disabilities and the Elderly. The Citizen. Retrieved from <https://www.thecitizen.in/index.php/en/NewsDetail/index/15/18639/COVID19-Implications-for-People-with-Disabilities-and-the-Elderly>

duced their access to human assistance.<sup>6</sup> The lockdown meant that persons with disabilities did not have access to their caregivers who did not live with them which meant that activities of daily living were compromised.<sup>7</sup> For groups of deafblind individuals touch is an essential part of their tactile communication. This also meant that social distancing also curbed communication and exacerbated isolation.<sup>8</sup>

For some living with various disabilities like blood disorders, the pandemic and the consequent lock down resulted in a life-threatening situation. They faced challenges in accessing donors and blood transfusion, which are essential for survival.<sup>9</sup> Persons with psychosocial or intellectual disabilities may require additional support and accessible formats of information to understand the impact of COVID-19 or the need for precautions and social distancing. The information overload or too little information may increase the levels of anxiety and stress for them. Many also find an increase in disputes and conflicts with families. The impact of heightened stress on family members (often elderly family members) also means there is an increase of vulnerability and impact both physical and psychological for both caregivers and persons with disabilities.<sup>10</sup> As a result few reports of increased violence on persons with disabilities have been recorded and the rest remain unheard.

Many persons with disabilities including psychosocial and intellectual disabilities continue to be institutionalized despite the State obligation towards the right of persons with disabilities to live independently and within the community. They are more vulnerable since they are unable to access any information, practice social distancing effectively and have access to clean water and sanitation as these institutions are overcrowded and lacking in utilities.<sup>11</sup>

Along with practicing social distancing, digital connections are emerging as the way of life for many individuals. For persons with disabilities this is both a boon and a curse. For many persons with disability with digital access, connection with each

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<sup>6</sup> Kumar A (2020 March 27) Here's how India can help the disabled during 21-day coronavirus lockdown. The Print. Retrieved from <https://theprint.in/opinion/heres-how-india-can-help-the-disabled-during-21-day-coronavirus-lockdown/389349/>

<sup>7</sup> Mukherjee R (2020 March 27) 'No Choice of Social Distancing': How India's Lockdown is Affecting the Differently-Abled. News 18. Retrieved from <https://www.news18.com/news/buzz/no-choice-of-social-distancing-how-indias-lockdown-is-affecting-the-differently-abled-2551101.html>

<sup>8</sup> Dhale Z (2020) Being Deafblind in a lockdown world. Newz Hook. Retrieved from <https://newzhook.com/story/deafblind-lockdown-zamir-dhale-society-for-the-empowerment-of-the-deafblind/>

<sup>9</sup> Salve P. (2020 April 1) COVID-19 Lockdown Causing Further Shortage At Blood Banks. IndiaSpend. Retrieved from <https://www.indiaspend.com/covid-19-lockdown-causing-further-shortage-at-blood-banks/>

<sup>10</sup> Ghosh N (2020 May 31) Factoring in disabilities. The Hindu. Retrieved from <https://www.thehindu.com/opinion/open-page/factoring-in-disabilities/article31710301.ece>

<sup>11</sup> Sharma, K. & Human Rights Watch, I. B. (2014) "Treated worse than animals": abuses against women and girls with psychosocial or intellectual disabilities in institutions in India. Retrieved from, <https://www.hrw.org/report/2014/12/03/treated-worse-animals/abuses-against-women-and-girls-psychosocial-or-intellectual>

other, caregivers, and social media has proved helpful. But this population is very small. Many persons with disabilities do not have access to independent or privately-owned phones or digital devices. Exact data on this is unavailable, but lack of income, rural location, illiteracy, exclusion from the education systems and lack of autonomy or agency in general combined together help conclude this. Those who own mobiles, computers etc., also face tremendous barriers in the digital world because of pre-existing inaccessibility in the digital environment, very much on the lines of the physical environment. The online financial, e-commerce and other daily living platforms are not in compliance with the basic requirements on web accessibility despite mandates in the law<sup>12</sup> which amounts to discrimination against person with disabilities in this pandemic.

With the breaking down of social networks, lack of availability of services and transportation, difficulty in finding personal assistants, the difficulty in practicing social distancing, lack of accessible information, lack of digital access or inaccessible digital platforms, and increased violence has meant several dire consequences for persons with disabilities. They are facing a range of issues from loss of mobility, lack of access to health care and critical medications, compromised independent living and disrupted access to daily needs.<sup>13</sup> In addition, increased anxiety and heightened fear and uncertainty is lacing the current existence of this population group.<sup>14</sup> It is not the disability that is preventing full and effective participation and survival, the cause is the structural barriers including the insensitivity of policy makers.<sup>15</sup> The pandemic has certainly heightened the isolation and discrimination that person with disabilities face in their daily lives. Hence, it would not be incorrect to state that the pandemic in India threatens more than 26.8 million people with disabilities.<sup>16</sup>

## **Gender and Disability- Where Do Women with Disabilities Stand?**

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<sup>12</sup> Rights of Persons with Disability (RPWD) 2016 s.42 (Ind). Available on [https://www.ncpedp.org/sites/all/themes/marinelli/documents/Rights%20of%20Persons%20with%20Disabilities%20\(RPWD\)%20Act%202016.pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/Rights%20of%20Persons%20with%20Disabilities%20(RPWD)%20Act%202016.pdf)

<sup>13</sup> National Centre for Promotion of Employment for Disabled People (NCPEDP) 2020. Locked down and left behind. Retrieved from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked\\_down\\_left\\_behind.pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked_down_left_behind.pdf)

<sup>14</sup> Kumar A, Priyadarshi M, Mehta S, Mehta B.S, Singh I.P, Kumar R, Gupta R, Mehta A , Kamaal K, Roy B, , Kumari P, Impact and Policy Research Institute (IMPRI) Team (2020, April 22) COVID19: Implications for People with Disabilities and the Elderly. The Citizen. Retrieved from <https://www.thecitizen.in/index.php/en/NewsDetail/index/15/18639/COVID19-Implications-for-People-with-Disabilities-and-the-Elderly>

<sup>15</sup> Astha (2020) Children and persons with disabilities in a humanitarian crisis of covid-19 in India: Challenges & Strategies.

<sup>16</sup> Disabled Population by type of Disability, Age and Sex. (2020). Retrieved from [https://censusindia.gov.in/2011census/population\\_enumeration.html](https://censusindia.gov.in/2011census/population_enumeration.html)

Globally 1 in 5 women live with some form of a disability.<sup>17</sup> Higher number of disabled women live in developing countries. They face multiple and intersecting discriminations, marginalization, and denial of rights.<sup>18</sup> Women with disabilities have less access to education due to the intersecting discrimination on the basis of their gender and disability in both the education system as well as within their families. Many women with disabilities face barriers to access employment and are in more informal workspaces. They also face lower pay than men with disabilities or other non-disabled women.<sup>19</sup> In the current crisis women with disabilities are likely to face more job losses and unlikely to have higher savings to survive because of the financial costs of the discrimination they face in accessing services like public transport and healthcare. They face two to three times higher levels of violence, discrimination and abuse than their non-disabled counterparts.<sup>20</sup> The lockdown has led to having to exclusively rely upon the immediate family which has in turn made it even more difficult to escape violent situations or reach out to their usual support systems outside of their homes.

Ana Pelez, chairperson European Disability Forum and current member of the CEDAW Committee, emphasized that "Responses should differentiate the particular needs of women and girls with disabilities, but also the specific needs they may have within each specific disability group."<sup>21</sup> It is evident that women with disabilities are still falling between the cracks of women's rights and disability rights' conversations and policy response. For instance, globally the focus on the shadow pandemic by UN and other agencies does not actively include violence against women with disabilities - further invisibilising their realities.<sup>22</sup> In India the "Comprehensive Disability Inclusive Guidelines for Protection and Safety of Persons with Disabilities for COVID-19 response" by the Department of Empowerment of Persons with Disabilities (hereinafter the Disability Inclusive Guidelines) does not mention gender inclusive response except through a single word mention in the context of healthcare.<sup>23</sup>

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<sup>17</sup> Women Enabled International (2020) Statement on Rights at the Intersection of Gender and Disability during COVID-19

<sup>18</sup> Women with Disabilities India Network (2019 Feb 10) Submission of Alternative Report (Article 6 ) To the Committee on the Rights of Persons with Disabilities : India 2019

<sup>19</sup> Women Enabled International (2020) Statement on Rights at the Intersection of Gender and Disability during COVID-19

<sup>20</sup> Women Enabled International (2020) Statement on Rights at the Intersection of Gender and Disability during COVID-19

<sup>21</sup> Narváez P. A (2020 March 24) Women with disabilities and COVID-19. European Disability Forum. Retrieved from <http://edf-feph.org/newsroom/news/message-ana-pelaez-narvaez-women-disabilities-and-covid-19>

<sup>22</sup> Shadow Report by Women with disability India Network to UNCRPD (2019 Feb)

<sup>23</sup> [Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities \(Divyangjan\) during COVID 19](http://disabilityaffairs.gov.in/content/Disability-Inclusive-Guidelines.docx) <http://disabilityaffairs.gov.in/content/Disability-Inclusive-Guidelines.docx>

In India, there are 11.8 million women with disabilities who experience considerable challenges, discrimination, isolation and marginalization.<sup>24</sup> Reeling under the stigma and prejudices of a patriarchal and ableist society, women with disabilities are considered a burden, infantilized regularly, stripped of decision-making powers, not considered to be “woman enough” and routinely discriminated against or abused and harassed.<sup>25</sup> <sup>26</sup> They face barriers in access to health, education, employment, social protection, and safety.<sup>27</sup> These barriers are heightened by the COVID-19 situation. Their access to information is reduced, and inclusion at homes is further impacted. Discrimination and isolation which existed before, has reached high levels impacting the mental health of women with disabilities. Domestic violence, which was difficult to document and report even before for disabled women, but which very much existed, has spiked, yet no formal records are available. Access to helplines has also been a huge challenge for women with disabilities.<sup>28</sup>

Affordability and access to digital devices are already a concern for persons with disabilities.<sup>29</sup> For women in general there are studies that show that ownership of a technology/ communication device like mobiles is disproportionately lower.<sup>30</sup> This disparity stems from lack of resources, deprioritizing women when it comes to ownership of technology, patriarchal control and lack of allowing privacy. In these societal conditions, it would be safe to deduce that women with disabilities have even more barriers to owning and accessing technology, since very little investment is done in their growth or aspirations. They are often considered a burden within families and not treated as adults with needs and requirements.

Inclusion in data has always been a grave issue for women with disabilities, with them being underreported in the census, with no disaggregated data available by disability in National Crime Records Bureau or even in the National Family Health

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<sup>24</sup> Disabled Population By Type Of Disability, Educational Level And Sex - 2011 (India & States/UTs) . (2020). Retrieved from [https://censusindia.gov.in/2011census/population\\_enumeration.html](https://censusindia.gov.in/2011census/population_enumeration.html)

<sup>25</sup> Shadow Report by Women with Disabilities India Network to UNCRPD (2019 Feb)

<sup>26</sup> CREA. (2011). Count me in! Retrieved from <http://www.creaworld.org/sites/default/files/The%20Count%20Me%20In%21%20Research%20Report.pdf>

<sup>27</sup> Bhandare N (2020 May 1) The lockdown is hard for women with disability. Hindustan times. Retrieved from <https://www.hindustantimes.com/columns/the-lockdown-is-hard-for-women-with-disability/story-4uOVBLxLOoukdlcqWvP1vJ.html>

<sup>28</sup> Inclusion Europe (2012 November 23) Domestic Violence and Disability. Retrieved from <https://www.inclusion-europe.eu/domestic-violence-and-disability/>

<sup>29</sup> Kulkarni M (2019 March) Digital accessibility: Challenges and opportunities. Retrieved from <https://www.sciencedirect.com/science/article/pii/S0970389617301131>

<sup>30</sup> Point of view (2019 July 29) Hacking Digital Gender Norms. Retrieved from <https://sexgendertech.org/blog/2019/07/29/hacking-digital-gender-norms/>

Survey.<sup>31</sup> This threatens to persist in relation to the experiences of this pandemic. In light of these issues, Rising Flame and Sightsavers documented first-hand experiences of women with disabilities across India to record the experiences of women with disabilities. We are hoping to fill the data lacuna and counter the risk of women with disabilities being left behind in the COVID-19 recovery policies, planning and economic packages going forward.

## **What are the Legal and Policy Frameworks and Responses in India?**

India has ratified the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), the Convention on the Rights of Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). It is a signatory to the 2030 Agenda for sustainable development which outlines the Sustainable Development Goals (SDGs). To realize global commitments at the national level the Government has enacted some progressive laws like the Rights of Persons with Disabilities (RPD) Act 2016, the Mental Healthcare Act 2017, and Criminal Law Amendment 2013. These laws have reflected issues faced by women with disabilities to some extent.

The CRPD mandates rights based approaches towards the inclusion of persons with disabilities in humanitarian frameworks (Article 11), twin track approaches towards the inclusion of women with disabilities (Article 6), the enjoyment of the highest attainable standard of health, including sexual and reproductive health, without discrimination on the basis of disability (Article 25), the right to access education within an inclusive education system (Article 24), the right to work on an equal basis with others (Article 27), right of persons with disabilities to an adequate standard of living for themselves and their families (Article 28) and the right to live free from exploitation, violence and abuse (Article 16). To deliver on these rights the RPD Act has sections corresponding to these Articles.

The Government of India declared COVID-19 as a national disaster under the Disaster Management Act of 2005.<sup>32</sup> In addition to this declaration by the central government, state governments additionally have imposed the Epidemic Act of 1897 and have also invoked state wise public health acts. Section 8 of the RPD Act mandates the National Disaster Management Authority and the State Disaster Management Authority to take appropriate measures to ensure inclusion of persons with disabilities in its disaster management activities.

The Disability Inclusive Guidelines consist of many important steps to be taken by the state governments and identify the state disability commissioners who areas the

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<sup>31</sup> Bhattacharjee S & Goyal N & Human Rights Watch (2018) Invisible Victims of Sexual Violence. Retrieved from <https://www.hrw.org/report/2018/04/03/invisible-victims-sexual-violence/access-justice-women-and-girls-disabilities>

<sup>32</sup> Mohan M.P & Alex J (2020 April 26) COVID-19 and the ambit of the Disaster Management Act. TheWeek. Retrieved from <https://www.theweek.in/news/india/2020/04/26/covid-19-and-the-ambit-of-the-disaster-management-act.html>

nodal authorities to implement these guidelines. Some of the key elements of the general guidelines include:

- Providing accessible information regarding COVID – 19 and preventive measures.
- Exemption of caregivers from the lockdown restrictions so that they can support persons with disabilities.
- Persons responsible for handling emergency response services be trained on the rights of persons with disabilities.
- During quarantine, essential support services, personal assistance, and physical and communication accessibility should be ensured, persons with disabilities should be given access to essential food, water, medicine, and, to the extent possible, such items should be delivered at their residence or place where they have been quarantined;
- Persons with disabilities should be given priority in treatment, and special care should be taken in respect of children and women with disabilities.
- In addition, on-line counselling mechanisms be developed to de-stress persons with disabilities as well as their families to cope with the quarantine period.
- A 24X7 helpline number is also to be established at state level be set up exclusively for persons with disabilities with facilities of sign language interpretation and video calling.

However, reports from the ground indicate that these guidelines have not been implemented – the nature of this policy indicates that the authorities would need long term preparedness and awareness. While the disability commissioners at the state levels are the nodal authorities to implement these guidelines, not much has been done at that level for implementation and the department failed to outline any accountability mechanism.

In early April, the central government announced various measures like 3 months of advance pensions under the Indira Gandhi National Disability Scheme under the National Social Assistance Program to persons with disabilities and announced an additional support of Rs. 1000 to be paid over a period of three months in two instalments.<sup>33 34</sup> Despite central guidelines and commitments, many social protection and relief measures particularly those outlined in the disability inclusive guidelines still remain a distant reality for persons with disabilities and more so for women with disabilities.<sup>35</sup>

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<sup>33</sup> Roy B & Mehrotra S (2020 April 3) Covid- 19: Implication for the Disabled. Hindu Business Line. Retrieved from <https://www.thehindubusinessline.com/opinion/covid-19-implications-for-the-disabled/article31250730.ece>

<sup>34</sup> PTI (2020 March 27) Elderly, differently-abled, widows to get 3 months' pension in advance. The Economic Times. Retrieved from [https://economictimes.indiatimes.com/https://economictimes.indiatimes.com/wealth/personal-finance-news/elderly-differently-abled-widows-to-get-3-months-pension-in-advance/articleshow/74847650.cms?utm\\_source=contentofinterest&utm\\_medium=text&utm\\_campaign=cppst](https://economictimes.indiatimes.com/https://economictimes.indiatimes.com/wealth/personal-finance-news/elderly-differently-abled-widows-to-get-3-months-pension-in-advance/articleshow/74847650.cms?utm_source=contentofinterest&utm_medium=text&utm_campaign=cppst)

<sup>35</sup> Chakraborty S (2020 May 8) COVID-19: No mechanism in place, persons with disabilities suffer in Bengal. DownToEarth. Retrieved from <https://www.downtoearth.org.in/news/health/covid-19-no-mechanism-in-place-persons-with-disabilities-suffer-in-bengal-71010>

From our research the main fault lines that have emerged are around the areas of accessing food, essentials, healthcare and rehabilitation services, education, and employment. The barriers in accessing these are worsened because of the lack of adequate social protection that covers the costs women have to bear because of the inaccessibility of the environment around them. Further, women with disabilities have had no recourse or support in dealing with situations of domestic violence and stress, which are grave threats to their physical and mental health.

# Methodology

The data to build this research study was collected across the month of May 2020 through a series of facilitated semi-structured group discussions (consultations) with women with disabilities.

Eight consultations were organized – four of which were held online over Zoom and four were conducted as conference calls over telephone. These calls were conducted in five languages – two in English and Indian Sign Language, one in Assamese, three in Hindi, and two in Odiya. 82 women with disabilities and 12 experts (both disabled and non-disabled) across 19 states of India participated - including those living in Assam, Bihar, Chhattisgarh, Delhi, Gujarat, Jharkhand, Karnataka, Orissa, Haryana, Tamil Nadu, Telangana, West Bengal, Maharashtra, Kerala, Madhya Pradesh, Punjab, Rajasthan, Jammu and Kashmir and Uttar Pradesh. Participants were from metros, tier 2 cities, semi urban areas, and rural areas.

## Participant Profiles – State wise

Statewise Division of Participants

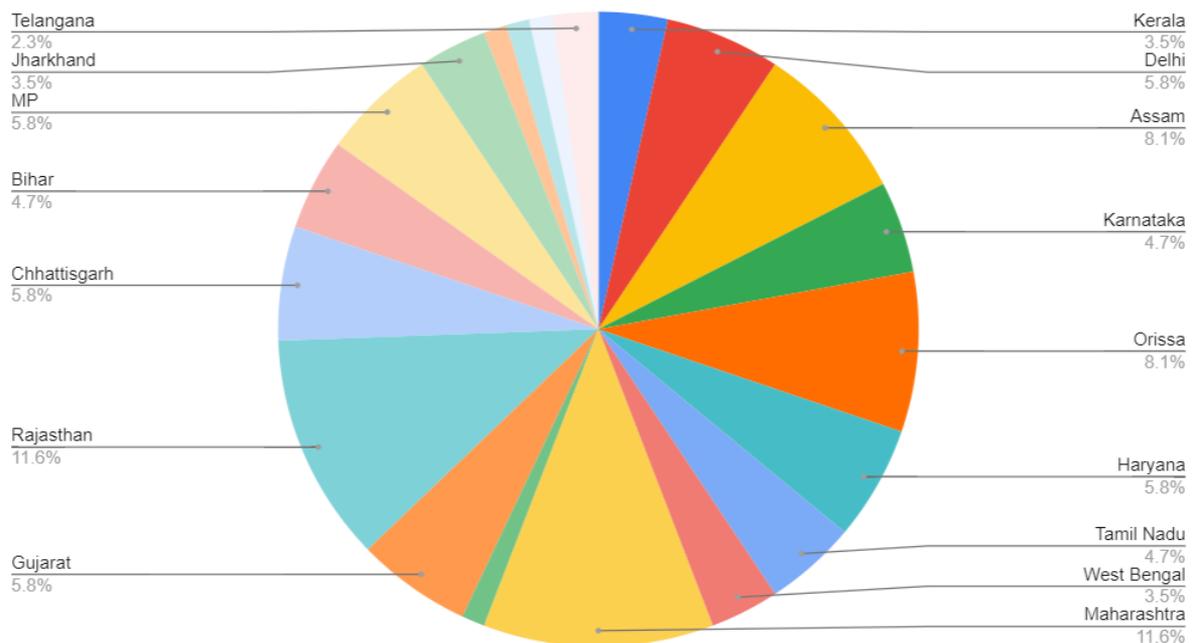


Chart Description: This pie chart explains the State wise Division of Participants. Below that, a circle with parts of it colour coded according to the number of participants from each state – labelled as follows:

- Assam – 8.2%
- Bihar – 4.7%
- Chhattisgarh – 5.9%
- Delhi – 5.9%
- Gujarat – 5.9%
- Haryana – 5.9%
- Jharkhand – 3.5%
- Karnataka – 4.7%
- Kashmir – 1.2%
- Kerala – 3.5%
- Madhya Pradesh – 5.9%
- Maharashtra – 11.8%
- Orissa – 8.2%
- Punjab – 1.2%

- Rajasthan – 11.8%
- Tamil Nadu – 4.7%
- Telangana – 2.4%
- Uttar Pradesh – 1.2%
- West Bengal – 3.5%

### Participant Profiles - Location

Location of Participants

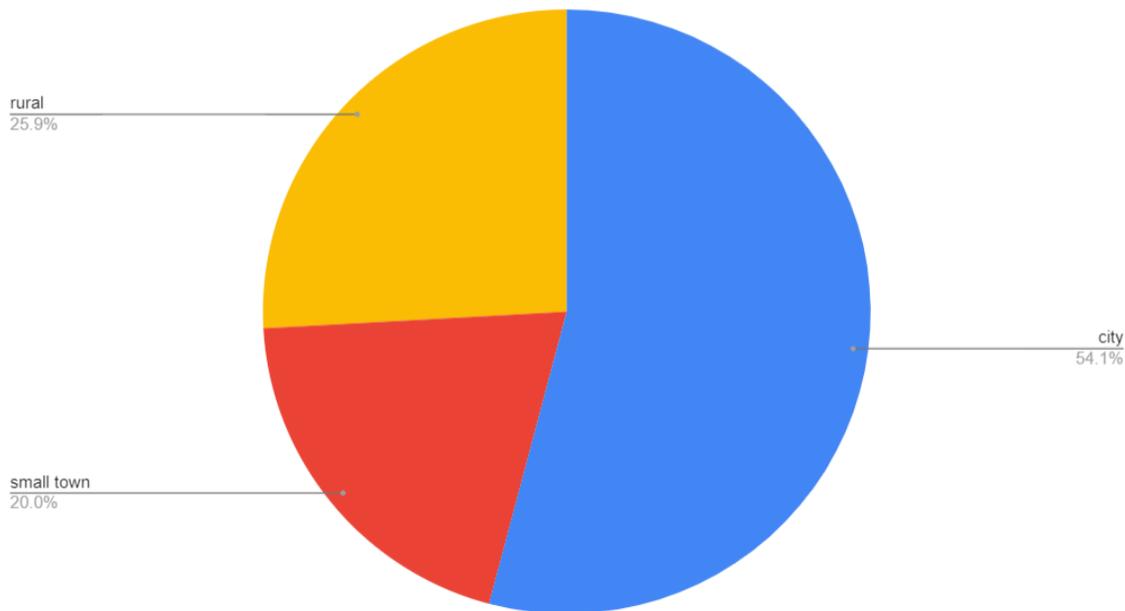


Chart Description: This pie chart depicts the location of participants. The pie chart divisions depict 25.9% of participants from rural areas, 20% from small towns and 54.1% from cities.

The women with disabilities respondents all belonged to different occupations and sectors ranging from students, freelance workers, independent workers – including small business owners and home based entrepreneurs, homemakers, activists, researchers, special educators, to professionals from corporates and different industries, and some unemployed persons as well.

### Participant Profiles – Disability Groups

The calls were open to people, who self-identified as women with disabilities, over the age of 18, currently living in India. Participants were given the option to identify themselves as having specific disabilities and were not required to show any diagnosis or certification.

Women who participated in the calls were from amongst several categories of persons with disabilities recognized as specified disabilities under the RPD Act as well as others such as persons with chronic illness (Sjogren's, Scoliosis, Rheumatoid Arthritis and its co-morbidities, Complex Pain Regional Syndrome). While many participants spoke of psychosocial distress and access to mental health services no one specifically identified as having psychosocial disabilities.

Disability	No. of Women
Blindness	10

Low Vision	4
Deafness/ Hard of Hearing	11
Deaf blindness	4
Autism Spectrum Disorder	1
Locomotor disability	37
Cerebral Palsy	4
Learning Disability	2
Other Chronic Illnesses	4

### **Outreach and Enabling Participation**

Dissemination of the invitation to the call was done largely over email, via social media – including WhatsApp, Facebook, Twitter and over phone conversations. It also involved a mix of intentional outreach to Disabled Peoples Organizations (DPO) and other partner organizations working with the two primary researching organizations. All participants attended the consultations voluntarily and without any compensation and gave consent for the calls to be recorded. The recordings will be kept confidential between the two organizations leading the effort. All of the names and identifying information have been excluded from the report to protect the respondents' anonymity, and details provided are merely to help the reader appreciate the diversity of participants and perspectives.

To ensure accessibility across disabilities reasonable accommodations by way of sign language and live captioning were provided. Calls conducted in languages other than English and Hindi had translators present. One call was specifically designed to ensure the full and effective participation of deaf, hard of hearing, and deafblind women.

The conversation within the call itself was conducted in smaller groups, with about 5-9 participants in each group, which were facilitated by team members of Rising Flame and Sightsavers India. Conversations were structured around experiences relevant to several categories that can be seen in the imminent chapters. Any fears the participants had for the future regarding these areas, as well as any recommendations were also discussed – although these can also largely be gleaned from the main conversation revolving around their immediate lived experiences as well. After the group conversations, the findings were reported back to the larger group by each facilitator. Out of the 82 women with disabilities who attended the calls, 77 of them stayed connected till the end – the rest could not participate for the entire duration due to technical issues. All calls were recorded and transcribed and translated into English wherever necessary. Data was generated from the participants' lived experiences verbatim.

An additional call was conducted, to record experiences specifically relevant to education. This call was open to women students with disabilities as well as parents of students with disabilities, special educators, teachers /professors, activists working in

disability rights or education and various stakeholders in education, and was facilitated in English, Hindi, and Indian Sign Language. This call saw participation from 3 special educators, 3 disabled professors, 2 students with disabilities pursuing their Ph.Ds., a sign language trainer, a trainer for blind students, and 2 researchers – from 7 different states (Maharashtra, Gujarat, Delhi, Karnataka, Kashmir, Tamil Nadu, Telangana) living primarily in urban spaces. So, in total this research report was written on the basis of data gathered from 94 participant's experiences from across India.

The primary data of this study has been contextualized and supplemented with global and national level reports and submissions, global and national laws and policy documents, and media reports.

### **Limitations**

Due to the restrictions on movement and the threat of COVID-19 at the time of the investigation, data could only be collected via phone calls and online communication. This meant that only those with sufficient access to digital and telephonic mediums could participate in this study. The invitation to participate in the study was publicized through social media and through individual outreach to organizations.

Despite the best efforts of the organizers under the circumstances, we acknowledge that there is a vast diversity in disabilities and women living with various disabilities including some specified under the RPD Act did not participate in the research.

The short time period to turn around the report because of its timely and current nature proved as a barrier to continue more conversations and capture specific testimonies from the groups where there were gaps.

Although the calls were conducted in five different languages, India is a multi-lingual country and there was a limitation on participation of research respondents who spoke other languages.

There was no intentional outreach made to intersecting marginalized groups like Bahujan women and queer people with disabilities, since the calls were open to women with disabilities across groups of class, caste, sexuality etc. However, many experiences of intersecting marginalization did emerge during the course of the calls in many ways.

# Access

## Global and Local Context

Accessibility and reasonable accommodation are the keys in enabling access for persons with disabilities. Accessibility has been recognized to be a precondition for persons with disabilities to live independently and participate fully and equally in society,<sup>36</sup> and without which, there can be no access, and denial of access amounts to discrimination against persons with disabilities. This approach reflects the paradigm shift from locating the problem within the person with disability to locating the barriers in the environment around them – that is a shift from medical and charity model to the social model. Accessibility is one of the general principles on which the CRPD is based<sup>37</sup> and encompasses the physical environment, transportation, information and communication, and services which are open to the public regardless of ownership.

Reasonable accommodation is a means of ensuring access in a particular case for a person with disability. The CRPD defines reasonable accommodation as: “Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.” Denial of reasonable accommodation amounts to discrimination on the basis of disability, and non-discrimination is also a general principle of the Convention.<sup>38</sup>

Both these concepts give us a good entry point to discuss how accessibility and reasonable accommodation allow for us to shift the burden of ensuring access to opportunities and full participation from the individual to the systems in our society.

The RPD Act recognizes that accessibility is a crucial part of ensuring rights of disabled people. In principle, it adopts many of the rights enshrined in the CRPD. One of the important developments under this Act is that it requires adherence to accessibility standards and “recognizes that reasonable accommodation and universal design are critical for facilitating access in an equitable manner and creating an accessible framework for India going forward.”<sup>39</sup> It also reflects the wider understanding of accessibility beyond physical infrastructure. It requires all infrastructure open to the public to be accessible including schools, colleges, universities, public and private sector companies, ATMs, bank branches, among others. The RPD Act states that

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<sup>36</sup> Committee on the Rights of Persons with Disabilities General Comment No. 2 (2014) CRPD/C/GC/2

<sup>37</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 3 (f) , available at: <https://www.refworld.org/docid/45f973632.html>

<sup>38</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 3 (b), available at: <https://www.refworld.org/docid/45f973632.html>

<sup>39</sup>Digital Accessibility in the Rights of Persons with Disability Act 2016. (2017) Retrieved from [https://cis-india.org/accessibility/blog/digital-accessibility-in-the-rights-of-persons-with-disabilities-act-2016#:~:text=The%20Rights%20of%20Persons%20with%20Disabilities%20\(RPD\)%20Act%2C%20which,ratified%20nearly%20a%20decade%20ago.](https://cis-india.org/accessibility/blog/digital-accessibility-in-the-rights-of-persons-with-disabilities-act-2016#:~:text=The%20Rights%20of%20Persons%20with%20Disabilities%20(RPD)%20Act%2C%20which,ratified%20nearly%20a%20decade%20ago.)

permissions to build infrastructure and completion certificates would be contingent on adhering to the guidelines on accessibility.<sup>40</sup> However, in the years after its implementation, civil society groups found that buildings were provided clearances with no requirement to meet the standards of accessibility.<sup>41 42</sup> In a newspaper report it was reported that only 3% of the buildings in the country are accessible, never meeting the goals set by the Accessible India Campaign.<sup>43</sup>

The failure of the Government to enforce accessibility in services and infrastructure has exacerbated the exclusion experienced by persons with disabilities during this pandemic. 75 out of 82 participants faced some form of access barrier during this period with regard to information, physical spaces, to communication, to digital spaces, to health services, to food and essentials, to remote/digital education etc. While some of these themes will be explored in detail in further chapters, this chapter will be looking at some of the experiences relating to access to information and communication, to digital platforms and to personal mobility outside and inside the home.

## **Access to Information and Communication**

Article 21 of the CRPD reiterates the right of persons with disabilities to express themselves and their opinions on an equal basis with others and the freedom to seek, receive and impart information in the communication modes of their choice. This includes all public dissemination of information in all accessible means without persons with disabilities having to bear the costs. However, the experiences of people with disabilities around COVID- 19 and the lockdown show us how this right was not realized.

When the Prime Minister announced the impending lockdown in the country, his announcement, which was made in the late evening, did not have captioning or sign language interpretation.<sup>44</sup> As a result many d/Deaf and hard of hearing people did not receive enough notice to act on the lockdown.<sup>45</sup> Our research discussed with women with disabilities the first step in the inaccessibility they experienced - one of inaccessibility to information.

This barrier to informational access is not new. It has been a constant struggle, especially for blind women, d/Deaf women, deafblind women, and intellectually disabled women to access information about their rights and to act on them. This results in a lot of information being filtered because of lack of direct access. For instance, receiving of information through caregivers, interpreters, and others.

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<sup>40</sup> RPD Act, Section 44

<sup>41</sup> United Nation (2017) Voluntary National Report

<sup>42</sup> National Council of Educational Research and Training (2016) Eighth All India School Education Survey.

<sup>43</sup> Editorials (2018) With just 3% of India's buildings accessible, our disabled are at a huge disadvantage. Hindustan Times. Retrieved from <https://www.hindustantimes.com/editorials/with-just-3-of-india-s-buildings-accessible-our-disabled-are-at-a-huge-disadvantage/story-Rh2rd4QzNzw9kHpmaTPV1H.html>

<sup>44</sup>Deaf Participant from Delhi, Call 8 (23<sup>rd</sup> May 2020)

<sup>45</sup>Deaf Participant from Delhi, Call 1 (10<sup>th</sup> May 2020); Deaf Participant from Gurgaon, Call 8 (23<sup>rd</sup> May 2020)

"Few of my friends told me everything is shut. I did not know what the problem was, but later on I learnt from ISH news - which is a news channel for the deaf community. I learnt from there that the virus is going around and to stay home. In the starting I was told to stay back at home, that is it. They just said, if you got out, you would die."

A 35-year-old Deaf woman, Delhi

An account published by the International Disability Alliance of the president of a DPO in Rajasthan highlights the dual impact of the lack of information accessibility and illiteracy on persons with disabilities in the rural areas. She particularly observed that the "lack of information hits persons with hearing disabilities the hardest, as they rarely have access to sign language interpretation or captioning".<sup>46</sup>

Shakuntala Gamlin, the secretary of the Department of Empowerment of Persons with Disabilities, had demanded in March 2020 to "Make all COVID-19-related information available in Braille and audio format for persons with visual disability, videos with sub-titles and sign language for those with hearing disability and information on all websites and social media with optical character recognition and e-PUB format"<sup>47</sup>. The Disability Inclusive Guidelines also emphasizes making information about COVID-19 accessible across formats. Despite this notice to states and union territories <sup>48</sup>, only the governments of Nagaland, Tamil Nadu and Kerala have made attempts to ensure sign language interpretation and accessibility in their messaging.<sup>49</sup>

Deaf and persons who are hard of hearing found particular challenges following the mandates on social distancing and the using of masks.

"They are wearing a mask and saying something, it will be more difficult to hear. I will need an interpreter; I will not be independent. I have to depend on somebody for communication."

A 31-year-old Deaf woman, Mumbai, Maharashtra

While masks and social distancing are both effective and necessary preventive practices the barriers to communication that they cause remain unaddressed by policy makers and those who are enforcing these policies on the ground – the Police. A participant narrates how communication barriers affected her ability as an essential worker (bank staff) from going to work during the lockdown.

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<sup>46</sup> International Disability Alliance (2020) COVID-19 in Rajasthan (India): What are women with disabilities' main challenges?. Retrieved from: <http://www.internationaldisabilityalliance.org/covid19-india-women>. This is also seen in other contemporaneous reports like in the media and through the research conducted by National Centre for

<sup>47</sup> Ministry of Social Justice and Empowerment (2020) Treatment of persons with disabilities should be given priority. Retrieved from <https://pib.gov.in/PressReleaseIframePage.aspx?PRID=1607950>

<sup>48</sup> News 18 (23 March 2020) Centre Directs States to Provide Covid-19 Info to Disabled Persons in Accessible Format <https://www.news18.com/news/india/centre-directs-states-to-provide-covid-19-info-to-disabled-persons-in-accessible-format-2548295.html>

<sup>49</sup> NCDEP (2020) Locked Out and Left Behind

"I decided to walk the whole distance. It was around 7-8 km. There was a letter from the bank, but the police were not understanding what I was trying to say to them. I was not understanding what they were saying to me. There was no proper access to information in all this."

A 35-year-old Deaf woman, Delhi

## Access to the Digital World/Spaces

As COVID-19 began its spread in India, there was a shift in many of our workplaces to remote working and education to distance learning. In these times of social distancing and remote operations, digital accessibility becomes a central question for us to raise.

Around 30 women with disabilities from cities such as Delhi, Mumbai, Bangalore, Chennai did speak about the benefits of having digital access to information and that they are relying on internet, apps on phones, and social media for information. Two blind participants from Jaipur stated that they are relying on information circulated by their company on email.<sup>50</sup> A blind participant from Guwahati but studying in Delhi pointed to the inaccessibility of the infographics and charts being shared as information regarding the virus and preventive measures. A Deaf participant in the research living in Delhi referred to information is shared via the television in India. This means that unless family members facilitate information access, direct access is hindered. She felt that lots of people do have smart phones which enabled information access and more, but she and others raised the concern about those without access to smart phones.

"Some of us who have learnt the technology are able to access it. There are people in the rural areas who cannot. There should be government workers or someone who should be asking them if they need any medicines and help and things."

A 31-year-old blind woman, Trivandrum, Kerala

In a country as vast as ours, access to accessible information, communication technologies are poor. The census 2011 data shows that 69% of the disabled population in India lives in rural areas<sup>51</sup>, which has limited internet penetration, with one study putting it at 21%<sup>52</sup>. Even then many may not communicate in the mainstream languages that most digital spaces are designed in.<sup>53</sup> Therefore, digital accessibility has been repeatedly raised as a concern of not just accessibility but availability, affordability and looking at the support people have to learn to navigate assistive tech-

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<sup>50</sup> Blind participant from Jaipur, Call 1 (10th May 2020); Deafblind participant from Jaipur, Call 8 (23rd May 2020)

<sup>51</sup> Enabled India (2017) Disabled Population in India as per census 2011 (2016 updated). Retrieved from: <https://enabled.in/wp/disabled-population-in-india-as-per-census-2011-2016-updated/>

<sup>52</sup> Rising Voices (2019) Exploring models of sustainability for rural connectivity in Indian villages. Retrieved from: <https://rising.globalvoices.org/blog/2019/01/20/exploring-models-of-sustainability-for-rural-connectivity-in-indian-villages/>

<sup>53</sup> Narasimhan, N. Sharma, M. and Kaushal, D (2012) Accessibility of Government Websites in India: A Report. Retrieved from: <https://cis-india.org/accessibility/accessibility-of-government-websites-in-india>

nologies. The Accessible India and Digital India campaign has only focused on a few initiatives and has broadly left out many websites including state and government websites and there is little updated information on how accessible websites are<sup>54</sup>.

## Banking and Finance

Banks have repeatedly informed customers to avoid visiting the banks and to rely on web and mobile banking. Many e-commerce websites have also prohibited cash payments to limit the exposure of their delivery staff<sup>55</sup> which requires enabling services related to e-payments. The blind women in particular spoke about accessibility to digital applications aside from the network related issues. Several news reports and research have covered that popular payment applications such as Paytm and Bharat Interface for Money (BHIM) remain inaccessible to the blind and low vision users in the country<sup>56</sup>. Participants from Bangalore and Delhi shared that they are able to access financial services such as money transactions online. However, this is dependent on a steady internet.

"I cannot ask anyone else to withdraw cash on my behalf from the ATM. But if I order grocery, then they require me to pay them via Google Pay, then I have not used all these apps. I only use Paytm for my transactions. So, to use these new things, and then ask permission from the bank, it is a bit difficult. This is also confusing for me."

A 39-year-old woman living with scoliosis, Thane, Maharashtra

"I was trying to make a payment and it was a sizeable amount. But the internet crashed, and the payment did not go through. However, the amount got debited. I contacted the bank and they said it will be credited and it hasn't yet."

A 36-year-old woman with cerebral palsy, Chennai

Despite RBI requiring banks to ensure all procurements of ATMs were those which were equipped with voice, braille navigation and designed to be accessible through ramps, this is still not abided by all companies.<sup>57</sup>

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<sup>54</sup> In 2012 a report by Centre for Internet and Society 7800 of the government websites tested were found to be inaccessible based on the Web Content Accessibility Guidelines (WCAG) 2.0, which is the universally accepted standard for web accessibility. Narasimhan, N. Sharma, M. and Kaushal, D (2012) Accessibility of Government Websites in India: A Report. Retrieved from: <https://cis-india.org/accessibility/accessibility-of-government-websites-in-india> The WCAG document explains how to make content more accessible to people with disabilities. Web Content generally refers to the information in a web page or web application, including text, images and sounds and even code or markup that defines design and structure of the application/content.

<sup>55</sup> The Economic Times (2020) No Cash as Etailers Go Completely Contactless. Retrieved from: <https://economictimes.indiatimes.com/industry/services/retail/no-cash-as-etailers-go-completely-contactless/articleshow/74837140.cms?from=mdr>

<sup>56</sup> Kameswaran, V. Muralidhar, S.H. (2019) Cash, Digital Payments and Accessibility - A Case Study from India. Retrieved from: [https://pure.au.dk/portal/files/163325316/Cash\\_Digital\\_Payments\\_and\\_Accessibility\\_A\\_case\\_study\\_from\\_India\\_2\\_.pdf](https://pure.au.dk/portal/files/163325316/Cash_Digital_Payments_and_Accessibility_A_case_study_from_India_2_.pdf)

<sup>57</sup> RBI-Notifications (2014) Need for Bank Branches / ATMs to be made accessible to persons with disabilities, order no: RBI/2013-14/598. Retrieved from: <https://www.rbi.org.in/scripts/NotificationUser.aspx?Id=8891&Mode=0>

"I am not able to go to the ATM. I took an auto or asked my mother to take me to the ATM. But autos are not available now. My mother is very scared to accompany me because of the pandemic. But it's okay because I mostly use the digital banking mobile app of the bank."

A 36-year-old woman with cerebral palsy, Chennai

This inaccessibility will pose a greater challenge as we are in the unlock phase of the pandemic with ongoing social distancing norms.

For many in rural India there are layers of exclusion to technology. For instance, all our rural/semi-urban calls with 15 women with disabilities had to be made via the telephone. These women often lost connection midway. Literacy rate amongst women with disabilities is so poor, where the general illiteracy rate among people with disabilities is assumed to be 45% while the national average is as low as 25%.<sup>58</sup> Women with disabilities living in the rural areas have had little exposure to financial and digital literacy, which means that they have difficulty in operating technology on their own and required either a DPO member/ volunteer or a family member to assist them. Many of these applications require smartphone devices as well. In these circumstances, expecting women with disabilities to entirely rely on digital payments is unreasonable.

## **Government issued COVID 19 Applications and Helplines**

The State and Central Governments have enacted several applications to provide information to persons about the virus and to track and monitor the spread within communities. The recently released Aarogya Setu app has also received criticism from the blind community about its inaccessibility.<sup>59</sup> The Aarogya Setu App is an application to track and monitor the spread of virus in India. This application was debated to be made mandatory if people wanted to travel within the city, inter-state travel and more. There is still no clarity on whether it is mandatory since in the latest information, the Centre told the Karnataka High Court that it was not mandatory, but "advisable".<sup>60</sup>

"The Aarogya Setu app is not accessible for people with disability. This is one of the most important apps. There are guidelines being circulated which is not accessible for blind people. It is a scanned document in pdf document. This is not readable by screen-readers. They should be following the web content accessibility guidelines."

A 31-year-old blind woman, Trivandrum, Kerala

"The information [on the app] is only spoken or written. It is not accessible, as there is no sign language on it. This accessibility for the disabled should have been there, especially due to the pandemic."

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<sup>58</sup> Salve, P. Yadavar, S. (2017) Why nearly half of India's disabled population is illiterate. Scroll.in. Retrieved from: <https://scroll.in/article/833784/why-12-1-million-45-indians-with-special-needs-are-illiterate>

<sup>59</sup> Rahman, S. (2020) Aarogya Setu remains inaccessible for disabled despite push from activists. The Indian Express. Retrieved from: <https://indianexpress.com/article/india/aarogya-setu-app-aarogya-setu-app-disabled-inaccessible-coronavirus-contact-tracing-6416094/>

<sup>60</sup> Mandavia, M. (2020) Aarogya Setu app not mandatory for air, rail travel: Centre to Karnataka HC Retrieved from: <https://economictimes.indiatimes.com/news/politics-and-nation/aarogya-setu-app-not-mandatory-for-air-rail-travel-centre-to-karnataka-hc/articleshow/76343053.cms?from=mdr>

A 32-year-old Deaf woman, Bhopal, Madhya Pradesh

Again, all of these applications depend on the availability of a smart phone.

“We know those women who live in very interior parts of villages, and who do not know about the intensity of this virus, who do not know that how they should be living with their children and with their families, despite the wide spread of Coronavirus. And the reason they do not know about it, is just that, they just have one house as a medium, in which they live along many others. Whereas, those women are not even equipped with any Android phones, what are they hearing and learning about the virus?”

A woman with locomotor disability, Patna, Bihar

The lack of digital accessibility thus reinforces the poor informational access, especially to accurate and pertinent information released by the government, as well as to support from the government and the community. A blind teacher asks the pertinent question, “Those of us that are digitally connected can coordinate our response, exchange views, show support, but what happens to persons with disabilities that don’t have access to phone or internet, how do we reach out to them?”<sup>61</sup>

Access to all services being elaborated in the following chapters are hindered directly by the access to information or communication. There was no data about the accessibility of helplines to Deaf and hard of hearing people - since it seems most of the helplines were voice based. A recent national report states that access to helplines by persons with disabilities was hindered by lack of information about such helplines even being available. Nearly 48% of the disabled people surveyed reported this to be the greatest barrier to accessing the helplines.<sup>62</sup>

## **Personal Mobility Outside and Inside the Home**

“I had gone to buy some ration, and there my crutches slipped. I fell down. In normal times, someone definitely used to come to pick me up if this sort of a thing happened. But that day, no one came. Then I took out my sanitizer from my purse, and gave it to the shopkeeper, and then he came to help me get up.”

A 39-year-old woman with locomotor disability, Ahmednagar, Maharashtra

As explained earlier, the progressive realization of accessibility for all has been slow in India. Physical spaces were often mediated and navigated by people with disabilities through a mixture of hacks, support from kind strangers and often entirely because of the help provided by passers-by. Social distancing norms are very strictly imposed to mitigate and protect from COVID-19. This discourages passers-by from helping people with disabilities they meet in public places. Across disability many of the women with disabilities in both cities and villages shared fears about the pandemic changing how access would be provided to them.

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<sup>61</sup> International Disability Alliance (2020) COVID19 and Disability in West Bengal, India: the story of two teachers. Retrieved from: <http://www.internationaldisabilityalliance.org/west-bengal-covid19>

<sup>62</sup>NCPEDP report

“Before the lockdown I was able to navigate alone because there was public on the road and there were some landmarks like smell or certain smell that help navigate and the sound of cars that help you. If you lose your way, you can always ask someone but in the lockdown, there are hardly any people on the road and it’s easier to cross, but sometimes you lose your way because you depend on certain landmarks like smells, shops, you bang your cane on the door. So, it is difficult to navigate for a totally blind person during the lockdown time and even after it is lifted - who will help?”

A 31-year-old Blind woman, Trivandrum, Kerala

Another participant with low vision from Bangalore shared how physical distancing is hard for her because she does not always know how far she is from another person. Though physical distancing has been pushed as the need of the hour, it can be hard for persons with low vision to maintain it. Often passers-by shout at people with disabilities for coming too close to them as well.

The fears of inaccessibility in the lockdown and post lockdown phase are steeped in the inaccessibility of society - which is worsened by the physical distancing norms. There are also very real concerns of persons with compromised immunity being forced to go back to work once the lockdown lifts. On paper, clearly, requests for support enabling them to stay home and reduce their exposure to the virus would entirely be reasonable accommodation, but there is no certainty.

“Until the vaccine comes in, the fear of touching will continue. The other fear we have is low immunity levels because we have been taking medications and we have to take certain medications, whose side effect is decreasing your immunity level. So, until the vaccine comes out you cannot think of exploring or doing a lot of things, you are restricted in a number of ways and you can’t get out of the house. I can’t do my work also as I tried to make it online, but I know right now there is no certainty of anything.”

A 28-year-old woman with chronic illness and compromised immunity, Gurgaon

For many persons with disabilities, personal mobility depended on live and personal assistance. Responding to a woman with disability’s concern on social media that her paid care giver was not able to travel to support her, Mumbai police<sup>63</sup> enabled the free movement of care givers and support staff who are essential to the support of many people with disabilities. On the other hand, a participant living with scleroderma from Faridabad addressed her difficulties in having to keep her environment clean with a debilitating condition, being immunocompromised and having the additional burden of no caregiver in these times.

“Since I am on oxygen, I can do very limited tasks. I can sit and work for hours but if there is anything physical it is a big challenge. It takes around an hour and half to take bath and get ready. I used to get little support from my help earlier, but after the lockdown began, I have started doing it alone and this takes a lot of energy out of me.”

A 42-year-old woman with scleroderma (a wheelchair user), Faridabad, Haryana

In many ways, this lockdown highlighted the lack of visibility of people with disabilities, their caregivers, and the family.

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<sup>63</sup> Ghosh, A. (2020) Mumbai Police Comes To Aid Of Disability Rights Activist. Femina. Retrieved from: <https://www.femina.in/trending/in-the-news/mumbai-police-comes-to-aid-of-disability-rights-activist-152410.html>

Thus, accessibility remains a huge concern for people with disabilities especially as government eases the lockdown and requires people to return to work and educational institutions. The COVID-19 pandemic has exposed the consequences of not ensuring accessibility in our infrastructure and services. One of the important aspects to recovery from disasters is to “build back better”<sup>64</sup>. This means that in our recovery we should be working towards making sure that we do not experience what we are experiencing now, by making sure our communities are better than they were before the disasters. There is the reality of a global economic crisis because of the impact of the lockdowns. Even so, the government should not regress from the small victories that have been achieved with regard to accessibility and should continue to work towards the progressive realization of access for all.

“I just want you to tell the government or the right authorities to give proper accessibility to the Deaf. It is not only about the Deaf but all kind of disabilities. So that we can lead a better life in India. I do not know after lockdown how the things would be, I just want accessibility then that would be much better, rest is ok we can manage. I don’t want to always be dependent on the hearing family member, I just want accessibility.”

A 35-year-old Deaf woman, Delhi

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<sup>64</sup> UNISDR (2017) Build Back Better. Retrieved from: [https://www.unisdr.org/files/53213\\_bbb.pdf](https://www.unisdr.org/files/53213_bbb.pdf)

# Food and Essentials

## Global and Local Context

Ending hunger, achieving food security and improved nutrition are a large focus of the SDG 2 of the Agenda 2030 that India is a signatory to. The right to food is a human right, and is also recognized as part of the fundamental to life right under Article 21 of the Constitution.<sup>65</sup> Ensuring the right to adequate food for persons with disabilities and their families is also a state obligation under the CRPD<sup>66</sup>. The State has taken on the obligation to ensure access by all people, in particular the poor and people in vulnerable situations, including infants, to safe, nutritious and sufficient food all year round. However, as a result of the COVID-19 crisis and the subsequent months long lockdown, many, especially those with disabilities,<sup>67</sup> are left with no access to food and essentials.<sup>68</sup>

When the central government announced the lockdown, they assured open supply chains of food and essential products. Subsequently, state governments additionally released a series of notifications which gave permission for shops and medical stores to remain open during the lockdown. None of the directives had any specific provisions to ensure access for persons with disabilities despite the Disability Inclusive Guidelines notifying disability commissioners as nodal officers charged with mandating assured access to food and essentials, and suggesting reasonable accommodation measures such as reserving dedicated timings in supermarket and other essential stores specifically for persons with disabilities to ensure the ease of access to food and daily essentials.<sup>69</sup>

Accessing food and essentials, whether it be through general stores, e-commerce or through the public distribution system, presented their own barriers. There was the further issue of then having access to food and essentials with gender stereotypical behaviours at homes which deprioritize women with disabilities.

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<sup>65</sup> PUCL v. Union of India [W.P. 196/2001]

<sup>66</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 28, Retrieved from <https://www.refworld.org/docid/45f973632.html>

<sup>67</sup> Narayanan J (2020 May 26) Helplines for people with disabilities abuzz with calls for food supplies, e-passes for caregivers, medicines. Indian Express. <https://indianexpress.com/article/lifestyle/life-style/lockdown-list-helpline-persons-with-disability-accessibility-food-mental-health-issues-coronavirus-pandemic-6372660/>

<sup>68</sup> Kohli R (2020 May 19) A starved Nation. The Telegraph. Retrieved from <https://www.telegraphindia.com/opinion/coronavirus-for-india-the-covid-19-pandemic-has-brought-about-general-starvation/cid/1774030>.

<sup>69</sup> Department of Empowerment of Persons with Disabilities (Divyangjan) (2020) Comprehensive Disability Inclusive Guidelines for protection and safety of persons with disabilities (Divyangjan) during COVID 19. Retrieved from <http://disabilityaffairs.gov.in/content/page/whats-new.php>

There has only been sporadic state support for persons with disabilities and not necessarily a dedicated or specific helpline to provide support for food and essentials and in other ways. In Chandigarh, the Department of Women and Child set up a helpline and not the disability department.<sup>70</sup> In Maharashtra the helpline was a call-in number and was not accessible to d/Deaf individuals.<sup>71</sup> Other helplines also witnessed that the persons at the other end were not really trained in needs and issues of persons with disabilities.<sup>68</sup> Only in Tamil Nadu did the disability commissioner along with Civil Society Organizations (CSO) set up an accessible helpline to support persons with disabilities and had received over 7000 calls from all across the state<sup>72</sup>. The state implementations were not uniform all through the country. Some of the positive initiatives by a few states<sup>73</sup> were:

- The Tamil Nadu Disability Commissioner issued instructions for specific timings or doorstep delivery of goods from Public Distribution System (PDS) ration shops to persons with disabilities.
- The office of Disability Commissioner in Nagaland is ensuring that essential food supplies/dry rations are delivered to the doorsteps of persons with disabilities in need in coordination with District Administrations, partner CSOs and local churches.
- Kerala has established common kitchens where cooked food is served. Dry rations are provided to those who cannot reach these common kitchens.

However, it is documented that distribution of ration or dry food is primarily done by state governments in the urban areas and the areas surrounding them. These practices had not yet reached disabled persons in other areas. In one survey, 67% of persons with disabilities interviewed reported to have no access to doorstep delivery of essentials by the government. Only 22% have access to delivery of essentials.<sup>74</sup>

In light of the scarcity of support from the state around accessing food and essentials, many civil society initiatives were constituted to provide door delivery and urgent support for basic necessities even at great risk to their own health and safety.<sup>75</sup> A participant with locomotor disability from Raipur, Madhya Pradesh shared that she

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<sup>70</sup> Astha (2020) Children and persons with disabilities in a humanitarian crisis of covid-19 in India: Challenges & Strategies.

<sup>71</sup> Meenakshi B (2020 May) Too little, Too Few

<sup>72</sup> Astha (2020) Children and persons with disabilities in a humanitarian crisis of covid-19 in India: Challenges & Strategies.

<sup>73</sup> Meenakshi B (2020 May) Too little, Too Few

<sup>74</sup> National Centre for Promotion of Employment for Disabled People (NCPEDP) 2020. Locked down and left behind. Retrieved from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked-down\\_left\\_behind.pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked-down_left_behind.pdf)

<sup>75</sup> Team Sahyog (2020 May 28) List of NGOs providing relief during Covid-19. Retrieved from <https://www.investindia.gov.in/bip/resources/list-ngos-providing-relief-during-covid-19>

along with 30-40 people have been buying food for the poor. They have also been making masks and distributing them in the village.

During our research consultations, we found that women living in cities, women living in semi urban and rural areas faced diverse barriers in terms of accessing food.

## Urban Areas

Women with disabilities reported to not be able to benefit from the free food distribution by the government. Women with locomotor disabilities were unable to go to the store themselves because of the inaccessible roads and footpaths, considerable distances between homes and nearest stores, and the lack of public transport which they used in the pre-COVID-19 days.

Two women with locomotor disability, both from Guwahati, spoke of the difficulties they had. One reported that she used to take the bus or auto to go to the shop for essentials, but now since those means are not available, she is very scared of going to the store. The other woman shared that she thinks twice before buying anything because she is scared, she will contract COVID-19, and additionally that if she goes out, she may be questioned for being outside. Many state policies have resulted in police excesses while trying to enforce the lockdown, as well as limited timings for shops to be open.

“They have also fixed the timings for the market, that you can come only from this time to this time. So, a woman who cannot walk, then how will she reach the market in the given timings? I do not understand this. Vegetables are still manageable since the sellers come outside the house and you can buy from there. How will those who are blind and with locomotor disability buy things by themselves? We do not have the option of getting things delivered at home.”

A 38-year-old woman with locomotor disability, Bikaner, Rajasthan

The irony for some participants was that the shopping options that offered accessibility – supermarkets in malls - were closed entirely.

“... many of the malls that offer accessibility were closed. The malls are more accessible than the small stores that are open, so I think that was a little bit of a challenge.”

A 42-year-old woman with locomotor disability, Bangalore, Karnataka

The impact of social distancing on those relying on tactile support and communication has been detailed in the previous chapter, but this has an additional impact on access to food and essentials for the blind, those with visual disabilities and the deafblind.<sup>7677</sup> Having compromised immune systems was another major barrier to

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<sup>76</sup> Kumar A (2020 March 27) Here's how India can help the disabled during 21-day coronavirus lockdown. The Print. Retrieved from <https://theprint.in/opinion/heres-how-india-can-help-the-disabled-during-21-day-coronavirus-lockdown/389349/>

<sup>77</sup> FICCI (2020) Impact of COVID-19 on Persons with Disabilities, India.

going out and accessing food and essentials because of the health vulnerability and lack of any support to do the same.<sup>78 79</sup>

Deaf and hard of hearing women faced their own challenges around access. Three Deaf and hard of hearing women, from Kalyan (Thane), Bhopal and Kolkata, outlined that communication proved to be a major barrier in actually buying food and essentials.

“With mask, lip reading is difficult, buying of vegetables, food, talking in gestures in difficult. Communication is tough. Misunderstanding is very normal. It is the first time I have faced something like this. And I have a doubt if the quality of materials [food] is good or not, but I can’t ask anybody or even understand what they are saying from under the mask.”

A 31-year-old Deaf woman, from Thane-Mumbai, Maharashtra

Even in cities where digital medium of procuring food and essentials was much celebrated by many urban women with disabilities, there were barriers to access on account of the shift to contactless payment through apps (see **Banking and Finance**, above). Older persons with disabilities who have been excluded from digital literacy also could not take advantage of these services even if they were available.

“My parents are deaf. They are very old. They do not know how to read and write. They cannot step out of home, nor do they know how to shop online. They only ate rice and daal for a week. Finally, they asked for help when they ran out of supplies completely. I live in another city and I had to call many relatives to get help for my parents.”

A 32-year-old Deaf woman, Bhopal, Madhya Pradesh

Ordering online is not a full proof solution. Two women from Maharashtra and Madhya Pradesh also reported that online deliveries were not always helpful because very often they were not stocked well or were not delivering in that particular area. Delivery is often where a new set of barriers arise. A Deaf woman from Kolkata shared that she was very comfortable with online shopping but when the persons came to deliver the parcels, she could not communicate because of the mask acting as the barrier to lip reading.

Another Deaf woman from Gurgaon shared that while she could order by herself, she needed her son, who is hearing, to go and pick up the groceries or communicate with the delivery person to ensure drop off. For many persons with disabilities, doorstep delivery is an absolute essential, and in the absence of regulations for delivery services to ensure doorstep delivery<sup>80</sup> many persons with disabilities find themselves at a loss for support. This is compounded by the gendered expectation

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<sup>78</sup> Zdanowicz C (2020 March 19) They're living with an invisible illness. Social distancing will save their lives. CNN. Retrieved from <https://edition.cnn.com/2020/03/19/health/immunosuppressed-coronavirus-wellness-trnd/index.html>

<sup>79</sup> Muralidharan (2020 May 8) For an inclusive response. Frontline. Retrieved from <https://frontline.thehindu.com/cover-story/article31402992.ece>

<sup>80</sup> Saikia N and Chopra S (2020) Contouring IPR and Service Sector Regulation against COVID-19. Retrieved from <https://www.barandbench.com/columns/contouring-ipr-and-service-sector-regulation-against-covid-19>

that taking care of the family and ensuring procurement of groceries is a woman's job<sup>81</sup>.

"Many times, people take me for granted. If online store people have dropped the groceries at my society gate, they do not offer to help. I am not able to pick up the 5 kgs and request them to carry this product. They refuse. They say we are not here to do any private work. So, I am forced to pick that grocery up from the gate to my home and then the whole night I spend in pain."

A 54-year-old woman with locomotor disability, Ghaziabad, Uttar Pradesh

The natural consequence of this challenge to independent living was a heavier reliance on others. This dependence caused by the situation resulted in abusive and negative experiences and definitely posed a challenge in procuring or having access to food and essentials. A participant spoke of bad experiences with her house help, also her primary caregiver, who eventually quit without warning. She also found it extremely difficult to find food substitutes, in this case, dairy substitutes, to meet her dietary restrictions under the conditions of the lockdown.

"Yesterday my lunch happened at 7 pm because that is how much time it took to cook my food."

A 28-year-old woman living with chronic illness and compromised immunity, Gurgaon

Three women with disabilities reported a greater reliance on family members. This not only added to the guilt of being a burden on them, in some cases it also resulted in threats and verbal abuse. What also stood out was the deep fear and anxiety for caregivers particularly when they were elderly and part of a vulnerable group themselves.

"I have a walking difficulty and also some balancing issues. My dad (70+) cannot go out. I order most stuff online. But my mother buys vegetables and other small things. But they're both in the vulnerable group so it is very anxiety inducing for me."

A 36-year-old woman with cerebral palsy, Chennai, Tamil Nadu

What got counted as essentials was also a big question. Some women reported that they could not get hearing aids or batteries.

"My hearing aid was not working one day, and everything was under lockdown. My backup aid was also giving me trouble and it was disaster upon disaster."

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

## Rural Areas

In rural areas, many women with disabilities are dependent on the public distribution system. This is a food security system by Ministry of Consumer Affairs, Food and Public Distribution to distribute food at subsidized price to people below the poverty line. During the lockdown, the Central Government has approved the world's largest

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<sup>81</sup> Mills A (2010) "Cooking with Love": Food, Gender, and Power. Retrieved from [https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1037&context=anthro\\_theses](https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1037&context=anthro_theses)

food ration security benefit scheme. The scheme will provide 7 kg ration per month for the next three months to the beneficiaries. People covered under the Public Distribution Scheme (PDS) will get wheat at Rs. 2 per kg and rice at Rs. 3 per kg instead of Rs. 27 and Rs. 37 per kg.<sup>82</sup> To qualify for these schemes persons or families must be in possession of the ration card.

It was reported that persons with disabilities including women with disabilities could not procure the food allocated to them within the food distribution schemes. This was also largely because of no ration cards. Women with disabilities who were also activists from three states- Bihar, Rajasthan, and Chhattisgarh- shared that many people with disabilities did not have ration cards and also struggled with having their names on the family cards. Even if a person qualified for this scheme, there were no state provisions to ensure door delivery for persons with disabilities, but in some cases activists successfully ensured that the Government officials made reasonable accommodations, while in some cases, the Government delegated last mile delivery to the DPOs. As activists themselves note, this is hardly a sustainable model.

"A few problems came to me. After 15 days of the lockdown, we wrote a letter to the Block Development Officer (BDO) and we sent it through WhatsApp. Then they went house to house to give 10 kg rice, oil, and another ration. I then confirmed with the women if they got supplies and they said yes. They aren't providing much help by themselves but when we made efforts, they are also making efforts."

A 29-year-old DPO leader participant with locomotor disability from Jamshedpur, Jharkhand

"As for ration, other than wheat and rice, we are not getting anything else. That is cheap so the government are giving it to us. It has been one and a half months; supplies have got over. In some houses there is nothing at all. We are also trying. Some 200-250 packets of ration we tried giving them. But we cannot do anything. Also, you have to collect the ration yourself. We all have to stand in line, that too we had to stand in one line. The government is not doing anything like giving the disabled people benefits and tending to them first or making them stand separately. And they are giving also 4 kilo per person. That much is not enough. We directly spoke to the disability commissioner, and then they told me to contact the collector. They from their side also told them to help us. They gave us 50 ration packets to distribute to the most needed."

A 37-year-old DPO leader participant with locomotor disability from Ratlam, Madhya Pradesh

"Actual problem is with those, for whom I tried to arrange for food items. The people I am talking about is a case of a blind couple, whose family asked them to live separately after their marriage, and who are disabled. They had a small shop, and both of them used to live alone without any support. They also had to pay rent, their shop is shut, so arrangement for food, they do not have ration card, so how will they eat with just Rs. 400. This is a bigger challenge for them. They used to manage everything by themselves, be it going out and getting the necessary material, and facing problems at every step. So, we got together, and created an account in the name of their neighbours, and we asked them to buy ration for them, and requested them to send those food items to their house. This is mostly problematic for those, who do not have a ration card. And most of the disabled persons do not have a ration card. Every state has its own rules and structure. And in Bihar women with disabilities, unmarried persons with disabilities, and single women are struggling to get their ration

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<sup>82</sup> Kaur G (2020 March 29) India Launches the Biggest Food Ration Subsidy Scheme in the World Amid Coronavirus Lockdown. Grainmart. Retrieved from <https://www.grainmart.in/news/india-launches-the-biggest-food-ration-subsidy-scheme-in-the-world-amid-coronavirus-lockdown/>

cards made. So, the problem is definitely there, in terms of eating food, getting food items, who will bring the food material, from where will be those items be managed, etc. And till how many days will NGOs or social workers be able to make these arrangements?"

A DPO leader participant with locomotor disability from Patna, Bihar

Despite the variation in reply, one common theme in all responses is – on account of the barriers to accessing or qualifying for the PDS, women with disabilities in rural areas have not been getting enough quantity of food, nor are they getting everything a person needs for a nutritious meal. Hence, some are forced to depend on the existing stock of food and groceries at home which is about to finish soon. Some others are using pre-existing relationships with people with access to get supply of other grocery items. Those who do not have supply or influential contact, or the support of DPOs are left to wonder how they will survive the pandemic.

Seven women across disabilities - all activists working at the grassroots level from Bihar, Rajasthan, Madhya Pradesh, Chhattisgarh, Orissa, and Maharashtra stated they knew of people in their communities that had no access to food. 12 women (10 with locomotor disability and two blind) from Bihar, Rajasthan, Chhattisgarh, Madhya Pradesh said they themselves had insufficient access to food. 10 women (9 with locomotor disability and, 1 blind participant) from Rajasthan, Chhattisgarh, Madhya Pradesh, Orissa, Jharkhand said they had trouble procuring the PDS supplies due to issues of access.

The loss of employment and income has also meant that women with disabilities have no means to procure food from the markets to supplement whatever they manage to get from Government distribution. One participant from Raipur with locomotor disability has reported trouble in accessing food as she is presently unemployed and is unable to supplement the bare minimum supplies, she is getting with the help of ration cards.

"I get Rs. 700 per month as pension. What can I do with so little? I need to buy medicines, food, clothes. It is not enough. I have to buy things on credit. I have spent all my pension. We have some land for agriculture but because of lockdown even that has stopped. I can only get things on credit now."

A 29-year-old blind woman, Orissa

No matter where women with disabilities are located, or their nature of disability, access to food and essentials has been a challenge that remains unaddressed in the design and implementation of schemes not only during this pandemic, but also in general.

# Social Protection

## Global and Local Context

The right of all persons to social security, including social insurance, was recognized under the Universal Declaration of Human Rights<sup>83</sup> and the International Covenant on Economic Social and Cultural Rights, 1966<sup>84</sup>. How to actually make this right real was first addressed in the ILO Social Security (Minimum Standards) Convention, 1952 (No. 102)<sup>85</sup> and further in the ILO Social Protection Floors Recommendation, 2012 (No. 202)<sup>86</sup> building social protection floors tailored to national circumstances and levels of development, as part of comprehensive social security systems, while moving progressively towards universal protection. Social protection consists of policies and programs designed to reduce poverty and vulnerability. In this process, most States have extended some form of social protection cover to groups deemed marginalized or vulnerable, which often includes persons with disabilities.

Article 28 of the CRPD categorically states that all state parties recognize the right of all persons with disabilities to an adequate standard of living and continuous improvement in their living conditions. It further recognizes their right to social protection without discrimination based on disability, and to that end to ensure access to disability related services and assistive devices, clean potable water, and to ensure to persons with disabilities, especially to girls, women and older persons, access to social protection programmes and poverty reduction programmes. Persons with disabilities are also to be given equal access to retirement benefits as well and to public housing programmes.

In India, Section 24 of the RPD Act places an obligation upon the government to formulate schemes to ensure that persons with disabilities have an adequate standard of living to live within the community or independently. Where there were schemes available for the general population, the quantum of assistance for persons with disabilities was to be higher by at least 25%. The schemes envisaged under this provision include support in times of manmade or natural disasters.<sup>87</sup>

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<sup>83</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 25, Retrieved from: <https://www.refworld.org/docid/45f973632.html>

<sup>84</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 9, Retrieved from: <https://www.refworld.org/docid/45f973632.html>

<sup>85</sup>International labour organisation (1952) C102 - Social Security (Minimum Standards) Convention, 1952 (No. 102) [http://www.ilo.org/dyn/normlex/en/f?p=NORMLXPUB:12100:0::NO::P12100\\_INSTRUMENT\\_ID:312247](http://www.ilo.org/dyn/normlex/en/f?p=NORMLXPUB:12100:0::NO::P12100_INSTRUMENT_ID:312247)

<sup>86</sup>International labour organisation (1952) R202 - Social Protection Floors Recommendation, 2012 (No. 202)[http://www.ilo.org/dyn/normlex/en/f?p=NORMLXPUB:12100:0::NO::P12100\\_INSTRUMENT\\_ID:3065524](http://www.ilo.org/dyn/normlex/en/f?p=NORMLXPUB:12100:0::NO::P12100_INSTRUMENT_ID:3065524)

<sup>87</sup> Rights of Persons with Disabilities(2016), Section 24 (3) (c)

Many of the provisions in the Disability Inclusive Guidelines touch upon aspects relating to social protection and coverage of persons with disabilities during the pandemic and the lockdown measures. These included relating to access to food and essentials, which are a part of social protection and are covered in the previous chapter. However, persons with disabilities and their families, like many others, were not able to go to work, and this resulted in a loss of income to the family. In such times, cash transfers were being looked at as a way to tide over this difficult time.

## **Cash Transfers**

The report "Too Little: Too Few" which focuses on social protection and persons with disabilities in India highlighted that despite the fact that people with disabilities are deprived of the most basic facilities, due to inadequate data about their numbers, service delivery is patchy at best. Many people are living under very difficult financial situation. Lock-down without adequate notice has led to a lot of hardships and even the people who were gainfully employed have become unemployed which has made them very vulnerable. The NCPEDP report also reports of the several financial challenges faced by persons with disabilities such as delayed pensions and the mandatory requirement to remain present in person to receive pension etc.

"Too Little: Too Few" states that a mere 0.03% of the total GDP is spent by governments both at central and state levels for providing social protection for persons with disabilities and a mere 0.7% people with disabilities (relying on the census 2011) are benefitting from Indira Gandhi National Disability Pension scheme. Even when a person with disability is living in poverty, they are ineligible for this scheme if they lack a disability certificate. Even when families have more than one disabled member, and there are 2 million families of this kind according to the 2011 Census, the additional expenditures caused by the discrimination and barriers faced by families are not taken into consideration while framing social protection schemes, leaving such families in a very precarious situation. Children with disabilities are not eligible for disability pensions. Even for those who are eligible, the disability allowance amount is so meagre that it is difficult to survive with that amount. It does not even cover the poverty line. The Astha report further confirms that the social security measures are very minimalistic for persons with disabilities and those that have been announced are not fulfilled on time. This makes them highly dependent and vulnerable.<sup>88</sup> In many states various announcements have been made but these have not been followed up by implementation. All this has led to utter confusion and exacerbated the situation.

Besides the national pension, some state governments announced advance release of disability pension. Under the Pradhan Mantri Garib Kalyan Yojana Scheme, an ex gratia payment of Rs. 1000 was to be made available to persons with disabilities who were eligible for the scheme. In addition, Rs. 500 per month was to be paid to women who had opened bank accounts under the Jan Dhan Yojana for a period of 3 months.

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<sup>88</sup> Astha (2020) Children and persons with disabilities in a humanitarian crisis of covid-19 in India: Challenges & Strategies.

## Accessing Social Protection Measures

The experience of the participants varied even within the same state. In Odisha, where advance payments of disability pensions were made, a 25-year-old woman participant with low vision, reported that she was handed this amount at her home. Another participant from Odisha, a 33-year-old woman with locomotor disability, stated that she got her advance pension of 4 months and rice as well on two occasions, but no one came to deliver it, and she had to go to two different places to collect it. Both participants were unanimous in reporting that the amount, while welcome, was too meagre. Another participant pointed out the issue with cash transfers to bank accounts:

“The cash is directly transferred to the account of the disabled women; many a times husbands keep the ATM cards and take the money and spend it on alcohol etc. Rather than this, money should be given in cash by home delivery to the person herself.”

A 39-year-old blind woman, Bhubaneswar, Orissa

Some of the state wise experiences have been:

**Assam:** In April, the participant, a 30-year-old woman, received the advance pension (Rs. 1000 per month). She had not received the pension for the month of May.

**Rajasthan:** Pensions were very erratic in general. A woman with locomotor disability from Bikaner informed that every April, eligible persons with disabilities were required to provide proof of their being alive to the authorities, which could not happen because of the lockdown and lack of transportation. Hence pensions were suspended till then.

**Chhattisgarh:** One blind participant reported that she had received only Rs. 600 while the actual pension amount was Rs. 1000.

**Maharashtra:** Eligible participants had experienced delays in receiving pension, and no ex gratia amounts were credited at the time of the interviews.

**Bihar:** Participants reported having to go to the bank to access the cash transfers. A 37-year-old participant with locomotor disability said that because of the closure of public transport her only option was to walk 3 km to the bank, which is why she could not access the amount. One participant reported to have heard from acquaintances who had received the ex gratia amount of Rs. 1000 though she herself had not received it.

None of the 28 women who identified to have been eligible for the PM Garib Kalyan Yojana Scheme ex gratia payment of Rs. 1000 said that they had received this amount. Many participants concurred that the government should plan to make pension available at home along with ration as being disabled women, it was difficult for them to travel with the lack of transport options.

The purpose of social protection programming is precisely to ensure that governments can prevent individuals and their families from falling or remaining in poverty. These programmes also contribute to economic growth by raising labor productivity

and enhancing social stability.<sup>89</sup> Strengthened and comprehensive social protection programming lessens the impact of situations which are exactly like the one we see before us today. A strong social protection scheme which will cover additional costs of disability is crucial to ensure the full and effective participation of persons with disabilities, and for women, specific social protection schemes which are gender responsive both in terms of what they provide and how they are delivered are crucial.

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<sup>89</sup> ILO (2015) Why a social protection floor? Retrieved from: <https://www.social-protection.org/gimi/Show-Theme.action?id=2485>

# Health, Sanitation and Hygiene

## Global and Local Context

Article 25 of the CRPD states that a person with disability should have access to the “highest attainable standard of health without discrimination”. They should be provided the same range, quality, and standard of care, including sexual and reproductive health and population-based public health programs, as other persons. They should be provided with health services needed specifically because of their disabilities, including early identification and interventions, and have access to services designed to minimize and prevent further disabilities; accessible health services near their community. Healthcare providers and professionals should provide persons with disabilities with the same quality of care as accorded to others, and their care should be on the basis of free and informed consent. There should be no discrimination in access to health insurance and life insurance, and no denial of access to health care, health services, food, and fluids on the basis of disability. Many of these rights are mirrored in Section 25 of the RPD Act. These standards lay the foundations for the idea that access to quality, non-discriminatory healthcare is a fundamental right of any person with disabilities. However, even prior to the pandemic, it has been observed that our health care systems in India are both discriminatory and inaccessible for many people with disabilities.<sup>90</sup> Many participants shared that the measures around addressing COVID-19 have built in another layer of barriers for people with disabilities, particularly since the government called upon citizens to not ‘burden the healthcare system’ with routine check-ups and non-essential procedures.<sup>91</sup>

When it came to COVID-19, the emphasis of messaging was that ‘prevention was better than cure’. SDG 3 of the Agenda 2030 relating to healthy lives and well-being also speaks about preventative healthcare and is closely linked to other Goals including SDG 6 relating to clean water and sanitation. The most effective means of preventing the spread or acquisition of COVID-19, through washing one’s hands with soap and water, was lost on many persons with disabilities without access to water supply. Much of the emphasis around preventive measures has been around maintaining personal hygiene – washing hands, wearing masks, coughing into elbows, which are all premised on able bodied individuals who could do all these by themselves. Many people with disabilities are at greater risk of fatal consequences to contracting COVID-19 because of weaker immune systems or pre-existing co-morbid conditions. Many others needed personal assistance for self-care including bathing, toileting and washing hands. The emphasis on reducing physical contact between

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<sup>90</sup> Abidi J (2018) A health care sector that is disability- challenged. BusinessLine. Retrieved from <https://www.thehindubusinessline.com/specials/pulse/a-healthcare-sector-that-is-disabilitychallenged/article9420239.ece>

<sup>91</sup> Ani (2020) Don't burden healthcare system, postpone non-essential surgeries: PM urges citizens. BusinessStandard. Retrieved from [https://www.business-standard.com/article/news-ani/don-t-burden-healthcare-system-postpone-non-essential-surgeries-pm-urges-citizens-120031901712\\_1.html](https://www.business-standard.com/article/news-ani/don-t-burden-healthcare-system-postpone-non-essential-surgeries-pm-urges-citizens-120031901712_1.html)

persons created barriers for persons with disabilities in keeping themselves safe and healthy.<sup>92</sup>

## Higher Risk, Vulnerabilities and Fear

Among all participants there was fear, anxiety and worry around exposure to COVID-19, both for themselves and for their caregivers and family members. Many elderly family members had to venture out to get groceries because of the necessity to not expose disabled people to potential infection. This instilled a lot of fear of losing a loved one and anxiety in participants especially those who needed the support of their family to function, as specifically expressed by participants living in the outskirts of Guwahati.

Even those in cities and areas surrounding these cities such as Gurgaon, Mumbai, Patna, Guwahati, and Chennai who can access hospitals are scared because they are vulnerable to infections or immunocompromised.

“It is challenging to get any blood test done. Firstly, I do not want to go to a hospital to get my test done. I also do not want anyone coming into my home taking my blood for my blood test. I am scared because as patients we have been asked to remain in the same isolation for the next 2-3 months minimum. If I have a medical emergency how am I going to coordinate with my doctor and how am I going to the hospital? How will I handle such situations?”

A 42-year-old woman with scleroderma (wheelchair user), Faridabad, Haryana

Two participants from Mumbai and outskirts of Guwahati shared that they had cancelled their scheduled check-up because of fear of contracting the virus. One other participant from a village near Guwahati was nervous to accompany her mother for her regular check-up due to her cardiac problems.

## Essential and Emergency Medical Services

A participant, who is a professional living alone in Bangalore who has been using a wheelchair after a spinal cord injury, injured her hand one night during the lockdown. She drove to the hospital for treatment. Doctors and nurses immediately addressed her concerns, helped sanitize her wheelchair and escorted her to back to the car. Unfortunately for the majority of participants in this research, their experiences around having to access healthcare during these times were not positive. Despite the advisory to state health departments to ensure priority in treatment of persons with disabilities as envisaged under Section 25 of the RPD Act<sup>93</sup>, many participants spoke about the difficulty in accessing essential treatment - as well as the confusion in hospitals and clinics about what counts as essential.

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<sup>92</sup> Pulrang A (2020) 5 Things To Know About Coronavirus And People With Disabilities. Forbes. Retrieved from <https://www.forbes.com/sites/andrewpulrang/2020/03/08/5-things-to-know-about-coronavirus-and-people-with-disabilities/#64fb50301d21>

<sup>93</sup> PIB Delhi (2020) Treatment of persons with disabilities should be given priority. Retrieved from: <https://pib.gov.in/PressReleaseDetailm.aspx?PRID=1607950>

A few participants from Patna, Bikaner, Raigad, Bhubaneswar, and Mumbai reported that hospitals, especially government hospitals, are prioritizing COVID-19 cases only. They shared that hospitals are not paying attention to patients with other conditions.

"All the government hospitals in our village are only seeing corona patients. Even if we go to them, they will not see us. There are some private hospitals, but they are far away."

A 23-year-old woman with locomotor disability, Raigad, Orissa

As a result, women with disabilities from these locations are forced to spend money for tests which would otherwise have been free at the government hospitals. A couple of the participants – from Bikaner, Rajasthan and from Mahasamund, Chhattisgarh, also spoke of the lack of public transportation during that prevented them from reaching hospitals in emergencies. Having to rely on private cars for transportation to hospitals is just adding to the costs of healthcare in these times.

"My 11-year-old daughter is in extreme pain. There is no female doctor in our village, and Bikaner district is 30 km away. So, we need conveyance to go. The financial condition also is not that strong in this situation. The drivers who used to charge Rs. 1000 to drive to Bikaner, is now charging Rs. 2500. We do not have enough money to take the car and drive to the doctor. My back is in pain. The doctor here did not even see me and told me to go to Bikaner district. We are laborer's who work for a month and manage our homes. So, we used to go via public transport. But now we have to face a lot of problems. And the doctor in our village has switched off his phone. If we visit them personally, then he does not check us. The government should make arrangements for some conveyance, because even the ambulance was not ready to take [my daughter]. They are only attending to Corona patients."

A 38-year-old woman with locomotor disability, Bikaner, Rajasthan

For people living with Thalassemia, which is a specified disability under the RPD Act, hospital beds and blood transfusion have been difficult to access.<sup>94</sup> Families are forced to move from one hospital to another to ensure the essential medicine is accessible. Others with debilitating conditions also had trouble accessing essential medicinal services at hospitals.

Several participants from cities like Mumbai, Delhi, Hyderabad, Kolkata, and Bengaluru are unable to consult specialists such as physiotherapists, pain specialists, occupational therapists, gynecologists, ophthalmologists, audiologists. Rehabilitation services can be essential for enabling persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full

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<sup>94</sup> Chitlangia, R. (2020) Covid crisis: Thalassemia patients struggle to find hospital beds, blood for transfusion. Hindustan Times. Retrieved from: <https://www.hindustantimes.com/delhi-news/covid-crisis-thalassemia-patients-struggle-to-find-hospital-beds-blood-for-transfusion/story-04oPG2iwwzxSp7FOHJfQ7H.html>

inclusion and participation in all aspects of life.<sup>95</sup> Facilitating access to quality assistive devices is essential to promote personal mobility.<sup>96</sup>

“I do have requirement for physiotherapy because my muscles are weak. But in this lockdown, I have not been able to visit physiotherapists because institutions are prioritizing patients in emergency situations and serious patients. Either I need to shell out huge amounts of money to call a physiotherapist home or wait for lockdown to end to avail physiotherapy from government run clinics.”

A 54-year-old woman with locomotor disability, Ghaziabad, Uttar Pradesh

Two participants - one from Mumbai city and the other from Ratlam district in Madhya Pradesh – had narratives about their assistive devices and response of the officials at the city and district level. Both of them needed urgent intervention for their assistive devices. The lawyer from Mumbai could not visit her doctor when her prosthetic broke due to lack of public transport. She used social media to seek help and the Mumbai Police got in touch with her immediately and provided her with transportation. A lady constable also accompanied her to the clinic, spent the full day with her, ensured she received the physiotherapy she needed and dropped her back home after the check-up.

While this was a positive experience, all experiences were not the same. For the woman in Ratlam, her calliper broke at 9pm. She messaged the collector and requested for a volunteer to help her. The collector responded with support of a man from operations who called her and gave her an address to go to get her callipers fixed. However, without any transportation and assistive support, she had no means to reach that address. Finally, she managed to fix it by going to the address by herself. Ever since, she has been rallying volunteers to provide support to other disabled people in the district.

While some women with disabilities, from cities like Jaipur, Patna, Delhi, and Mumbai, have been able to consult their doctors online or via the telephone; not all doctors were available for such consultations over phone or video call.

One participant felt that that not all medical emergencies can be dealt with remotely. In some cases, the doctor will need to observe the patient to make a diagnosis or prescribe medicines.

A participant from Mumbai shared about the difficulties of tele consulting when it comes to gynecological problems or with respect to sexual and reproductive services. She raised privacy concerns when you have to discuss private and intimate details via a telephone or through digital conversations.

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<sup>95</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 26. Retrieved from <https://www.refworld.org/docid/45f973632.html>

<sup>96</sup> UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, Article 20. Retrieved from <https://www.refworld.org/docid/45f973632.html>

## Quarantine Centers and Women with Disabilities

A blind woman in Mumbai who had contracted COVID shared her experience of inaccessibility in the hospital, in a media report. Since the facility lacked the resources required for the specific access needs of the disabled, she had to sometimes rely on other patients for even using the bathroom.<sup>97</sup>

One of the concerns raised by three participants from Kolkata, Chittorgarh in Rajasthan and Mumbai was: how will d/Deaf people/hard of hearing people communicate if they are tested positive? The use of PPE by medical professionals has made lip reading impossible. There are no interpreters. This fear compounded with growing isolation from conversations and everyday interactions that enabled community integration has many d/Deaf and hard of hearing people struggling.

“I worry that if I were to get hospitalized in this situation, I wouldn’t be able to hear the doctors and the nurses.”

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

## Medication and Healthcare Products

“Because of the inaccessible stores, we cannot go by ourselves. If the attendant cannot take us, then we will not get medicines. This is also a concern.”

A 37-year-old woman with locomotor disability, from Ratlam, Madhya Pradesh

Seven participants from Mumbai, Gurgaon, Hyderabad, a small town in Jharkhand, Bhubaneswar, from a village in Bikaner district and Chittorgarh district in Rajasthan highlighted the lack of access to necessities such as medicines, products required for menstrual hygiene, sanitizers, assistive devices such as hearing aid, batteries for hearing aid, gloves for arthritis, and adult diapers. While some of them were unable to access it because of lack of availability, some others were unable to access it because they could not step out of their home because of their heightened vulnerability. Two participants living in villages also shared that sanitizers are expensive and hard to access in small stores.

Many women with disabilities in urban areas, small towns and in villages reported having to seek support from family, friends, domestic help, and neighbours to enable access to healthcare and healthcare products. In other cases, in Mumbai and Hyderabad, women with disabilities had to rely on long standing relationships with their chemist to get easy access to their medicines. In contrast, participants from Bikaner and Chittorgarh district in Rajasthan were forced to travel to cities to get access to medicines. The distance from a city, the access to internet connections, the knowledge of services/people who can provide services and social media platforms played a role in determining access to essential services.

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<sup>97</sup> Dhupkar A (2020) Blind Covid patient’s ordeal exposes dearth of facilities for the disabled. Mumbai Mirror. Retrieved from: <https://mumbaimirror.indiatimes.com/coronavirus/news/blind-covid-patients-ordeal-exposes-dearth-of-facilities-for-the-disabled/articleshow/76487257.cms>

Affordability is also a huge concern, especially in situations where medication is not covered through insurance and incomes have taken a hit.

“Women having auto immune disorders and those on regular medication might have to compromise on their health issues due to less money at their disposal.”

A 42-year-old woman with scleroderma (wheelchair user), Faridabad, Haryana

## Menstrual Hygiene

Menstruation and discussions around menstrual hygiene is still a taboo in our society. Many of these products, sanitary pads, napkins, tampons etc. are inaccessible to many in rural India.<sup>98</sup> When the first phase of lockdown started, the government failed to add menstrual products in the list of essential services.<sup>99</sup> While it was subsequently changed, due to sudden and abrasive closure of economy and transportation, many women were left with no supply at home<sup>100</sup>. Girls who depended on their schools for free menstrual products have been deprived of that support system.<sup>101</sup> This is also true for women with disabilities.

Two participants in villages in Mahasamund, Chhattisgarh shared that their nearest pharmacies had ran out of supplies. One of them said that women with disabilities are forced to use cloth which was adversely affecting their health as it was hard to maintain hygiene while washing the cloth by themselves.

Several others living in cities shared that they had to seek help from family members or neighbours to purchase these products for them. One participant with locomotor disability in Raigad, Orissa shared that she would have had to travel 10 km to buy pads and hence has asked her mother to buy them for her. Another participant from Bangalore shared that as she lives only with male family members, she was hesitant to access their help.

“I usually have a habit that every month I get all the cosmetics and sanitary pads ready. But because of the sudden lockdown these things were not planned. This was also a worry because I stay with my father and brother and I am a little hesitant to ask them, so I order online. Luckily, I had the contact number of a medical store because I go regularly to him, so it was very helpful for me.”

A 34-year-old woman with low-vision Bangalore, Karnataka

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<sup>98</sup> Gopalan, M. (November 2019) Less than 20% menstruating girls & women in India use pads. Here's how to overcome barriers, The Print. Retrieved from: <https://theprint.in/health/less-than-20-per-cent-menstruating-girls-women-in-india-use-pads/317570/>.

<sup>99</sup> Krishnan, M. (2020) Women in India suffer as Covid-19 lockdown hits sanitary pads supply. RFI. Retrieved from: <http://www.rfi.fr/en/international/20200524-asia-india-coronavirus-women-health-sanitary-napkins-supply-chain-lockdown-migrants-charity>

<sup>100</sup> Shukla, I. (2020) With No Clear Govt Order, Production Of Sanitary Pads Stops Cos Apparently They Aren't 'Essential'. Scoopwhoop. Retrieved from: <https://www.scoopwhoop.com/news/production-of-sanitary-pads-stops-during-lockdown/>

<sup>101</sup> BBC News (2020) Coronavirus sparks a sanitary pad crisis in India. Retrieved from: <https://www.bbc.com/news/world-asia-india-52718434>

## Water Access and Toilet Access

In many areas especially in rural India where there is water scarcity, washing of hands, a recommendation by WHO to prevent COVID-19, is not always possible. One participant from a village in Orissa said that there was limited water supply in their villages while another shared that water supply was not regular in her area which was “forcing her and others to purchase water”. Even news reports of interviews with people with disabilities during the pandemic discusses the difficulties of needing to minimize physical contact by not taking assistance which for many who use wheelchairs or need to be lifted to use the wash basin to wash their hands<sup>102</sup> which brings up the issue of accessibility of toilets and handwashing facilities, which has been facilitated under the Swachh Bharat Mission in both rural and urban spaces.

While there are guidelines on accessibility of these toilets and mandates for accessible toilets in community complexes, outreach and specific targeting and inclusion of women with disabilities is extremely important particularly because the lack of accessible toilets disproportionately impacts health and hygiene of women and girls with disabilities.

The understanding of health and hygiene has been reimaged in the aftermath of this pandemic and with new information coming forth on the spread and effect of the Coronavirus there is a need to ensure that people with disabilities particularly women are not left behind, and at the same time are able to continue to access healthcare related essential services. The accessibility of healthcare related communications and services for persons affected or suspected to affected by the COVID-19 need to immediately have protocols ensuring full accessibility and dignified experience.

There are multiple reports of the costs of the lockdown on the general population having access to healthcare services like vaccinations<sup>103</sup>, check-ups and follow up treatments<sup>104</sup> and cancer screenings.<sup>105</sup> The framing of the state obligation in the post COVID-19 era to ensure access for persons with disabilities to health services and interventions designed to minimize and prevent further disabilities is also important and the impact of the lockdown on the non-COVID-19 health concerns of persons with disabilities needs to be fully addressed and prioritized.

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<sup>102</sup> Narayanan, J. (2020) Pandemic and a lockdown: Persons with disabilities grapple with more challenges. The Indian Express. Retrieved from: <https://indianexpress.com/article/lifestyle/life-style/persons-with-disabilities-day-to-day-challenges-coronavirus-covid-19-lockdown-pandemic-handwashing-social-isolation-distancing-6383363/>

<sup>103</sup> IANS (2020), Over 80 million children at risk as Covid-19 disrupts routine vaccination Retrieved from: <https://www.livemint.com/news/world/over-80-million-children-at-risk-as-covid-19-disrupts-routine-vaccination-11590201592805.html>

<sup>104</sup> Singh P. (2020) Non COVID-19 patients are paying the price of India’s efforts against the Coronavirus Retrieved from: <https://science.thewire.in/health/healthcare-non-coronavirus-patients/>

<sup>105</sup> The Lancet (2020) Lockdown poses new challenges for cancer care in India Retrieved from: [https://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045\(20\)30312-0.pdf](https://www.thelancet.com/pdfs/journals/lanonc/PIIS1470-2045(20)30312-0.pdf)

# Education

## Global and Local Context

Education is considered to be the most significant area in human development and the one which brings the most potential for transformation of both the individual and society. The quality of education provided, and the importance given to it in a given society would determine the social fabric and the developmental level of that society. Historically viewed as welfare recipients, persons with disabilities are now recognized under international law as rights holders with a claim to education without discrimination and on the basis of equal opportunities.<sup>106</sup> This has taken a long journey, the progress and understanding and evolution of inclusive education from the 1990 World Declaration on Education for All in Jomtien, Thailand to the 2015 Incheon Declaration on Education 2030 towards inclusive and equitable quality education and lifelong learning for all.<sup>107</sup> The framing of the right of all children with disabilities to inclusive education is seen in Article 24 of the CRPD and was further elaborated by the General Comment No. 4 on the right to inclusive education.<sup>108</sup> Inclusive education is no longer something meant only for students with disabilities.<sup>109</sup> The evolution of the understanding of inclusive education is that it is no longer seen to be a disability specific policy though the broader vision of inclusion in education of all learners is still largely lacking in legislation worldwide.<sup>110</sup> This may be a key in addressing a system that is deeply facing a 'crisis of learning'.<sup>111</sup>

In India, national policies on education for all largely followed the mandates under international law and political commitments, with the enactment of the Right of Children to Free and Compulsory Education Act in 2009 which was preceded by the recognition of the right to free and compulsory primary education as a fundamental right in 2002.<sup>112</sup> The Sarva Shiksha Abhiyaan programme was developed to ensure

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<sup>106</sup> General Comment No. 4 (2016) on the Right to Inclusive Education CRPD/C/GC/4

<sup>107</sup> UNESCO (2015) Incheon Declaration and Framework for Action. Retrieved from: [http://uis.unesco.org/sites/default/files/documents/education-2030-incheon-framework-for-action-implementation-of-sdg4-2016-en\\_2.pdf](http://uis.unesco.org/sites/default/files/documents/education-2030-incheon-framework-for-action-implementation-of-sdg4-2016-en_2.pdf)

<sup>108</sup> General Comment No. 4 (2016) on the Right to Inclusive Education CRPD/C/GC/4

<sup>109</sup> International Disability Alliance (2020) What an inclusive, equitable, quality education means to us. Retrieved from: [http://www.internationaldisabilityalliance.org/sites/default/files/ida\\_ie\\_flagship\\_report\\_29.06.2020.pdf](http://www.internationaldisabilityalliance.org/sites/default/files/ida_ie_flagship_report_29.06.2020.pdf)

<sup>110</sup> UNESCO (2020) Global Education Monitoring Report, "All means All". Retrieved from: [https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef\\_0000373718&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach\\_import\\_1ed46d67-eda4-437b-b054-7777e8743ffe%3F\\_%3D373718eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000373718/PDF/373718eng.pdf#%5B%7B%22num%22%3A737%2C%22gen%22%3A0%7D%2C%7B%22name%22%3A%22XYZ%22%7D%2C-1%2C794%2C0%5D](https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef_0000373718&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach_import_1ed46d67-eda4-437b-b054-7777e8743ffe%3F_%3D373718eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000373718/PDF/373718eng.pdf#%5B%7B%22num%22%3A737%2C%22gen%22%3A0%7D%2C%7B%22name%22%3A%22XYZ%22%7D%2C-1%2C794%2C0%5D)

<sup>111</sup> World Bank (2018) Learning to Realize Education's Promise: World Development Report. Retrieved from: <https://www.worldbank.org/en/publication/wdr2018>

<sup>112</sup> The Indian Constitution, Article 21-A

universal enrolment and also provided for a financial component to ensure reasonable accommodation of students with disabilities. This scheme is subsumed under the Samagra Shiksha Abhiyaan.<sup>113</sup>

The RPD Act gives students with benchmark disabilities the right to free education till the age of 18 either in a neighborhood school or in a special school.<sup>114</sup> While education in general is governed by the Ministry for Human Resource Development, special schools for students with disabilities are under the Department of Empowerment of Persons with Disabilities. Any certification obtained in these schools are not considered equivalent to completing the national or state curriculum and so most children with disabilities in these schools are enrolled in National Institute of Open Schooling (NIOS). In 2012, the Right to Education Act was amended to include children with disabilities under the category of 'disadvantaged group' who were included and allow students with multiple or severe disabilities the right to home based education which perpetuates exclusion and in most cases, services do not reach families.<sup>115</sup> For other children with disabilities the RPD Act provides for various provisions for reasonable accommodations and adaptations in schools.<sup>116</sup> However as seen in the UNESCO report on the state of education and children with disabilities in India there are great disparities in enrolment and in dropout rates of students with disabilities.<sup>117</sup>

The impact of the COVID-19 lockdown on children and families across the world has been an issue and there is enough and more research to support the view that efforts to maintain learning continuity may exacerbate exclusion<sup>118</sup> and this is true in India as well.<sup>119</sup> We organized a focused call to discuss the impact of the lockdown on the education of girls and young women with disabilities in India with different stakeholders in the education system.

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<sup>113</sup> Ministry of Human Resource Development (2019) Samagra Shiksha. Retrieved from: <http://samagra.mhrd.gov.in/>

<sup>114</sup> RPD Act (2016) Section 31

<sup>115</sup> CRPD (2008) Parallel Report

<sup>116</sup> RPD Act (2016) Sections 16 to 18

<sup>117</sup> UN (2019) N for Nose: State of the Education Report for India 2019: Children with Disabilities. Retrieved from: [https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef\\_0000368780&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach\\_import\\_7f18081f-fd62-4e19-946f-8a838af0f2da%3F\\_%3D368780eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000368780/PDF/368780eng.pdf#%5B%7B%22num%22%3A76%2C%22gen%22%3A0%7D%2C%7B%22name%22%3A%22XYZ%22%7D%2C34%2C794%2C0%5D](https://unesdoc.unesco.org/in/documentViewer.xhtml?v=2.1.196&id=p::usmarcdef_0000368780&file=/in/rest/annotationSVC/DownloadWatermarkedAttachment/attach_import_7f18081f-fd62-4e19-946f-8a838af0f2da%3F_%3D368780eng.pdf&locale=en&multi=true&ark=/ark:/48223/pf0000368780/PDF/368780eng.pdf#%5B%7B%22num%22%3A76%2C%22gen%22%3A0%7D%2C%7B%22name%22%3A%22XYZ%22%7D%2C34%2C794%2C0%5D)

<sup>118</sup> UNESCO (2019) Global Education Monitoring Report, "All means All" p. 58

<sup>119</sup> Kulkarni, S. (2020) Push for e-learning raises questions about accessibility. Retrieved from: <https://www.deccanherald.com/specials/insight/push-for-e-learning-raises-questions-about-accessibility-841217.html>

## **School Education**

Accounts relating to the experience of children with disabilities in school were led by educators based in various parts of the country, including a special educator working in inclusive schools in Chennai, a Ph.D. student working with students with visual disabilities, and special educators working in special schools. They raised the following issues:

- Although the lessons are relayed through online method, accessibility of various online platforms is a huge challenge, and awareness of gadgets that enable student participation is another challenge.
- Internet connectivity and phone signals are a challenge preventing longer calls. This greatly hinders teaching of lessons efficaciously. Teaching is mostly done through conference calls or online platforms.
- There is lack of sensory and tactile inputs which is important for children require that support, and while they can receive that in an inclusive classroom it is almost impossible to give the same in online environment. This made it difficult for them to teach difficult concepts to blind students, though they have tried to do so with a mix of braille textbooks and conference calls.
- Autistic and ADHD students have difficulties with overstimulation due to bright screens, surrounding noise etc. Some children are also impacted due to constant camera glare in a video classroom.
- Multi-sensory learning cannot take place online and the teachers cannot pay individual attention. Individualized need-based learning is missing, and experiential learning is almost impossible. This is especially relevant while teaching math and science, where practical are next to impossible.
- Teacher training does not include addressing the problem of children with disabilities especially in this time of crisis. This places the burden on special educators Even when in school, there is little inclusion in classrooms and students are highly dependent on the special educators.
- Parents are unable to support the online education of their children as often they themselves have limited education or exposure and in many cases they cannot provide a child with a smart phone or other device, nor are they aware of the accessibility features.

Many children with disabilities need regular access to physical therapy and rehabilitation. Home visits of rehabilitation professionals are presently out of the question, and participants shared that right now therapists and teachers are limited to WhatsApp video calls to help the disabled children. This does not yield a desirable result.

## **Education for Students with Disabilities in Kashmir**

As pointed out by a disabled activist based there, students with disabilities in Jammu and Kashmir have a unique difficulty. Children with disabilities have had no access to education for almost a year. They had a state-imposed internet shut down for a long time and 2G services have been restored for just the last 3 months. Although schools for non-disabled children have started virtually, disabled children who have yet not been included in the mainstream education system are still excluded. Most

of them belong to poor families lacking access to smart phones. There are also difficulties for children with high support needs due to this situation.

## College/Higher Education

There are 74,435 students with disabilities enrolled in various universities across the country<sup>120</sup>. Their access to education in the present era has been hit with several barriers. A deafblind woman who studies in Delhi pointed out the inaccessibility of online classes where teachers just give lectures and talk. She requires a family member to sit next to her throughout class to ensure she can catch a little bit about what is being told in the classroom.

"No special assistance, no captions or text are shared. Most of the assignments are PDFs scanned and sent which mean someone needs to read out to me."  
A 20-year old Deafblind college student, Delhi

Since, she had some hearing, extra support from family members allowed for listening and understanding assignments. However, she also spoke of how the continuous usage of phone for study led to technological fatigue. She was of the opinion that "captioning and transcription should be mandatory of any online study programme".

While there is an increased reliance on self-study of materials, a professor from Hyderabad who is also blind reported that there is difficulty in getting material for reading as many of the soft copies are not accessible for students or they are used to a particular software that is not compatible with these materials. There is little flexibility and no holistic approach in various government schemes to provide assistive devices. Also, there is lack of awareness on the general public regarding the legal requirement for documents to be readable for the print disabled, leading to confusion.

## Teachers with Disabilities

School teachers, university lecturers and professors with disabilities had to quickly adapt to the new normal of teaching, but they had to encounter several barriers because the understanding of online teaching was not inclusive of their needs. A blind lecturer at a central university in Gujarat spoke of a discomfort with video calls and the issues caused as she was not given any preparation to use various apps.

"There was complete apathy towards teachers with disabilities. here was absolutely no provision for training them with new platforms and hence they had to figure it out for themselves and negotiate the situation. The intermittent disturbances while using the platform impacted on students' interest in the classes as well."  
A 35-year-old blind university lecturer, Gandhinagar, Gujarat

According to the professor from Hyderabad, in some universities some training gaps for lecturers were identified, and it was felt that if there are special enabling units

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<sup>120</sup> Kulkarni, S. (2020) Push for e-learning raises questions about accessibility. Retrieved from: <https://www.deccanherald.com/specials/insight/push-for-e-learning-raises-questions-about-accessibility-841217.html>  
<https://www.deccanherald.com/specials/insight/push-for-e-learning-raises-questions-about-accessibility-841217.html>

they could be harnessed in this task. Even organizations that have expertise could be roped in to assist the faculty in this regard. However, in most cases teachers were left to fend for themselves leading to a lot of anxiety. There was a lot of anxiety both amongst teachers and students with disabilities.

A sign language interpreter and trainer from Pune, who has a Deaf brother who is a teacher, said that in case of Deaf teachers they were already using technology so it was slightly easy for them but they had other difficulties caused by the insensitivity of their colleagues. Hearing teachers sometimes did not co-operate or used audio medium to communicate leaving Deaf teachers highly dependent on some help from hearing people. Further, many hearing teachers were not proficient in sign language and that caused additional burden on Deaf teachers to interact with Deaf children. She also shared that Deaf teachers face difficulties in interacting with parents since parents often sent voice notes.

## **Abuse, Discrimination, and Gender Bias at Home**

The teachers and special educators pointed to the role of schools and teachers as safe spaces for children to discuss their problems and how that has been compromised with the lockdown. As the special educator from Chennai explains:

“In normal times if there were any abuse children shared it with teachers as trusted adults but in these times, they are inhibited since parents are around. Even where counselling is required, it became impossible to do it use virtual medium and also there is no confidentiality.”

A 37-year-old who is a special educator working in Chennai, Tamil Nadu

While discussing discrimination amongst children, she also observed that there is also discrimination between nondisabled and disabled siblings. Disabled siblings are not given priority and they are only given access to smart phones and other gadgets late in the evenings when there is a lot of disturbance. Even when lessons are given to disabled and nondisabled children, disabled children's lessons are given much less importance as compared with their nondisabled siblings.

The sign language trainer from Pune pointed out that there is also gender bias in that girls are expected to complete household work and then attend to their school-work which hinders their study time. This restriction is not put for boys who are not engaged in household chores.

## **Assessments and Future Prospects**

All students that participated expressed fear regarding continuing their education and opportunities that they could get. One of the participants is a young blind college student who studies in Delhi but had to go back home to Guwahati halfway through her semester.

“I am now worried about my masters and the opportunities that will follow. It is very uncertain.”

A 21-year-old blind woman from Guwahati (studying in Delhi)

Students were also apprehensive as their exams were incomplete or whose preparation for competitive examination was interrupted. A student living with locomotor disability who was preparing for competitive exams in Chittorgarh district Rajasthan, expressed great concern and was scared that this lockdown may ruin her career.

The diversity of participants in this research show the discrimination and barriers to education that are proving to be a great challenge for both disabled students as well as disabled teachers/professors. The potential of education to change the trajectory of the lives of youth with disabilities is severely under threat. At the same time, the use of inclusive and accessible ICT has the potential to revolutionize classrooms for children with disabilities. As the lockdown is lifted and the education term begins, a collective effort must go into reimagining of safe and inclusive education. We must also examine what the right to education means in the reality of a digital divide which is even more stark when it comes to young women and girls with disabilities.

# Employment and Livelihood

## Global and Local Context

Women with Disabilities value their economic independence as quite an essential aspect of their lives. According to the International Labor Organization, globally less than 20% of people with disabilities have some source of income.<sup>121</sup>

In general, persons with disabilities face difficulties getting into the labor market, but, seen from a gender perspective, men with disabilities are almost twice as likely to have jobs than women with disabilities. Women with disabilities often experience inequality in hiring and promotion standards, access to training and retraining, access to credit and other productive resources, pay for equal work and occupational segregation. They hardly participate in decision making in financial matters.<sup>122</sup>

According to the Census of 2011 data, the unemployment rate of women with disabilities was 77.4 % as opposed to 52.8% among men with disabilities. This shows that majority of women with disabilities are out of the job market or lack livelihood prospects. The Social Statistics division, Ministry of Statistics and Program Implementation reports on employment status of persons with disabilities; however, it lacks gender disaggregated data hence it does not reflect number of women with disabilities.<sup>123</sup>

According to the Survey of Persons with Disabilities conducted by the National Statistical Office (NSO) India in December 2018, Labor Force Participation Rate among women with disabilities was 8% versus 36.8% for men with disabilities.<sup>124</sup> Most women with disabilities find that self-employment and working in the unorganized sector are often the only option.<sup>125</sup>

Article 27 of the CRPD reinforces the right of all persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labor market and to a work environment that

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<sup>121</sup> Handicap International (2016 September) Situation of wage employment of people with disabilities: country profiles. Retrieved from [https://d3n8a8pro7vhmx.cloudfront.net/handicapinternational/pages/1479/attachments/original/1480713329/EmploymentWhitePaper-WEB\\_Dec2.pdf?1480713329](https://d3n8a8pro7vhmx.cloudfront.net/handicapinternational/pages/1479/attachments/original/1480713329/EmploymentWhitePaper-WEB_Dec2.pdf?1480713329)

<sup>122</sup> Arthur O'Reilly. IFP/Skills Working Paper No. 14. International Labour Organization 2003. Employment Barriers for Women with Disabilities in The Right to Decent Work of Persons with Disabilities.

<sup>123</sup> Submission of Alternative Report (Article 6) To the Committee on the Rights of Persons with Disabilities : India (2019) Women with Disabilities advocate for their Rights in Geneva. Retrieved from <https://commonwealthfoundation.com/author/wdin/>

<sup>124</sup> C-23 Table Disabled Population by Main Workers, Marginal Workers, Non-Workers By Type Of Disability, Age And Sex- (India & States/UTs) – Survey of Persons with Disabilities by National Sample Survey, December 2018. Retrieved from [http://censusindia.gov.in/2011census/population\\_enumeration.html](http://censusindia.gov.in/2011census/population_enumeration.html)

<sup>125</sup> The Wire (7<sup>th</sup> June 2019): What Work Choices are Indian Women Making And Why – by Monika Banerjee. Retrieved from <https://thewire.in/women/indian-women-work-care-informal-sector>

is open, inclusive and accessible to persons with disabilities.<sup>126</sup> Indian legislation is well formulated with specific directives for employment related rights for all persons with disabilities. The RPD Act states that the government should facilitate and support employment of persons with disabilities especially for their vocational training and self-employment.<sup>127</sup> though government data reveals that only 1.4% of persons with disabilities reported receiving formal vocational training and 1.7% had been trained on other than formal vocations".<sup>128</sup>

The RPD Act also mandates establishments, both public and private, to provide reasonable accommodation and appropriate barrier free and conducive environment to employees with disability, including through the adoption of Equal Opportunity Policies. The Act also provisions for 4% reservation for certain categories of persons with benchmark disabilities in Government employment without any mandate for inclusion of women with disabilities in this.

The Mahatma Gandhi National Rural Employment Guarantee Scheme is the most important scheme in India regarding the right to work. The scheme provides minimum 100 days of employment in a year to one adult per qualifying household to work as unskilled manual labor. Despite the 4 percent reservation for persons with disabilities in poverty alleviation schemes, measures were not taken for their inclusion in MGN-REGS.<sup>129</sup> Only 0.59% of the total individuals who worked were people with disabilities in the year 2018-19,<sup>130</sup> and a 2011 study revealed that many persons who were reported to be blind/low vision availing of the scheme were actually sighted.<sup>131</sup>

## The Impact of the Lockdown

For women with disabilities, like many others, their access to work and livelihood on account of the lockdown have been adversely affected leading to financial instability.

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<sup>126</sup> United Nations Convention on Rights of Persons With Disabilities, 2008

<sup>127</sup> Right of Persons With Disabilities Act, 2016

<sup>128</sup> NSS Report 583 (July – December 2018) Retrieved from [http://www.mospi.gov.in/sites/default/files/publication\\_reports/Report\\_583\\_Final\\_0.pdf](http://www.mospi.gov.in/sites/default/files/publication_reports/Report_583_Final_0.pdf)

<sup>129</sup> INCLUSION OF PERSONS WITH DISABILITIES UNDER MGNREGS : A STUDY ACROSS THREE STATES – by Dr K.P. Kumaran for National Institute for Rural Development (January 2013). Retrieved from [http://nird-pr.org.in/nird\\_docs/rss/RS%2094.pdf](http://nird-pr.org.in/nird_docs/rss/RS%2094.pdf)

<sup>130</sup> Employment Scenario of People with Disabilities in India 20 Years of The Disability Act, 1995 (published in November 2015) By Ankit Rajiv Jindal and Rama Chari from Diversity and Equal Opportunity Centre (DEOC) For National Centre for Promotion of Employment for Disabled People (NCPEDP). Retrieved from <https://www.deoc.in/wp-content/uploads/2018/03/White-paper-on-Employment-updated-27-Nov.pdf>

<sup>131</sup>All India Confederation of the Blind (2011) INCLUSION OF THE VISUALLY IMPAIRED IN REPRESENTATIVE EMPLOYMENT ORIENTED GOVERNMENT SCHEMES—AN IMPACT STUDY Retrieved from <http://www.aicb.org.in/images/aicbAtAGlance/Inclusion%20of%20the%20Visually%20impaired%20an%20impact%20study.doc>

50% of the respondents reported to have issues and challenges on account of their access to work and livelihood. The majority of the participants in this research either had a job or were self-employed - except for 8 women who were unemployed at the time. The women who participated in this study were working in corporates, NGOs, schools, banks, as Anganwadi workers, government offices, as domestic helps or engaged in self or group entrepreneurship like tailoring, handicrafts, etc. Their experiences were similar and sometimes starkly different owing to the factors like whether they were from a rural or urban area and the nature of their disability and work. Losing their livelihoods and jobs was observed to be the most common concern that all these women had. Earning a living brings with it sense of pride, independence, and dignity for women with disabilities, therefore sustaining it is most essential for them. Working provides an opportunity for people with disabilities to prove that they can contribute to and participate in society<sup>132</sup> which leads to improved self-esteem and capacity to socialize with other people.

## **Working from Home**

Some of the women reported the issues of balancing work and home life that have become very challenging. As they do not have any domestic help, they have to manage all the household work, take care of children, elderly and sick family members and attend to job responsibilities.

“Few friends (with disabilities) have told me they don’t get even a single minute to spend on themselves, because there is so much work - they are working like a machine. And they cannot even quit because that is their own home. As a woman all the responsibility comes to them, the family members are not helping.”

A 42-year-old woman with scleroderma (a wheelchair user), Faridabad, Haryana

Many persons with disabilities have organized their workspaces including procurements of furniture at their offices which helps them to work with comfort. This is not available to them at home and the sudden nature of the lockdown meant that there could be no transition to home with similar supports. As narrated by a participant with low vision from Bangalore:

“The ergonomics is not working for me as in the office we had very flexible chairs, the table would be the right height, I could hold my laptop any way I wanted. Right now, I find it very difficult for me. My brother had to order a flexible table for me finally, so with that I am able to manage. But initially I had lot of back pain because of this problem.”

A 34-year-old woman with low vision, Bangalore, Karnataka

## **Access to technology**

25 women – all with locomotor disability - from rural Rajasthan, Bihar, Jharkhand, Chhattisgarh, Madhya Pradesh, Maharashtra, and Orissa reported not having computers at home and good quality internet connection. Since the lockdown was an-

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<sup>132</sup> Handicap International (June 2011) – Policy Paper on Inclusive Employment. Retrieved from [http://d3n8a8pro7vhmx.cloudfront.net/handicapinternational/pages/266/attachments/original/1369073561/Livelihoods\\_InclusiveEmploymentPaper.pdf?1369073561](http://d3n8a8pro7vhmx.cloudfront.net/handicapinternational/pages/266/attachments/original/1369073561/Livelihoods_InclusiveEmploymentPaper.pdf?1369073561)

nounced suddenly, they have been finding it difficult to perform official tasks just through their smart phones with intermittent internet connectivity.

The 11 women who were Deaf or hard of hearing expressed that they found it very challenging to work from home. Few offices used captions as a form of accessibility in meetings.

“During physical meetings and face-to-face interactions, lipreading was easier, but with so many people on the call, it was very time consuming and tiring to lip read and understand what people were saying. Also, many colleagues were not considerate enough to keep their videos on all the time or speak slowly. Due to this, I missed a lot of content discussed during meetings and could not participate.”

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

She also shared about the power dynamic she is experiencing with her colleagues who do not have disabilities.

“At work my manager is aware [that I am hard of hearing], but everyone else doesn’t know. For me physical presence and reading the lips matter a lot. The lockdown has been a disaster. For those of us who depend on lip reading, it is exhausting. We spent so much time reading the room, by the time we have grasped the conversation we are exhausted. There are so many calls I have to attend. I do not know whether I would be working or not. No one turns on the video. When they talk fast, I totally lose track of the conversation. At the end when they say “we decided this” - I just agree. Later I call a colleague and to find out what I actually signed up for. I cannot tell them to slow down in all meetings. In person it is easier to follow, but virtually, it is impossible. I have communicated this to my manager. I have requested them to speak slowly.”

A 35-year-old woman who is hard of hearing, Mumbai, Maharashtra

The four deafblind women found it difficult to access virtual platforms. With the upgrades to apps and software, it became even harder to get acquainted with the interface and manage work around it.

“It has been very exhausting for me to work on my computers or phone with my limited vision for long hours, as it stresses my eyes and I have a constant headache because of that.”

A 26-year-old deafblind woman, Ahmedabad, Gujarat

Another participant from Chennai who is hard of hearing, shared that she had just joined a new job and adapting to remote working without any guidance was a bit tough.

## **Experiences of Working in the Unorganized Sector**

Nine women respondents from rural areas of Rajasthan, Chhattisgarh, and Madhya Pradesh - all with locomotor disabilities - who were running small businesses talked about the difficulties they have been facing due to the lockdown. Many participants reported a complete loss of income. A participant from rural Rajasthan, who used to take coaching classes said that her work has stopped completely, and she had to borrow money to run the household.

"I have a sewing shop but due to the lack of customers, I am not able to make ends meet."  
A 24-year-old woman with locomotor disability, Chhattisgarh

"I used to sell banana leaves, but now since the shops are closed, it has really affected our business."  
A 35-year-old woman with locomotor disability, Betul, Madhya Pradesh

A 26-year-old participant from rural Rajasthan who had a locomotor disability and worked as domestic help also expressed concern over lack of finances due to discontinuation of her work.

Even as many participants contemplated a difficult present, others have started afresh as the lockdown is beginning to lift.

"At the beginning of the lockdown, livelihoods seem to be getting affected, but now we have been able to form a Self-Help Group (SHG) and are getting orders for masks regularly. That is working well for us."  
A 24-year-old woman with locomotor disability, rural Rajasthan

Six respondents from Rajasthan, who were part of SHGs, and one respondent from Orissa (independently with her husband) – all with locomotor disability, have taken the lead proactively to take orders to make masks. Two of them even reported that they made and donated masks to their communities free of cost sometimes. However, one of the participants- reported there were issues with this as well.

"About the mask making – that work is available, but we are expected to come collect the cloth to make it and go deliver the masks also on our own. How will that happen in lockdown? Also, about the work under NREGA is a couple of kilometers away. So disabled people, those walking with one leg – how will they go work?"  
A 45-year-old woman with locomotor disability, Sirohi district Rajasthan

## **Issues of Mobility and Sustainability**

With an economic crisis looming on the horizon, participants foresee that there would be downsizing of staff and within that, women with disabilities would be the ones to be laid off first. Losing their jobs, having no / irregular income, not getting business, uncertainty about resuming their entrepreneurship, losing the sense of pride and dignity that came with financially supporting the family were some of the things that women felt anxious about. It was also expressed that not having a regular source of income starts effecting other aspects of life as well.

Five women said either they themselves or other disabled women they knew of have either been told not to come to work, or not given new assignments or had their salaries discontinued by the employers. This has resulted to lack of finances, as the pension amount was inadequate even for buying food and other essential supplies. One of the Deaf participants spoke of a woman in her twenties with hearing disability who used to work in a grocery store in Delhi. She stopped going to work during the lockdown. However, once the store opened after the lockdown was relaxed, all

the other employees resumed work, but she was told not to come to work. With this she lost the only source of income.

Some employers have ensured that their entire staff has received salaries during this period including employees with disabilities.

"I work as a school counsellor in a private school. so, once the COVID situation got worse, I was permitted to stay home. Since then I have not been able to go to school as the COVID situation worsened. Fortunately, school has been very kind to give me my salary for this month as well as for last month."

A 36-year-old woman with cerebral palsy, Chennai, Tamil Nadu

'Unlocking' policies are permitting workplaces to function, but not public transport or taxi aggregator services. This is creating an uncertainty on work prospects for many participants.

"Recently the government said that 30% employees can resume work. So, my company was thinking, we will bring all employees using personal vehicles. I use public transport. So, I always have a question that will this be a problem for me to resume my work? Also, because most of the companies are terminating employees. So, I am also worried about employment. and especially for people with disabilities finding a new job is also very difficult."

A 34-year-old woman with low vision, Bangalore, Karnataka

"My concern is about transportation because I use private transport. Uber and Ola and autos are operating at a very low rate right now. So, I do not know when it will come back to normalcy. But in case the educational institutions are allowed to function, then my transportation will be a problem because we don't have a driver. I depend on auto and cabs."

A 36-year-old woman with cerebral palsy, Chennai, Tamil Nadu

On the other hand, the fact that employers can see the benefits of enabling working from home is an opportunity for women with disabilities to advocate for themselves.

"Earlier I had to travel two hours to get to work, and my manager always used to hesitate to give me more responsibility because I had to leave early – but now I'm able to do so much more. As persons with disabilities, we have asked for work from home for years but now everybody is working from home."

A 34-year-old woman with low vision, Bangalore, Karnataka

We must remember that while remote working would enable more people with disabilities to be part of workplaces and institutions,<sup>133</sup> without accessibility measures and reasonable accommodations in place, they are bound to be excluded and isolated in the digital workplace as well.

Women with disabilities, who are marginalized from opportunities for employment in law, policy and on paper, have experienced an exacerbation of the situation thanks to the COVID-19 lockdown. The impact of losing livelihood is not just an economic setback as their economic empowerment has been linked to their own self-respect,

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<sup>133</sup> Keegan M (2020) Why coronavirus may make the world more accessible. Retrieved from <https://www.bbc.com/future/article/20200513-why-the-coronavirus-can-make-the-world-more-accessible>

and the consequences of not contributing to the family financially results in abuse and marginalization as we will see in the next chapter. It is crucial that the government and appropriate authorities must come up with relevant interventions and provisions to prevent these women from being further marginalized.

# Domestic Violence

## Global and Local Context

Globally, violence against women is not a novel phenomenon. One in every three women faces domestic violence at some point of time in her life. Even this does not represent the full and accurate picture, because domestic violence is grossly underreported.<sup>134</sup> This violence impedes women's human rights and enjoyment of fundamental freedoms. "Violence against women is an obstacle to the achievement of equality, development and peace", as recognized in the Nairobi Forward-looking Strategies for the Advancement of Women.<sup>135</sup>

To combat this, the Convention on Elimination of all forms of Discriminations against Women (CEDAW) was adopted in 1979 and came into force in 1981. Till date 189 countries have ratified this convention. India ratified the convention in the year 1993 thus undertaking a state obligation to prevent and eliminate discrimination and violence against women. This Convention clearly recognizes the unequal power relation between men and women and marks violence in private and public spheres both a cause of grave concern for women all over the world. To rivet more attention and provide further guidelines to combat violence against women, the CEDAW committee published General Recommendation 19 in 1992<sup>136</sup>, and updated this in the General Recommendation 35<sup>137</sup> to talk about gender-based violence that women face and which lays special emphasis on women with disabilities. It outlines their vulnerabilities and rights in public and private spheres.

To compliment this convention, the United Nations also proclaimed a Declaration on the Elimination of Violence against Women in the year 1993. The definition of domestic violence is to be understood to encompass, but not be limited to physical, sexual and psychological violence occurring in the family, including battering, sexual abuse of female children in the household, dowry-related violence, marital rape, female genital mutilation and other traditional practices harmful to women, non-spousal violence and violence related to exploitation.<sup>138</sup> The declaration recognizes the unique vulnerabilities of women at the margins including rural women, indigenous women and those living with disabilities. the vulnerability and the multiple and

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<sup>134</sup> Mohammed A (2020 April 6) UN backs global action to end violence against women and girls amid COVID-19 crisis. UN News. Retrieved from <https://news.un.org/en/story/2020/04/1061132>

<sup>135</sup> Barr S (2019 November 25) How did international day for elimination of violence against women begin? Independent. Retrieved from <https://www.independent.co.uk/life-style/women/international-day-elimination-violence-against-women-un-history-white-ribbon-a9216426.html>

<sup>136</sup> UN Women (1981) Convention on the Elimination of Discrimination against Women. Retrieved from <https://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm>

<sup>137</sup> Committee on the Elimination of Discrimination against Women (2017) General recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19. [https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1\\_Global/CEDAW\\_C\\_GC\\_35\\_8267\\_E.pdf](https://tbinternet.ohchr.org/Treaties/CEDAW/Shared%20Documents/1_Global/CEDAW_C_GC_35_8267_E.pdf)

<sup>138</sup> Article 2 (a) Declaration on the Elimination of Violence against Women. (n.d.). Retrieved from <https://www.ohchr.org/EN/ProfessionalInterest/Pages/ViolenceAgainstWomen.aspx>

intersecting forms of discrimination and violence faced by women with disabilities is covered in depth in Article 6 of the CRPD. The CRPD has several articles which are relevant in ending violence against women, including Article 5 (equality and non-discrimination), Article 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment), Article 16 (Freedom from exploitation, violence and abuse), Article 17 (Protecting the integrity of the person), Article 23 (Respect for home and family) and linked to all of these are the right to access justice (Article 13) and the right to legal capacity (Article 12).

The Protection of Women from Domestic Violence Act (PWDVA) 2005 expanded the domain of what act amounts to domestic violence in India. It also protects those in live-in relationships with their partners. It establishes authorities and mechanisms like protection officers, shelter homes and other supportive services for women facing this violence. In a 2014 report the special rapporteur Rashida Manjoo raised many concerns around the implementation of this Act including a dearth of protection officers.<sup>139</sup> The domestic violence legislation does not adequately address the issues of domestic violence against girls and women with disabilities. The provisions do not take into consideration the specific types, the intensity and magnitude of violence perpetuated against women with disabilities<sup>140</sup> for instance, denying assistance, hiding assistive devices, withdrawing essential medications, denying food, isolation etc.<sup>141</sup>

An India civil society shadow report for CEDAW states that almost 80 per cent of women with disabilities are victims of some form of violence or the other.<sup>142</sup> It is hard to determine the number of women with disabilities who are victims of domestic violence – as for all women, domestic violence is often under-reported for fear of shame, stigma and re-victimization.<sup>143</sup> In cases of girls and women with disabilities it

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<sup>139</sup> Manjoo R (2014) Report of the Special Rapporteur on violence against women, its causes and consequences. United Nation. Retrieved from <https://undocs.org/en/A/HRC/26/38>

<sup>140</sup> Daruwalla N, Chakravarty S & Chaterji S (2013) Violence Against Women With Disability in Mumbai, India: A Qualitative Study. Retrieved from <https://doi.org/10.1177%2F2158244013499144>

<sup>141</sup> International Network of Women with Disabilities (2010 October 4) Document on Violence against Women with Disabilities. Retrieved from <http://wwda.org.au/wp-content/uploads/2013/12/inwwdviol2010.pdf>

<sup>142</sup> DPI-India's parallel report to the Committee on Elimination of Discrimination Against Women (CEDAW) (2013 September 16) UN Committee on the Elimination of Discrimination against Women Pre-session Working Group for the 58th session.

<sup>143</sup> Shalu Nigam (2005) Understanding Justice Delivery System from the Perspective of Women Litigants as Victims of Domestic Violence in India, Occasional Paper 25, CWDS, New Delhi. Retrieved from <https://www.cwds.ac.in/wp-content/uploads/2016/09/UnderstandingJustice.pdf>

is far more complex.<sup>144</sup>

In India, in the light of lack of data and visibility of the issues of women with disabilities, there have only been a few sporadic research studies indicating the level of violence faced by girls and women with disabilities. All of the women with disabilities who responded to a 2004 survey in Orissa, India, reported to have been beaten at home, 25% of women with intellectual disabilities had reported to have been raped and 6% of the women with disabilities had been forcibly sterilized.<sup>145</sup>

Another research in 2011 conducted by CREA shares that women with disabilities face higher rates of domestic violence and they reported that the violence was brought about by different causes.<sup>146</sup> But similar to other Indian data sources, there is again no disaggregated data around how many women with disabilities have sought intervention under the PWDVA.

Women with disabilities also face barriers to accessing justice - courts are not accessible in terms of physical infrastructure or communication.<sup>147</sup> They also face systemic, institutional, and societal barriers at every stage of the justice system. Helplines and shelter homes are more often than not accessible or inclusive of women with disabilities as well.<sup>148</sup>

## The Shadow Pandemic

A global report states that women with disabilities are 2 to 3 times more likely to face violence and abuse at home and may find it harder to report abuse or escape the situation. This only gets exacerbated in a lockdown and a crisis.<sup>149</sup> Domestic violence has been named the 'shadow pandemic' by UN Women globally. With the rising rates of infections and lockdown policies being strictly implemented, more people

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<sup>144</sup> Girls and women with disabilities face abuse for a longer duration and have very few opportunities to escape or end the abuse. Very often they are financially, physically and emotionally dependent on their families and caregivers, who may also be the abusers, and thus have no opportunities to report the violence and have negligible alternatives. Access to Justice for Women and Girls with Disabilities in India (2018 April 3) Invisible Victims of Sexual Violence. Retrieved from <https://www.hrw.org/report/2018/04/03/invisible-victims-sexual-violence/access-justice-women-and-girls-disabilities>

<sup>145</sup> Badjena S.S, (2014) Sexual Violence Against Women with Disabilities and the Legislative Measures in India. Retrieved from <http://magazines.odisha.gov.in/Orissareview/2014/April-May/engpdf/46-57.pdf>

<sup>146</sup> When asked about the reasons behind the violence that they had experienced, 99 (81%) women felt that it was related to their disability, 40 (33%) to poverty, 34 (28%) to their inability to work, 21 (17%) to stigma, 13 (11%) to dowry, 7 (6%) to the remarriage of their partner, and 7 (6%) to their partner's alcohol or drug problems. CREA. (2011). Count me in! Retrieved from <http://www.creaworld.org/sites/default/files/The%20Count%20Me%20In%21%20Research%20Report.pdf>

<sup>147</sup> Women with Disabilities India Network (2019 Feb 10) Submission of Alternative Report (Article 6 ) To the Committee on the Rights of Persons with Disabilities : India 2019

<sup>148</sup> Access to Justice for Women and Girls with Disabilities in India (2018 April 3) Invisible Victims of Sexual Violence. Retrieved from <https://www.hrw.org/report/2018/04/03/invisible-victims-sexual-violence/access-justice-women-and-girls-disabilities>

<sup>149</sup> Women Enabled International (2020) Statement on Rights at the Intersection of Gender and Disability during COVID-19

are staying at home and helplines are facing increased number of calls.<sup>150</sup> However at the global level in the women's rights space and in India as well, women with disability did not find a specific mention in violence and protection conversations in the current times, nor is there any specific data on it.<sup>151</sup> <sup>152</sup> Independent and assisted community living which enables better mental health for people with disabilities was disrupted by the lengthy lockdown. This resulted in women having to relocate to live with their family - who might have an abusive relationship with them.

A participant with locomotor disability, also associated with a DPO, from a village near Bikaner Rajasthan shared the challenge of learning about domestic violence cases because of the hesitation, shame and stigma attached to reporting something that is considered a 'private matter'.

"We haven't been able to talk to people or go outside to meet people properly. So, we have not come across domestic violence cases currently. It is very difficult to find out about this violence because women will not be able to talk about it easily either. If there are problems like this, we are usually only able to find out after we visit them 4-5 times. Only then they are able to speak freely. On the phone they will not be able to speak of such things at all."

A 29-year-old DPO leader with locomotor disability from rural Rajasthan

One participant with locomotor disability from Orissa shared that in rural areas, with everyone locked up in a small house, women have no privacy to talk on the phone about their concerns which is compelling them to be in constant proximity with abusers at home. Confinement in one single space (often small living arrangements) and frustrations, worry, and insecurity around health, finances and others are leading to increased arguments and conflicts at home.

Three participants from Kerala, Patna and Mumbai shared that with everyone at home, and not having a regular life, frustrations are higher, resulting in women often being forced to bear the brunt of other's mood swings.

In another case, a family is experiencing a cycle of abuse because of loss of employment and access to food.

"In a household where both husband and wife are disabled, the husband lost his job. They are unable to afford basic things like milk for their children. With grown frustration, he is beating his wife, and his wife is beating their children."

A DPO leader with locomotor disability, from Bihar

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<sup>150</sup> Mlambo-Ngcuka P. (2020 April 6) Violence against women and girls: the shadow pandemic. UN Women. Retrieved from <https://www.unwomen.org/en/news/stories/2020/4/statement-ed-phumzile-violence-against-women-during-pandemic>

<sup>151</sup> United Nations Human Rights (2020 April 29) COVID 19 and the Rights of Persons with Disabilities: Guidance. Retrieved from [https://www.ohchr.org/Documents/Issues/Disability/COVID-19\\_and\\_The\\_Rights\\_of\\_Persons\\_with\\_Disabilities.pdf](https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf)

<sup>152</sup> Bhandare N (2020 May 1) The lockdown is hard for women with disability. HindustanTimes. Retrieved from <https://www.hindustantimes.com/columns/the-lockdown-is-hard-for-women-with-disability/story-4uOVBLxLOoukdlcqWvP1vJ.html>

Lockdown and consequent cautions even after opening up leads to further isolation, particularly for women with disabilities who routinely face isolations at home.<sup>140</sup> Women with disabilities from are often seen as 'not woman enough' because the assumption is that they cannot discharge gender stereotypical roles. They are often seen as receivers of care while a woman is presumed to be a care giver, an assumption countered in the [previous chapter on employment](#). Many of them are under the strain of providing for the home and taking care of those in it, without support.

"I asked [my husband] about meal planning since I had a two-hour meeting. He shouted, "I don't know! You take care of it!". So, I had to take a break in the middle of the meeting and make something quickly."

A 54-year-old woman with locomotor disability, Ghaziabad, Uttar Pradesh

A 24-year-old postgraduate student from Mahasamund district, Chhattisgarh living with locomotor disability reported that her friend – another disabled woman - living nearby, who was dependent on her family members for accessing basic essentials, was being mistreated. Her family forced her to cook all their meals and refused to provide her with the essentials that she needed until she completed the household chores.

Many families also see women with disabilities as a financial, physical, and psychological burden. This has only exacerbated in the crisis where women with disabilities are facing substantive access and other barriers. One participant from Kolkata who is hard of hearing reported that her father was very angry with her because she was not able to go and buy vegetables, as she could not communicate with the vendors as everyone was wearing a mask.

Another participant shared that she was in an abusive marriage and had separated from her husband. She was living with her brothers and their families.

"They told me that they could not support me physically or my expenses anymore and asked me to return to my husband's house with my small daughter."

A 42-year-old woman with locomotor disability (Scoliosis), Thane, Maharashtra

Another woman with locomotor disability from Hazaribagh, Uttar Pradesh shared a case about a disabled woman from the area who lived in her aunt's house and was routinely physically abused. During the lockdown, they felt she was a burden and so they threw her out of the house.

A blind participant from Bhubaneswar shared that disability pension which directly gets transferred to bank accounts which are primarily controlled by their husbands because of the patriarchal set up. The choice of how this money is spent does not rest with the woman with disability.

One participant with locomotor disability from a village in Sirohi district believes that with alcohol shops open and with no work available, the cases of domestic violence have increased. This has resulted in increased trauma and pain. This belief was supplemented by another woman with disability from Bikaner who shared the case of a woman living with locomotor and hearing disability whose husband and two young

children who spends all his income on alcohol and gives her no money to even buy food for her and her two young children.

A participant from Chhattisgarh narrated the case of a Self-Help Group of women in a village in Chhattisgarh who run their own canteen in a rural area and who have lost their income after their canteen was closed. Whatever little money they have, their husbands are spending it on alcohol.

The COVID crisis has isolated women with disabilities and further pushed them under the power of their non-disabled family members. Thus, exacerbating their situations of violence and abuse.

A woman with physical disability from Mahasumand, Chhattisgarh shared that her disabled friend was forced to cook food for the entire family with the threat of neglect and withholding basic amenities if she did not do so. A Deaf activist from Bhopal reported a case of a Deaf woman from rural Madhya Pradesh. She had been physically abused by her father in law before lockdown as well but on complaint by DPOs and activists the police had intervened. But the Deaf woman was hit again after the lock down and the COVID crisis started, but the police was busy and did not take any action.

“We do not have a streamlined process on how to reach out for help and subsequent steps. Where will they take shelter? What is the strategy? We need to work this out urgently. No woman will risk their safety by making a call if there is no follow up. There needs to be a fool proof system in place. There should be trust in the system that works.”

A Deaf woman, Delhi

There are no specific platforms for women with disability to seek help in cases of domestic violence. While there are some helplines, how can d/Deaf or deafblind women “call” to seek help? Besides the barriers, there is not much clarity in intervention strategy in domestic violence cases especially with regard to availability of care alternatives for women with disabilities facing violence from caregivers. This often deters women with disabilities from reporting abuse. Measures to address domestic violence in situations of disasters, particularly for vulnerable groups, needs to be a part of disaster management policy and the leadership of women with disabilities must be prioritized at the local level.

## Emotional Wellbeing

The WHO estimates that one in four people worldwide live with mental health conditions. Despite the fact that the number is so high, very few actually access mental health support.<sup>153</sup> According to a WHO report, many of the development programs fail to reach persons with disabilities who require them. It is estimated that nearly 75-85% do not have access to any form of mental health treatment.<sup>154</sup>

However, lived experiences of people with disabilities across the world show us the mental health impact of dealing with everyday discrimination and inaccessibility. This constant exposure to ableism for people with disabilities has led to them sharing their concerns about the effects on their emotional and mental well-being. In her article on the trauma of an ableist world, Nidhi Goyal says: "Discrimination is a constant, with abuse and violence not far away. In such an environment, many persons with disabilities tend to internalize the stigma and behaviours they encounter. These realities shape the conversation around persons with disabilities, which is generally couched in terms of their basic survival, rather than of their right to live their lives to the fullest."<sup>155</sup>

This reveals to us the intense trauma that each person with disability carries just to negotiate and navigate the everyday barriers they face in society. Additionally, many people with disabilities talk about the difficulties in projecting an independent self in order to be accepted in our society as "able".<sup>156</sup> It is evident when we listen to lived experiences of people with disabilities that traumatic experiences accompany them throughout their lives. The pressures to navigate this and the stigma already present with their disability - forces many people with disabilities to remain silent about their emotional and mental well-being. Since this has not been studied much, we are still learning how fear, anxiety, inaccessibility, and everyday discrimination hinders the development of the self.<sup>157</sup>

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<sup>153</sup> World Health Organisation (2001) Mental disorders affect one in four people. Retrieved from [https://www.who.int/whr/2001/media\\_centre/press\\_release/en/](https://www.who.int/whr/2001/media_centre/press_release/en/)

<sup>154</sup> World Health organisation (2010) People with mental disabilities cannot be forgotten. [https://www.who.int/mediacentre/news/releases/2010/mental\\_disabilities\\_20100916/en/](https://www.who.int/mediacentre/news/releases/2010/mental_disabilities_20100916/en/)

<sup>155</sup> Nidhi Goyal (2018) Unrecognized and Unaddressed. Mariwala Health Initiative. Retrieved from <https://mhi.org.in/voice/details/unrecognized-and-unaddressed/>

<sup>156</sup> *ibid*

<sup>157</sup> Khetarpal A (2018) Swimming upstream: Keeping my emotional self-intact through years of pain and humiliation. Retrieved from <https://medium.com/skin-stories/swimming-upstream-keeping-my-emotional-self-intact-through-years-of-pain-and-humiliation-33bea9a69c22>

Several other access barriers also prevent them from seeking therapy<sup>158</sup> – for example lack of familial support, paucity of therapists trained in sign language, accessible locations for mental health clinics and specialized training to cater to the emotional needs of persons with disabilities.

## **The Ongoing Mental Health Crisis**

The pandemic has shifted and made worse many of these situations. It has even been labelled as a mental health crisis because of the isolation, the fear and anxiety of contracting the illnesses. These are all worsened for people with disabilities. Especially when a lot of the initial messaging around the pandemic in opposition to lockdown measures has been that only people with pre-existing conditions, elderly, disabled will be susceptible to dying. This messaging has been overwhelming and a stark reminder for people with disabilities that we are disposable.<sup>159</sup> Thus, it was imperative that the effects of the ongoing pandemic on the emotional wellbeing of women with disabilities be recognized, recorded, and addressed during this investigation.

## **Isolation and Lack of Social Integration**

Article 19 of the CRPD places an obligation on the state to ensure that persons with disabilities can live in the community with the supports that they require to live independently. There is also an obligation to ensure the availability of services to prevent persons with disabilities from being isolated or segregated from society. Forming support networks and staying connected to people they feel close to alleviates a lot of the anxieties that may emerge during the course of the everyday lives of disabled persons. These networks create a safe and supportive space.

However, with the social distancing being the need of the hour, many persons have not been able to maintain access to these networks. Respondents all across the board reported a sense of loneliness and isolation. More than 50% of the participants stated that they missed their friends or colleagues, were bored of not being able to work/ study/ have fun, and were frustrated at being confined to their homes only with their families – something they were not used to, and this created tensions at home. One of the participants – a newly married Deaf woman living in Mumbai who is currently at her parents' house and is planning to move in with her husband's family, stated how she has been forced to contemplate the implications of the communication barriers between her and the rest of the family members that are hearing. She mentioned how this is the first time she has been at home the entire day and has to navigate and negotiate communication with her family (who are not as fluent in sign language). This forces her to think about what that entails, which is reflective of the barriers that deaf women otherwise face at homes because often their families or hearing family members do not learn sign language.

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<sup>158</sup> Morrison (2020) When a Physical Disability Keeps You from Getting Mental Health Help. Retrieved from <https://www.healthline.com/health-news/when-a-physical-disability-keeps-you-from-getting-mental-health-help>

<sup>159</sup> Kukla E (2020) My Life Is More 'Disposable' During This Pandemic. Retrieved from <https://www.nytimes.com/2020/03/19/opinion/coronavirus-disabled-health-care.html>

“Even though they try to include me, I know this is a barrier for them. I still feel left out and negative about the situation. I wonder - do they love me? Do they care about me? When I go to my husband’s house, will all my relations with my natal family break? These kinds of thoughts do come up since I am in isolation in my house.”

A 31-year old Deaf woman, Mumbai, Maharashtra

The impact of the isolation and the anxiety around the pandemic has had adverse effects on women with psychosocial disabilities. A report by the Bapu Trust for Research on Mind & Discourse includes narratives of several women with psychosocial disabilities and notes their increased anxieties due to the unique stressors that have emerged during this time. The sudden change in structures and systems, being confined in abusive situations, and being exposed to very disturbing news cycles, have affected many of them and have even exacerbated their conditions. How the lack of structure or the additional barriers to going out have affected autistic adults and those with developmental disabilities is yet to be understood. For autistic adults there has been a higher psychosocial impact and even autistic persons who did not have high support needs now require it because of this, but the situation has put them at risk for experiencing violence and self-harm.<sup>160</sup>

There were also reports of a feeling that their independence had been restricted. For women with disabilities in particular, families are often either overprotective or do not invest enough in them for them to have an opportunity to live alone, or even undertake daily tasks on their own.

“...when I used to live alone that was not a problem, I had the freedom to just explore things because I had nobody around and had to do everything on my own. That independence and freedom to an extent goes away when you are living at home.”

A 21-year-old blind woman from Guwahati (studying in Delhi)

Another student with low vision who was pursuing her MPhil in Delhi talked about how not being able to meet friends now that she is back with her parents in Haryana, and being confined to her home has led to a lot of irritation and agitation amongst her family.

“These days you can say something rude even though you don’t mean it and it affects your relationship with family and friends.”

A 28-year-old woman with low vision from Haryana (studying in Delhi)

Homes also created a stressful and even dismissive environment. 7 women across disabilities reported of an increase in household fights and disagreements at either their own homes, or in homes of other disabled women they knew - who were being insulted or abused by their families with no escape during this situation, as has been detailed in the preceding chapter on domestic violence.

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<sup>160</sup> Fernanda Santana, President of Brazilian Association for Action in Rights of Autistic People during the HLPF side event “Will the SDGs Still be Relevant after the Pandemic for Persons with Disabilities?” [https://youtu.be/LLBxon\\_bN6Y?t=2400](https://youtu.be/LLBxon_bN6Y?t=2400)

## **The Burden of Activism**

A stress of maintaining the networks they had established and communicating through whatever methods they could use, was also observed in the testimonies of 45% of the respondents across disabilities, specifically activists already working in the disability sector in urban areas and currently living in Chennai, Orissa, West Bengal, Delhi, Gujarat, and Mumbai, members of DPOs in Rajasthan and Chhattisgarh, Bihar, Maharashtra, and Jharkhand. They all reported that they are trying their best to speak to other disabled women living in their communities, even helping them through their problems of accessing food and essentials.

A participant with a locomotor disability, from a district in Maharashtra reported how she helped a disabled pregnant woman get access to a nearby hospital. The participants even tried to build networks of solidarity while participating in our research calls and asked to be connected to each other after the process.

Apart from being able to access these networks themselves, one of the participants from Kerala - the trustee of an organization that offers palliative care to patients, who lives with spinal cord injury herself, also reported a sense of guilt that came from not being able to support other women during this time. She mentioned how she had to stop going to counsel people in the ICU of the institute she stays at, due to her limited lung capacity which puts her at high risk right now.

“There are people who want to talk to me, but I am not able to meet them personally. One of the patients wanted to meet me and talk to me, but I could not go, and she died in two weeks, so I felt so guilty. She really wanted to meet me before her situation deteriorated, but I couldn’t do it, so somehow I felt I didn’t do justice to her.”

A 38-year-old woman with a spinal cord injury, Trivandrum, Kerala

## **Impact on Interpersonal Relationships**

Cases of tensions arising within interpersonal relationships – especially with partners and spouses have emerged. These may not be instances of domestic violence, but they are just examples of stress of the situation making it difficult for people in relationships to support each other. A 28-year-old activist living with complex regional pain syndrome from Gurgaon shares how her relationship with her partner was affected when the latter was diagnosed with depression, and how they have decided to break things off and re-evaluate whether they will be able to find a solution after the lockdown has ended. A 39-year-old blind participant from Bhubaneswar, Orissa mentioned how her husband has been frustrated because his construction business has been suffering due to the lockdown, and this preoccupation has made it difficult for her to discuss her medical issues with him sometimes because he tends to be more annoyed than usual, and doesn’t have the space to discuss her concerns. She spoke of how difficult it was for them to work through these misunderstandings and support each other through these tense times. Women with disabilities facing domestic violence and abuse at home also expressed intense anxiety, fear, depression, and helplessness about their situations.

Women with disabilities shared feeling fearful of not being able to access information on time, not receiving adequate food supplies or proper medical care when they

need it, and also the fear of either losing or not finding employment. Amongst most participants there was a general sense of fear, anxiety, insecurity, and uncertainty around the shifting ideas of access that the next few months would bring, which pervaded the discussions.

The very immediate fear that everyone had was of themselves and their family members/ caregivers falling sick. Those who lived alone and did not have access to support were worried about being able to go to the hospital on their own during an emergency. Those with children or elderly parents reported being constantly worried about their health. A 33-year-old woman from Ganjam, Odisha living with a locomotor disability, who cannot leave her house, reported being extremely worried for her 70-year-old father who has to go get basic essentials for them instead. Another participant who as discussed earlier shared how she managed to get some support for her Deaf parents to access food and essentials, finds herself constantly worried for their well-being.

Another very common experience was anxiety caused from listening to the news. There was a general sense of sadness regarding the overall situation – of being scared of what would happen next and of hearing about terrible cases. Three participants – two living with locomotor disability in Bikaner district Rajasthan, and the other – an autistic woman from Hyderabad had a detailed conversation about the overwhelming hopelessness this made them feel. One of them mentioned that it distresses her to the point of losing her appetite. All three mentioned that they developed certain coping mechanisms to deal with this – they would either avoid the news completely or ask people close to them to give them only the important announcements.

For all eight Deaf women who participated in the study, not being able to access exact and accurate information about what was happening, was a major reason for anxiety. One of these participants – a bank employee who lives in Noida with her family members who are all hearing, said that all she was told by her family and friends in the beginning when the lockdown was just announced, was that she needs to stay at home, because if she went out she would die.

Financial independence and livelihoods are important for the progress, stability, and safety of women with disabilities. The fear of additional disability costs not being met, along with the loss of status that they held in their homes and communities due to financial independence, can also be the cause of immense stress and concern for women with disabilities, especially when these factors are exacerbated during a pandemic situation. One participant who is the sole earner in her family and supports her mother as well expresses her feeling.

“There was a little balance earlier when we were getting incomes, which is going away. We are scared about not being able to earn.”

A 39-year-old woman with locomotor disability Ahmednagar district, Maharashtra

“In my case, I am joining a new job at a school. What will happen if I am not able to go if transportation is not available? How will it impact my economic resources? I can say I am very anxious.”

A 36-year-old woman with cerebral palsy, Chennai, Tamil Nadu

The constant anxiety and frequent breakdowns that was reported by the women was definitely affecting their everyday lives. A participant spoke to her therapist over the phone every two days because of the impact of both her mental health and deteriorating physical health due to her condition.

An autistic participant spoke of how the lack of routine – something that is very important for many autistic women to function – has taken a huge toll on her. She spoke of the problems this had created for her, especially since she had a young son. Lack of support and routine were causing her great distress.

“When he used to go to school, I used to get a break during which I used to calm myself down, and deal with myself. I used to plan and prepare accordingly because things had their own timings. Now everything is in a frenzy. There is no routine, no time left. Now the kid is with me the whole time, and my husband is busy with his own work. In this situation, I feel depressed. And then there is no help available for me, so I do not know when I will be able to get out from this stress. Many times, due to this, I feel that I am not a good mother.”

A 32-year-old Autistic woman, Hyderabad, Telangana

There was also a sense of dissatisfaction with policy response towards women with disabilities. Two of them clearly articulated their frustrations.

“The government is not at all paying attention towards us, which makes us feel that we are not the citizens of this country. Even after living between 10 people, I feel alone.”

A 29-year-old DPO leader, Bikaner district, Rajasthan

The other participant – the president of a district level DPO from Rajasthan expressed sadness and disappointment while noting how even when policies and schemes for persons with disabilities are introduced, they are not implemented, and the benefits do not reach them.

“Everything is on papers, and nothing in reality. Sometimes there is satisfaction that at least someone is getting something. But then there is nothing of this sort. Only letters are being made, and they just reach the official level. After that, nothing gets done. No facilities reach the disabled. We are always being made to wait and suffer. Whenever we see any letter, be it from the women and child development center, or from the state or the central government, whenever we read it, we feel happy about it. But that happiness gets locked down in those papers itself.”

A DPO leader, Rajasthan

## Recommendations

In the light of the gaps that have emerged through our research, it becomes urgent more than ever to review legal provisions, policies and guidelines and ensure their implementation with systematic accountability mechanism in place. This will be important to ensure persons with disabilities and in particular women with disabilities' human rights are upheld during this current pandemic and in disaster situations in the future. We urge central and state governments, civil society initiatives, private actors, and other stake holders to take necessary steps to ensure implementation of following short term and long-term recommendations.

### Recommendations for Immediate Actions

In the absence of a clear disability inclusion strategy, the **Disability Inclusive Guidelines** by issued were prompt and timely in the pandemic. They are inclusive and contain many important measures though it lacks a gendered approach to ensuring that women with disabilities have access to their requirements and that the unique barriers experienced by women with disabilities are addressed in the planning of interventions and responses. The guidelines also lack any accountability mechanism or implementation strategy and their effectiveness in many places was marred by the fact that the post of the State Commissioner of Persons with Disabilities remains vacant in several states or is an additional charge for already overburdened officials. **The implementation of the RPD Act, notification of Rules in all States, and the appointment of all officials in accordance with the Act and Rules requirements is of utmost priority.**

Besides this, we would strongly recommend that disability inclusive guidelines be strengthened, and all central and state policies mainstream the concerns of persons with disabilities within them.

1. The Disability Inclusive Guidelines must ensure a **gender inclusive response** for ensuring access for persons with disabilities to food, essentials (including menstrual care products), quality healthcare and rehabilitation services, in urban and rural areas. Clear budgetary allocations to implement these guidelines at central and state levels must be provided including to provide reasonable accommodation to persons with disabilities.
2. The Disability Inclusive Guidelines must contain **an accountability mechanism** to ensure that other departments, state authorities and the state commissioner for persons with disabilities, who is the nodal officer under the guidelines, and other relevant authorities at all levels follow these guidelines.
3. All guidelines and policies developed around prevention and interventions in cases of **domestic violence** experienced during the lockdown and its aftermath must be inclusive of and accessible to women and girls with disabilities and designed to address barriers to reporting.
4. All authorities providing relief services and schemes during this period including under the Disability Inclusive Guidelines must collect **disaggregated data by**

**gender and other intersections** on the number of persons with disabilities who have been reached.

5. Implementing the RPD Act, appointing all authorities and strengthening the role of the State Disability Commissioners to take Suo moto action on discrimination against persons with disabilities in accessing services and essentials during the pandemic.

## Access and Accessibility

1. Make **all communications/ information/ announcements** regarding COVID-19, the lockdowns and the unlocking processes be in plain language and made available in a range of accessible formats including sign languages, braille, audio versions, easy to read versions and in languages used by the local population at the same time as it is available to the general population. The accessible information should be up to date and made available to even underrepresented groups among the disabled such as the deafblind and persons with disabilities who continue to remain in group homes and institutions.
2. Set up and widely disseminate information regarding **local helpline numbers** for persons with disabilities to access food and essential services as well as information. Provide for options for communication including text and video facility for deaf and deafblind persons. Ensure availability of sign language interpreters for the calls and for home visits where necessary.
3. Design, in consultation with persons with disabilities, **social distancing norms** which consider the access and support needs of persons with disabilities and ensure public awareness on the same.
4. In containment zones or other notified areas, persons providing caregiving or personal assistance services should be given **priority for passes** to access the areas.
5. Ensure that personal assistants or interpreters required by persons with disabilities are exempt from the **limitations on maximum number of people** visiting public places, gathering for weddings or funerals, taking taxis and autos, etc. and that these exemptions are widely publicized.
6. Ensure support services to persons with disabilities such as sign language interpretation, tactile interpretation, personal assistance etc. and for this purpose the **support persons are to be categorically exempted from norms of physical distancing.**
7. Ensure that there is **awareness and training of public and private transport providers** staff to ensure access for and to provide support passengers with disabilities now and in the coming months.
8. Ensure that all **existing health services for the public** like fever surveillance camps and other medical services, ambulances, telephone helplines, mental health counselling are available, affordable, and accessible for all persons with disabilities.

9. **Digital media** should include their materials in accessible formats and meet the accessibility guidelines as well as provide for sign language interpretation for all new bulletins. This includes all websites, apps, communication platforms, news portals.
10. A dedicated section with information for persons with disabilities on the Aarogya Setu App and on **all Government issued COVID-19 apps**. The app should meet the web accessibility guidelines and also have videos of information in sign language.

## Food and Other Essentials

1. Ensure **access to food and other essentials to the doorstep of recipients**; especially for those who may be unable to leave their homes due to social distancing and communication challenges (blind, deaf, deaf blind), or experience difficulty with leaving home as they are immunocompromised or more vulnerable, even beyond the period of lockdown. For this purpose, **officials should not insist on production of disability certificates**.
2. The States/UTs/ district authorities must direct their own public run enterprises to ensure, and advise private enterprises to reserve, **specific opening hours in retail provision stores** including dairies, ration shops, general provision stores and supermarkets **for persons with disabilities, the elderly and persons with compromised immunity** to ensure easy access to food and essentials.
3. The system of **delivery services should be retained** during the lockdown period and also the unlock phases, since it is difficult for persons with disabilities to go out and purchase essentials given the long queues, social distancing norms and lack of transport facilities.
4. To clearly recognize **menstrual hygiene products as essentials** and ensure that a range of products are made available at the doorstep for women and girls with disabilities to facilitate their choice, including being provided free of charge to those who cannot afford them.
5. To recognize **assistive devices as essentials** and to ensure the availability and upkeep of the same during the lockdown and unlocking periods for persons with disabilities. This should include all lists mentioned in the WHO Priority Assistive Products List. Manufacturers and repairing agencies for assistive products should be treated as essential goods and receive all benefits accorded to similar manufacturing units and industries.

## Social Protection

1. Release **disability pensions** in a timely manner and where possible in advance during the current crisis.
2. Make the **disability pension uniform across states and UTs** in keeping in mind the additional costs incurred by persons with disabilities in overcoming barriers to participation.

3. Ensure that the ex gratia amount of Rs. 1000 under the **Pradhan Mantri Garib Kalyan Yojana** is released for retrospective support at the earliest to people with disabilities and extend it to all persons with disabilities living in poverty regardless of certification status by working with local authorities and panchayats to identify persons with disabilities.
4. Extend the duration of additional financial support for persons with disabilities and increase the amount in order to create resilience for persons with disabilities and their families during the current crisis.
5. Extend **disability allowances to children with disabilities** to cover costs of nutrition and for educational materials. Ensure access to families by working with the local authorities, registered service providers and Anganwadis for identifying families with children with disabilities.
6. All the employment guarantee schemes such as MGNREGA etc. should be made more accessible and inclusive and include people with disabilities with 25% additional compensation to meet their additional disability costs and regularity in payment of compensation to be ensured.
7. Strengthen the rural and urban livelihood missions to include people with disabilities.

## Education

1. Ensure that all children with disabilities, regardless of whether they are presently in mainstream schools, special schools, or home-based education, **have equal access to quality and ongoing education and allied activities**. While all education is now home based, the model of home-based education under the RTE Act is providing any education and must not at any cost become the default adopted for any children with disabilities, and this practice must be phased out.
2. The National Commission for Protection of Child Rights should frame **mandatory directives to schools on the inclusion of children with disabilities in all online education proposals at all levels of school education in public or private educational institutions**. This includes the provision of accessible teaching and learning material to ensure uninterrupted education at the earliest for blind, deaf, deafblind and other students and reasonable accommodation in the design of online classes for students who find it inaccessible to attend classes through video conferencing.
3. The Samagra Shiksha Abhiyan should include a **component on allowance to students with disabilities** for the additional costs of having to study from home including support persons like readers, sign interpreters, learning assistance, procurement of assistive devices or software etc.
4. All **procurements of e-learning platforms** must comply with the Web Accessibility Guidelines from the perspectives of both learner and instructor. Teaching staff with disabilities should have access to accessible training materials or personal assistance where requested to organize and deliver their teaching.
5. **Awareness campaigns** should be targeted at parents and families to prioritize and take the education of women / girls with disabilities seriously and to not box them in gender stereotypical roles particularly during this pandemic.

6. **Consultative processes** regarding modification of syllabus, examination and evaluation proposals should include students and teachers with disabilities.
7. All online books, reference journals, other reading material must be made available in **multiple accessible formats** and this should be a prerequisite of UGC and School boards for their approval as reference material. Online repositories such as Sugamya Pustakalaya<sup>161</sup> should be available for all students and schools should be incentivized to continue uploading accessible formats of books for sharing.
8. Concerted efforts to **identify dropouts and students who are out of school** should be made with specific emphasis on vulnerable groups including children with disabilities, and programmes to bring them into the education system, including through incentives for families, should be developed.
9. A rights-based approach to persons with disabilities should be made a mandatory component of mainstream teacher training program at undergraduate and post-graduate levels and **identification and sharing of good practices for inclusion** should be developed by the National Council for Education Research and Training.

## Health, Sanitation, and Hygiene

1. Persons with disabilities should be able to access, **without discrimination, the same level of healthcare** as persons without disabilities are able to access. Persons with disabilities should be able to access **emergency healthcare services** not related to COVID-19 and access to healthcare should not be hampered by the lack of availability of public transport services.
2. During **quarantine or hospitalization due to COVID-19** persons with disabilities must have access to essential support services, personal assistance, and physical and communication, with due consideration to the specific requirements of women and girls with disabilities who may be under treatment.
3. Medical and para medical staff, particularly those frontlines, must receive **basic training and guidelines to work with and support persons with disabilities** and on the requirements of women and girls with disabilities. Video modules to be developed in consultation with civil society that they can watch on their own would be ideal as organizing formal trainings are not possible at this point.
4. In preparation for the widespread use of masks, to encourage the **manufacture of masks which comply with the standards of safety while also made of transparent material**, particularly covering the mouth to facilitate access to lip reading for deaf individuals. The use of these masks by essential workers should also be promoted.
5. Facilitate the design and manufacture of **adaptive Personal Protection Equipment (PPE)** for deaf and hard of hearing persons who rely on lip reading, deaf blind persons and even for those persons who may find wearing masks uncomfortable because of their sensory issues.
6. Emergency and health settings like hospitals and quarantine centers should hire or empanel **sign language/guide interpreters and other persons trained to support persons with disabilities who should be treated as essential**

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<sup>161</sup> <https://library.daisyindia.org/NALP/welcomeLink.action>

- frontline workers** and given the same level health and safety protection as other health care workers.
7. **Persons with disabilities and their caregivers must be provided with PPE**, including masks, gloves, and sanitizers, at affordable rates and free of cost, where necessary, which should be made available at the doorstep of their homes.
  8. All persons responsible for handling emergency response services, including quarantine and testing centers, should be **trained on the rights of persons with disabilities, and on risks and co-morbidities** associated with persons with specific disabilities acquiring COVID-19.
  9. Ensure everyone has access to **regular healthcare and rehabilitation services** such as physiotherapy, pain therapy, blood transfusion, chemotherapy, dialysis, occupational therapy, blood test, and access to gynecologists, ophthalmologists, audiologists etc. Telemedicine services should enable users, including persons with disabilities, to communicate with the health professionals with utmost concern for their privacy.
  10. **Home delivery of medicines** and essentials should be ensured for those who are unable to go to the pharmacy or health centres or those who live alone or those who do not have support to go outside.
  11. With regard to persons with disabilities in institutional living arrangements, the Government must **prioritize a deinstitutionalization strategy**. In the interim, persons living in institutional arrangements including psychiatric units, social care institutions and group homes must be given access to requirements including sanitary supplies such as soap, hand sanitizer, toilet paper, paper towels and menstrual hygiene products without discrimination and be provided necessary support to ensure that they.

## **Livelihoods and Employment**

1. Persons with disabilities **must not be discriminated against at the workplace**, particularly in the evolving scenario post lockdown. This includes persons who are currently or who may come to be employed by the Government, private sector or in not for profit organizations. Requests from persons with disabilities and persons with compromised immunity to continue to work from home must be considered as a form of reasonable accommodation. The Chief Commissioner of Disabilities must frame additional guidelines under the RPD Act to ensure this protection and direct organizations to implement **equal opportunity policies** as mandated under the Act.
2. The Ministry of Labor and Employment must develop **schemes to support private sector organizations who are forced to downsize** in the face of the coming economic crisis, and this support must have a specific component to encourage the retention of persons with disabilities employed by them.
3. Schemes mandated under Section 24 of the RPD Act should be prioritized including provision of **unemployment allowance** for persons with disabilities registered with Special Employment Exchange for more than two years who could not be placed in any gainful occupation and **care-giver allowance** to persons with disabilities with high support needs.
4. Schemes for creation of employment including those run by the Ministry of Micro, Small & Medium Enterprises, Ministry of Labor and Employment, Ministry of Rural

Development and Ministry of Housing and Urban Affairs should focus on **creation of a range of home-based work options for women with disabilities residing in villages and/or urban settlements**, including provision of livestock or contracts for mask making to support them with income generation options. Access to the market and raw supplies/materials must be ensured within these programmes.

5. All **procurement or adoption of remote working apps, software and other tools must comply with all requirements on web accessibility**, be they related to remote working, file sharing, conferencing etc. For the Deaf and hard of hearing, organizations should enable full participation through engagement of sign language interpreters or captioning services. Regional and State level chambers of commerce and industry associations should empanel sign language interpreters and collate best practices in inclusion for remote working.
6. **Skill development programmes** run by the public and private sector which are now moving online **must also comply with accessibility requirements** and also be designed to **address barriers faced by women with disabilities** in accessing trainings. The courses must also adapt to training participants including persons with disabilities in remote working and provide opportunities for specific job profiles that can be performed from home e.g. remote event management and virtual personal assistance which can create great opportunities for women with disabilities. Specific outreach through DPOs should be made to encourage the training of women with disabilities.

## **Domestic Violence**

1. **Closely consult with and actively involve women with disabilities** while building awareness and strategy around domestic violence by the ministries and departments relation to women and children, the national and state's women commissions, the child protection commissions and other relevant authorities.
2. **Disseminate information in accessible formats** informing women with disabilities of their **legal rights** under the Protection of Women from Domestic Violence Act as well as the provisions under the RPDA for protection against violence, and the mechanisms available in the current pandemic.
3. **Train and sensitize protection officers and the first response authorities** to help identify and support women with disabilities experiencing domestic violence and to guide them through the justice process.
4. Make **helplines, websites, and other complaint mechanisms** regarding gender-based violence **operational and accessible** for women with disabilities facing domestic violence. Helplines should also be available at the local levels to ensure that information is available in local languages and in the regional sign language.
5. Ensure that women with disabilities facing domestic violence have **access to safe and accessible shelter** particularly during this pandemic to move to, in order to avoid prolonging contact with the abuser at home, and that they receive reasonable accommodation towards accessing their requirements including assistive devices and personal assistance, interpretation etc.

## **Emotional and Psychological Wellbeing**

1. Ensure access to support for all persons, including those experiencing mental or emotional distress during the COVID-19 outbreak, **to call-in, in person and online psychosocial support and peer support, based on respect for individual will and preferences.** All counselling and psychosocial support services should be deemed to be essential services. This includes access to personal assistance and interpretation where required which adhere to privacy requirements.
2. Ensure the **development and availability of a wide range of community-based services** that respond to the needs of persons with disabilities and respect people's autonomy, choices, dignity, and privacy.
3. **Mental health responses** need to be embedded in the COVID-19 recovery for persons with disabilities with specific focus on women with disabilities and the National and District Mental Health Programme should be adapted and redesigned to deliver rights based mental health support at the community level.

Finally, as persons with disabilities and organizations working on disability rights, we strongly recommend central and state governments as well as local authorities should ensure the active and informed participation of persons with disabilities in the processes and policies around the COVID-19 recovery process.

They should ensure that women across disabilities, including those from underrepresented groups such as Deaf women, deafblind women, women with intellectual and psychosocial disabilities, across age groups, those living in remote and rural areas as well as those experiencing multiple or intersectional discrimination are included in leadership and decision making capacities, in policy, planning and execution of COVID-19 responses.

We also urge all concerned stakeholders to set timelines according to the immediacy of the above recommendations and to ensure that existing accountability mechanisms address violations of rights during this period.

## **Specific Recommendations on Inclusion of Women with Disabilities in Disaster Management Guidelines and Processes**

It is crucial that the concerns of persons with disabilities, and women with disabilities in particular, are mainstreamed into disaster management guidelines. In this regard we draw the attention of National Disaster Management Authority to the **IASC Guidelines, Inclusion of Persons with Disabilities in Humanitarian Action, 2019**<sup>162</sup>.

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<sup>162</sup> Inter-Agency Standing Committee (2019) Inclusion of Persons with Disabilities in Humanitarian Action Retrieved from: <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>

It is important that the learnings from this experience are used to build a stronger, more resilient, and more inclusive disaster management response. In this regard, our recommendations are:

1. Organizations of persons with disabilities should be involved in the development of training of members of disaster management task force on issues related to the inclusion of persons with disabilities and their requirements including the requirements of women with disabilities. The understanding of disability should be beyond the list of disabilities under the RPD Act and should adopt an approach in line with the wider understanding of persons with disabilities under the CRPD to prevent discrimination.
2. Enable the participation of women with disabilities, including from underrepresented groups, in advisory committees at Central, State and District level. These committees are meant to advise National, State and district level disaster management authorities. This includes supporting **building the capacity and leadership of women activists with disabilities on disaster management.**
3. Section 61 of the Disaster Management Act 2005 should be amended to include **disability and gender identity as categories protected from discrimination.**
4. Guidelines under Section 12 should also include **guidelines related to the inclusion of persons with disabilities with due attention to the requirements and vulnerabilities of women and girls with disabilities,** with reference to the IASC guidelines, 2019.
5. Local authorities should use effective and **human rights-based methods of data collection and identification of persons with disabilities** and particularly women with disabilities, to ensure that it is quick and easier to reach out and provide relief support during any disasters. This includes involving grassroot organizations working with persons with disabilities.
6. Conduct **surveys on the impact of the recent pandemic** on persons with disabilities including women with disabilities in order to understand the vulnerabilities experienced across different groups of persons with disabilities and across intersectionalities and regions in order to make more strategic interventions and plans.

Every disaster brings with it the opportunity to build back better – be it systems of resilience among communities, service delivery or design of programmes and interventions. In many respects the pandemic has opened a discussion over issues which were earlier not considered feasible and which can be enabled through technology. All stakeholders in the Government as well as private sector must be cognizant of the 'double edged' potential of technology to either close barriers of accessibility or throw them wide open. It is crucial that all stakeholders adopt inclusive approaches to rebuilding our communities and systems in the aftermath of COVID-19 and provide opportunities for leadership and showcasing of social innovations that organizations of and for persons with disabilities have developed in these challenging times, specifically around the inclusion and experiences of women and girls with disabilities.

## ABBREVIATIONS

CEDAW: Convention on the Elimination of All Forms of Discrimination Against Women

CRPD: Convention on the Rights of Persons with Disabilities

CSO: Civil Society Organization

DPO: Disabled People's Organizations

IASC: Inter Agency Standing Committee

MGNREGA: Mahatma Gandhi National Rural Employment Guarantee Act/ Scheme

NDMA: National Disaster Management Authority

NGOs: Non-Government Organizations

PDS: Public Distribution System

PWDA: Protection of Women from Domestic Violence Act, 2005

RPD: Rights of Persons with Disabilities Act 2016

RTE: Right to Education Act, 2009

SDG: Sustainable Development Goals

WHO: World Health Organization?

## **Terminology**

This report understands the term “person with disability” as per the RPWD Act and the UNCRPD – “a person with long term physical, mental, intellectual or sensory disability which, in interaction with barriers, hinders their full and effective participation in society equally with others”.<sup>163</sup> It also understands that disability as a concept is evolving (according to the UNCRPD).<sup>164</sup>

The participants in this study self-identified themselves as persons with disabilities. Terminology used throughout this report is reflective of the manner in which they have identified themselves. In other usages, the terminology and understanding of the disability categories has been taken from Schedule 1 to the RPWD Act 2016 which lists 21 specified disability categories. This report does not endorse the framing of those definitions and acknowledges the conflicts that many groups of persons with disabilities have with those definitions. Many respondents live with conditions that have not been recognized as specified disabilities under this Schedule, and those have been specifically mentioned.

Following is a list of terms used in the report:

**Accessible India Campaign (AIC):** A Nation-wide Campaign launched by the Department of Empowerment of Persons with Disabilities of the Ministry of Social Justice and Empowerment to provide universal accessibility to persons with disabilities. The campaign aims at providing equal opportunity to persons with disabilities to participate in all the aspects of life and live independently. It focuses on developing accessible physical environment, transportation system and Information and communication ecosystem.<sup>165</sup>

**Build Back Better:** This is a principle of the ‘recovery’ phase of disaster management functions. The UN General Assembly explained the concept to mean The use of the recovery, rehabilitation and reconstruction phases after a disaster to increase the resilience of nations and communities through integrating disaster risk reduction measures into the restoration of physical infrastructure and societal systems, and into the revitalization of livelihoods, economies, and the environment.

**Chronic Illnesses:** Conditions that last one year or more and require ongoing medical attention or limit activities of daily living or both.<sup>166</sup>

**Civil Society Organization:** Non-State, not-for-profit, voluntary entities formed by people in the social sphere that are separate from the State and the market and represent a wide range of interests and ties. They can include community-based organizations as well as non-governmental organizations (NGOs). In the context of the UN Guiding Principles Reporting Framework, CSOs do not include business or for-profit associations.<sup>167</sup>

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<sup>163</sup> Rights of Persons with Disabilities Act (2016)

<sup>164</sup> United Nations Convention on Rights of Persons with Disabilities (2006)

<sup>165</sup> Retrieved from <https://www.india.gov.in/spotlight/accessible-india-campaign#tab=tab-1>

<sup>166</sup> Retrieved from <https://www.cdc.gov/chronicdisease/about/index.htm>

<sup>167</sup> Retrieved from <https://www.ungpreporting.org/glossary/civil-society-organizations-csos/>

**Deaf:** We have d/Deaf to refer to the deaf individuals at large because of variance in preferences and we have used Deaf with a capital D to refer to people who self-identified as Deaf.

**Digital India:** An initiative taken by the Government of India for providing high-speed internet networks to rural areas. Digital India Mission was launched by PM Narendra Modi on 1st July 2015 as a beneficiary to other government schemes including Make in India, Bharatmala, Sagarmala, Start-up India, BharatNet and Standup India. Digital India was established with a vision of inclusive growth in areas of electronic services, products, manufacturing, and job opportunities. Digital India Mission is mainly focused on three areas: providing digital infrastructure as a source of utility to every citizen, governance, and services on demand, to look after the digital empowerment of every citizen.<sup>168</sup>

**Disabled people's organizations:** The characteristics of organizations of persons with disabilities as described by the CRPD Committee are as follows:

(a) They are established predominantly with the aim of collectively acting, expressing, promoting, pursuing, and/or defending the rights of persons with disabilities and should be generally recognized as such.

(b) They employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves.

(c) They are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of.

(d) They may represent one or more constituencies based on actual or perceived disability or can be open to membership of all persons with disabilities.

(e) They represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women, or indigenous people with disabilities) and comprise members with various disabilities.

(f) They can be local, national, regional, or international in scope.

(g) They can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice for persons with disabilities in their interactions with, among others, public authorities, international organizations and private entities.

**IASC Guidelines:** The guidelines set out essential actions that humanitarian actors must take in order to effectively identify and respond to the needs and rights of persons with disabilities who are most at risk of being left behind in humanitarian settings. The recommended actions in each chapter place persons with disabilities at the centres of humanitarian action, both as actors and as members of affected populations. They are specific to persons with disabilities and to the context of humanitarian action and build on existing and more general standards and guidelines.

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<sup>168</sup> Retrieved from <https://digitalindia.gov.in>

**Mahatma Gandhi National Rural Employment Guarantee Act (MGNREGA):**

A demand driven scheme which provides 100 days of work as part of provisions that do not overtly exclude disabled people, but the conditions do not promote inclusion – example for some women with disabilities to be involved in a work, they require modification of implements etc.<sup>169</sup>

**Protection of women from Domestic Violence Act (PWDA):** An Act to provide for more effective protection of the rights of women guaranteed under the Constitution who are victims of violence of any kind occurring within the family and for matters connected therewith or incidental thereto. The Protection of Women from Domestic Violence Act, 2005 gives the legal definition of “Domestic Violence” under Section 3. The DV Act is applicable to whole of India except the State of Jammu and Kashmir. It is a civil law which focuses on the reliefs given to the aggrieved woman such as compensation, protection, right to residence in the “shared household”, among others.<sup>170</sup>

**Psychosocial Disability:** A disability that may arise from a mental health issue<sup>171</sup>

**Public distribution system (PDS):** An Indian food Security System established under the Ministry of Consumer Affairs, Food, and Public Distribution, which evolved as a system of management of scarcity through distribution of food grains at affordable prices. It operates under the joint responsibility of the Central and the State Governments. <sup>172</sup>

**Ration Card:** Ration cards are an official document issued by state governments in India to households that are eligible to purchase subsidized food grain from the Public Distribution System (under the National Food Security Act). They also serve as a common form of identification for many Indians.<sup>173</sup>

**Rights of Persons with Disability Act, 2016:** The law which covers all aspects of the rights of persons with disabilities in India such as equity in opportunities in all aspects of life including education, work, sport, and entertainment. It also mentions the requirement for all buildings and public areas to be made accessible for persons with disabilities.<sup>174</sup> It was enacted as part of India’s state obligations under Article 4 of the CRPD.

**Sustainable Development Goals:** These were established by the United Nations in September 2015. It is a joint plan that has 17 goals highlighting three dimensions of development: economic, social, and environmental. Governments of developing and developed countries alike, UN agencies, non-governmental organizations and

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<sup>169</sup> Shadow Report by Women with disability India Network to UNCRPD (2019 Feb)

<sup>170</sup> Retrieved from [http://chdsla.gov.in/right\\_menu/act/pdf/domviolence.pdf](http://chdsla.gov.in/right_menu/act/pdf/domviolence.pdf)

<sup>171</sup> Retrieved from <https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis#what-is-psychosocial-disability>

<sup>172</sup> Retrieved from <https://www.drishtiiias.com/to-the-points/paper3/public-distribution-system-1>

<sup>173</sup> Dfpd.nic.in. Retrieved 11 June 2016. <http://dfpd.nic.in/index.htm>

<sup>174</sup> Retrieved from <https://enableme-access.com/rpwda-2016/>

other stakeholders have agreed to aim to end poverty, promote peace, share wealth, and protect the planet by 2030. This plan is also known as 'Agenda 2030'.<sup>175</sup>

**Swachh Bharat Mission:** To accelerate the efforts to achieve universal sanitation coverage and to put focus on sanitation, the Prime Minister of India had launched the Swachh Bharat Mission on 2nd October 2014. The mission was implemented as nation-wide campaign/ Janandolan which aimed at eliminating open defecation in rural areas during the period 2014 to 2019 through mass scale behavior change, construction of household-owned and community-owned toilets and establishing mechanisms for monitoring toilet construction and usage. The latest project is to make accessible toilets for persons with disabilities.<sup>176</sup>

**The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW):** Adopted in 1979 by the UN General Assembly, it is often described as an international bill of rights for women. Consisting of a preamble and 30 articles, it defines what constitutes discrimination against women and sets up an agenda for national action to end such discrimination.<sup>177</sup>

**The Right of Children to Free and Compulsory Education Act or Right to Education Act (RTE):** An Act of the Parliament of India enacted on 4 August 2009, which creates a legislative framework for the realization of free and compulsory education for children between 6 and 14 in India, which is also recognized as a fundamental right under Article 21a of the Indian Constitution.<sup>178</sup>

**The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):** An international treaty which identifies the rights of disabled people as well as the obligations of States parties to promote, protect and ensure those rights. It aims to ensure that disabled people enjoy the same human rights as everyone else and that they can participate fully in society by receiving the same opportunities as others.<sup>179</sup>

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<sup>175</sup> Retrieved from <https://sustainabledevelopment.un.org>

<sup>176</sup> Retrieved from <https://swachhbharatmission.gov.in/SBMCMS/about-us.htm>

<sup>177</sup> Retrieved from <https://www.un.org/womenwatch/daw/cedaw/>

<sup>178</sup> Retrieved from <http://righttoeducation.in/know-your-rte/about>

<sup>179</sup> Retrieved from <https://www.equalityni.org/Delivering-Equality/Addressing-inequality/UNCRPD-Disability/What-is-UNCRPD>