



The Leprosy Mission
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PANDEMIC AND PEOPLE'S PLIGHT

Experiences that echoed
across India

Challenges that COVID-19 posed in terms of
Leprosy Screening & Diagnosis | Treatment | Livelihood | Education

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When the idea of doing this report was conceived and shared with some of the programme heads at The Leprosy Mission Trust India, the response was encouraging. “Yes, we should do this,” they said unanimously. But they did not stop at saying ‘yes’ but ensured that all the units mobilised their resources and time to support this endeavour. For a geographically diverse organisation, which was already dealing with the aftermath of the first wave of COVID-19, it was not a convenient exercise to undertake. Moreover, time was not on our side. The second wave was wreaking havoc and panic was at its peak.

From hospital superintendents and medical and non-medical staff to programme heads and program managers, who have their boots on the ground, all of them went an extra mile to understand the objective of this endeavour and plan one-on-one interviews, online surveys and document them. We are grateful to each one of them for thinking through this and encouraging us to think deeper and capture more diverse components.

This report would not have been possible without the ready support of the respondents, including residents of leprosy colonies, people undergoing leprosy treatment, persons with disabilities (PwDs), health workers, and ASHA workers.

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We are also grateful to members of TLM’s extended family and experts, who shared their insights into the COVID-19 crisis at different online forums we were privy to. The report draws from their experiences and recommendations, which are precise and pragmatic.

Abbreviations & Acronyms

ACF: Active Case Finding

ANCD: Annual New Case Detection

ASHA: Accredited. Social Health Activist

CFAR: Centre for Advocacy and Research

CIU: Community Intervention Unit

CPHC: Comprehensive Primary Health Care

CwD: Children with Disabilities

G2D: Grade-2 Disability

HKNS: Hind Kusht Nivaran Sangh

IADVL: Indian Association of Dermatologists Venereologists and Leprologists

LCDC: Leprosy Case Detection Campaign

MB: Multibacillary Leprosy

MCD: Municipal Corporation of Delhi

MDT: Multidrug Therapy

NCPEDP: National Centre for Promotion of Employment for Disabled People

NLEP: National Leprosy Eradication Programme

NSO: National Statistical Office

NUHM: National Urban Health Mission

PwD: Persons with Disabilities

RBSK: Rashtriya Bal Swasthya Karyakram

RKSK: Rashtriya Kishore Swasthya Karyakram

RPwD: Rights of Persons with Disabilities

SDR-PEP: Single Dose Rifampicin Post-Exposure Prophylaxis

SIG: Special Interest Group

TLMTI: The Leprosy Mission Trust India

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1. Introduction

Of all the things that COVID-19 pandemic taught us, the most important was, perhaps, the fact that the ‘vulnerable population’ is not a homogenous entity. Their vulnerability is sometimes a complex intersection of different social variables: poverty, disability, stigma, exclusion, etc. Much to our dismay, the pandemic demonstrated how it affects different vulnerable groups differently, with adverse consequences being the constant factor.

The first wave of COVID-19 pandemic struck India towards the second quarter of 2020. The government, as a pre-emptive measure, imposed a nationwide lockdown and strict social distancing norms along with other measures to curb transmission of COVID-19 virus. Media reports documented the plight of a large section of our society—migrant workers—and their struggle for food and transportation, and rightly so. There was public outrage over lack of oxygen supply and medical support across cities and towns.

Amid all these, did we at least begin to fathom how the complete shutdown of the country hurt a not-so-visible vulnerable group: the people affected by leprosy and other disabilities? When the lockdown was announced, we at the TLMTI gathered ourselves to answer an obvious question: how will the people affected by leprosy continue with their treatment? While some need to visit health facilities to continue multidrug therapy (MDT) and get their dosage of the steroids adjusted, others need ulcer dressing. Number of patients dwindled in our hospitals as vehicles went off the road. The anxiety of our patients became palpable. We started receiving desperate calls for food, medicines, and other essential commodities. COVID-19 had clearly disrupted whatever limited access they had to resources and support systems.

We realised that the demand for specialised leprosy care was growing in leaps and bounds, with general hospitals and health care facilities prioritising COVID-19 over any other “non-urgent” treatments. We were quick to respond. All our units were pressed into service. From taking health care services to the doorstep through state-of-the-art mobile therapy clinics and running teleconsultation services for patients to providing food, ration supplies, medicines, and sanitary items to those in urgent need, we tried every possible avenue to mitigate the impact of this pandemic.

As the longest running leprosy-focused organisation in the country, which also works with persons with disabilities (PwDs) and those from marginalised communities, it was incumbent upon us to document how COVID-19 and the economic shutdown was affecting not just access to treatment and health outcome, but also several other socio-economic indicators: income security, food security, educational outcome, etc. The idea was to present different facets of COVID-19-related consequences before different stakeholders so that they can trigger a discussion on how to fill in the gaps and prepare ourselves better for future contingencies.

Please note that this report is not an academic exercise, but a humble attempt at distilling information from shared experiences and capturing the scale and diversity of the challenge that COVID-19 posed before those who were already living on the margins. The report has been prepared based on on-ground interviews of public health consultants, residents of leprosy colonies, ASHA workers, children affected by leprosy and those working for healing,

inclusion and dignity of people affected by leprosy. In the process of drafting the report, we have gone through peer-reviewed research papers and conducted an online (and partly telephonic) survey of students from leprosy and disability backgrounds, who are studying / have passed out from The Leprosy Mission's vocational training centres. The objective was to get as close to the lived realities.

This exercise was challenging for several reasons. Firstly, it called for physically reaching out to the far-off communities when lockdown was in effect. Information gathering, especially granular data pertaining to leprosy cases and the number of PwDs in a district, was a challenge because there was none. Data on spatial and temporal distribution of new and existing leprosy cases across states and districts could have helped us further connect the dots for planning future interventions. Non-availability of India-specific study on how social distancing norms and other restrictions affected mental well-being of those who have already been experiencing isolation and a depleted social network prevented us from exploring this aspect in detail.

We are aware of the limitations of this report. The in-house survey of patients, residents of leprosy colonies, public health consultants, ASHA workers and students from vocational training centres is restricted to six states and UT: Andhra Pradesh, Chhattisgarh, Delhi, Maharashtra, and Tamil Nadu. The report also has constraints in terms of the sample size it reached out to. Collectively, we could reach out to around 400 respondents for getting first-hand information on the impact of COVID-19.

2a. Impact of COVID-19 on screening and diagnosis

In November 2020, more than seven months after COVID-19 lockdown was announced for the first time in India, the Pune administration launched a special drive to detect unreported leprosy cases in the district under the “Leprosy-free Pune” programme. As the existing machinery was overwhelmed due to the pandemic, the annual drive for detection of new leprosy cases and providing medication and treatment could not be carried out. The district, in the 11 months of 2020, reported only 118 new leprosy cases as opposed to more than 600 new cases it had reported in 2019.¹

In the eastern state of Odisha, screening, detection, and treatment of several bacterial and viral diseases such as malaria, tuberculosis and leprosy took a back seat after the outbreak of COVID-19, which called for mobilisation of a majority of workforce for handling this outbreak. The latest National Health Profile (NHP) released by the Union Ministry of Health & Family Welfare revealed that the leprosy prevalence rate in Odisha is the second highest in the country after Chhattisgarh. The disease is reportedly prevalent in 18 districts, but the campaign for fresh case detection almost stopped following the outbreak. The state government, at the end of 2020, decided to intensify leprosy screening in the high-prevalence districts and selected 208 high-endemic blocks in the first phase.²

How did states fare in terms of active case finding?

Eradicating leprosy and meeting proposed targets, as mentioned in the WHO Global leprosy strategy 2021–2030, depends largely on Annual New Case Detection (ANCD). The importance of active case finding, especially in high-endemic and hard-to-reach areas, is ever growing as the percentage of voluntary self-reporting of leprosy is almost miniscule. Therefore, the Government of India implemented house-to-house case detection from 2016 to 2019 under the Leprosy Case Detection Campaign (LCDC).

However, after the outbreak of COVID-19 and ensuing WHO recommendations on social distancing and lockdown, active case finding activities were suspended in most states since April 2020. In four states—Andhra Pradesh, Odisha, Bihar, and Madhya Pradesh—detection of new cases fell by 62.5% between April and September 2020, compared to the corresponding period in previous years. In 2019, the four states accounted for 35% of the total new cases reported in the country. These four states reported 22,000 new cases during April-September 2019, but only 8,270 for the same period in 2020.

Location	Leprosy cases in 2019	Leprosy cases in 2020	% age change
Andhra Pradesh, Odisha, Bihar, and Madhya Pradesh	22,000 (Apr-Sep)	8,270 (Apr-Sep)	-62.5%
Pune	600+	118	-80%

Source: Media reports

Two other worrying trends emerge. The proportions of multibacillary (MB) leprosy and grade-2 disability (G2D) among the new cases increased by 20% and 12%, respectively, during April-September 2020, compared to the same 6-month period in 2019. The proportion of both women and children among new cases decreased by 70% compared to the same two quarters in 2019. These figures were shared by the National Leprosy Eradication Programme (NLEP).³ Other Indian states may have experienced similar outcomes, especially when the second wave put brakes on LCDC for the entire second quarter of 2021 (April-June).

Estimates had suggested that six in 10 leprosy cases in the selected states could go undetected by the end of this fiscal year if active case finding activities were not implemented from October 2020–March 2021. “We hypothesise that even if ACF activities are implemented during the next 6 months (October 2020–March 2021) many new cases will be missed. Grade 2 disability rates will probably increase further this year (2020). An important proportion of women, children and marginalised communities will go undiagnosed this year (2020),” the LEpra study claimed.

Some states are already witnessing a turnaround by virtue of their consistent focus on early detection. Let’s consider Indore. Early detection of cases in Indore—a district with a prevalence rate of more than one infection per 10,000 population—has reportedly⁴ helped in preventing grade 2 disability in the last two-and-a-half years. Between April-July 2021, the authorities identified over 206 new leprosy cases, which is almost half of total infection reported from April 2020-March 2021. Interestingly, of those 206 cases, only one person was found with grade two disability till August 31.

District leprosy in-charge, Dr Madhav Hasani said, “In the last two-and-a-half years, the detection of new leprosy cases has increased in the district helping in prevention of grade two disability. Even when we are severely affected with COVID-19, the case detection is high this year in the first four months, said Dr. Hasani.”

After a setback in detection of cases due to the second wave of COVID-19 in April-May 2021, the district threw its weight behind the activity and launched an active case detection survey through 526 teams from July 19 to August 31 in endemic areas. It helped in detection of 158 new cases. The infection level of leprosy is low this year in the district in comparison to the last year.

Similar outcome was witnessed in Odisha, when the three-month-long (May 24 – August 23) house-to-house survey to identify people with COVID symptoms led to the detection of 1,625 leprosy cases, along with 76,816 new cases of hypertension, 56,552 cases of diabetes and 7,399 new TB cases. Even as Odisha had declared itself a leprosy-free state in 2006-07, the detection of fresh cases from across districts suggests otherwise.⁵

Challenges in early screening of leprosy during COVID-19

Travel restrictions, social distancing norms and overwhelmed healthcare services and frontline health workers are some of the factors that collectively contributed to the suspension of active case finding activities in different states, which, in turn, affected early

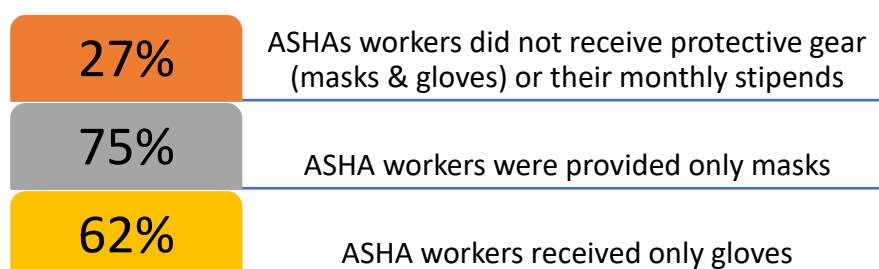
detection of people affected by leprosy. There is palpable fear in the communities about the virulence of different strains of COVID-19 virus, which turned more aggressive during the second wave.

Sushila Verma, an ASHA worker from Chhattisgarh's Janjgir-Champa district, witnessed people's reluctance to get themselves screened for leprosy as a lot of scaremongering had already happened due to COVID-19. Like the stigma associated with leprosy, fear of COVID-19 and people dying in hospitals were enough motivations for them to hide their disease.

While ASHA workers like her continued to visit the households despite a raging pandemic, they were also under the grip of fear. "I did not have sanitisers and gloves to keep myself protected during a door-to-door survey in the time of COVID-19. I used to feel scared. While touching patients for screening of leprosy, I used to have this fear at the back of my mind that I might be putting my family at risk. I have two small children. In non-COVID times, we would visit a household, talk to an individual at length and then do screening of leprosy by touching them or through pen, but this time, with social distancing norms being followed, it was hard for us to discuss and understand the person's condition," said Taravati, an ASHA worker from Uttar Pradesh.

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ASHA workers like her play a crucial role in screening for leprosy, contact tracing, and engaging in sensitisation campaigns among people. The rural healthcare system rests on ASHAs, who fill in for the shortages in qualified medical personnel. They try to detect new cases at an early stage by door-to-door screening of people and referring suspected cases to a medical officer. However, a survey by Oxfam India and its partner organisation revealed that about 27% of the ASHAs workers in Uttar Pradesh, Odisha, Bihar, and Chhattisgarh did not receive protective gear (masks and gloves) or their monthly stipends. While only 75% ASHA workers were provided only with masks, and only 62% received gloves to perform their duties. This is despite the evidence that use of masks reduces the transmission rate of coronavirus infection.⁶



Source: Oxfam India

According to a report by the NLR - until No Leprosy Remains, the number of newly diagnosed patients globally reduced by up to 70% compared to 2019. "Late diagnosis and treatment lead to continued transmission and an increase in the number of people living with disabilities due to leprosy. Consequently, the number of contacts screened and receiving preventive SDR-PEP (Single Dose Rifampicin Post-Exposure Prophylaxis) also reduced by as much as 90% globally and stopped completely during lockdowns in some areas," the NLR report suggests.⁷

The number of newly diagnosed leprosy patients globally reduced by up to 70%, and the number of contacts screened and receiving preventive SDR-PEP reduced by as much as 90% globally and stopped completely during lockdowns in some areas. – NLR

Leprosy screening activity was either paused or scaled down at a time when it was needed the most, especially when the same restrictions, which were imposed to prevent COVID-19 transmission, also increased the risk of increasing leprosy cases. With the vulnerable population living in overcrowded and poor living conditions, staying in such an environment round the clock may have further heightened the risk of leprosy. Travel restrictions prevented most of them from going out and pursuing their livelihoods, creating impending food insecurity, which is another important risk marker for leprosy.

Government's efforts

In 2020, as a part of the National Leprosy Eradication Programme (NLEP), the government took decisive steps towards ensuring early screening for leprosy among the vulnerable population. It announced new operational guidelines for "Active Case Detection & Regular Surveillance" for active case detection throughout the year. To ensure leprosy screening of children (0-18 years), the government included this activity under the Rashtriya Bal Swasthya Karyakram (RBSK) and Rashtriya Kishore Swasthya Karyakram (RKSK) and issued a detailed screening guidelines to all the States and UTs.

The Ministry of Health & Family Welfare also included leprosy screening under Comprehensive Primary Health Care (CPHC), Ayushman Bharat for population-based screening of women and men of 30 years and above. Similarly, training & skill upgradation of the primary health team in all functional Health and Wellness Centres was undertaken. To ensure screening of peri-urban and urban slums / colonies and migratory population, Urban Leprosy Screening was included under the National Urban Health Mission (NUHM).

With active case finding activities gradually picking up in states, it is important not only to plan vertical and systematic ACF campaigns to identify the backlog cases, arrest transmission and address the decline in numbers of women and children being diagnosed, but also to screen people beyond household contacts, argued LEPROA.

2b. Impact of COVID-19 on Access to Treatment

Kewali Devi, a 73-year-old leprosy patient, developed an ulcer on her right leg. Due to the lockdown, she could not travel beyond her village in Mirzapur district of Uttar Pradesh. Hence, she consulted a local practitioner, who covered the ulcer with some crepe bandage, which worsened it further. She had to wait for months before the lockdown was eased and she could reach The Leprosy Mission Hospital Naini on another doctor's recommendation. By then, the wound had grown more extensive and complicated, leaving the doctors with no other option other than doing a below-knee amputation. "Doctors told me that the delay has allowed the infection to spread, and they would not be able to save my mother's leg. Travel restrictions made us wait for so long," rues her daughter Reeta Devi.

Doctors told me that the delay has allowed the infection to spread, and they would not be able to save my mother's leg. Travel restrictions made us wait for so long. - Daughter of Reeta Devi, a leprosy patient who had to undergo leg amputation

Samme Lal Jangade—a resident of Baloda Bazar district in Chhattisgarh—had just completed the first month of the 12-month course of MDT for multibacillary leprosy when the nationwide lockdown was announced in the second-half of March 2020. For the next one year, he could not travel. It was when his simple ulcer on left foot turned into a complicated ulcer with maggots on it that he decided to leave aside the fear of COVID-19 and approached a mission hospital in the neighbouring district, Janjgir-Champa.

These are not one-off stories, but a small piece of the puzzle. Along with early detection, timely and effective treatment is one of the cornerstones for leprosy control and elimination. When the first wave of COVID-19 hit India, the WHO released a set of recommendations. It emphasised on continuing clinic-based patient care, including diagnosis, treatment of reactions, and doing nerve function assessment to reduce risk of disability. It also stressed on the need for contacting patients undergoing leprosy treatment by phone or through social media to ensure they are taking all possible precautions against COVID-19. It also recommended providing MDT supplies to patients for 2-3 months to reduce attendance at a healthcare facility.

But, how much of that translated into reality?

Access to healthcare facilities

With the large share of the country's healthcare workforce deputed for COVID-19 work, activities such as regular leprosy screening camps and contact tracing were interrupted. This, in turn, led to delayed diagnosis of leprosy from the community. "We registered more new cases in the first-half of this year (2021). More patients with reaction and neuritis got admitted to our hospital after the first wave," said a medical superintendent of one of the leprosy hospitals in Tamil Nadu. It is a clear indication of the backlog of undiagnosed and unreported leprosy cases, which are now surfacing after the easing of lockdown restrictions.

There had also been instances where patients, who had leprosy relapses, could not access a hospital despite waiting for weeks. Take the example of Vishwanathan—a leprosy patient, who completed MDT many years ago, recently presented with reactions at The Leprosy Mission (TLM) hospital in Vadathorasalur (Tamil Nadu). “I had developed severe pain, swelling and nodules just above my eyeballs, and could not use both my hands. I had lost sensation in both my hands and feet. I feared death, hence, consulted a local health worker. He promised to take me to a government hospital. I waited for two weeks with no help in sight. Meanwhile, a neighbour informed me about the hospital in Vadathorasalur. My wife and I decided to visit there. I was admitted to the hospital on the same day. I am now better, only the loss of sensation in hands and feet remains,” said Vishwanathan.

One of the other fallouts of lockdown and restrictions on mobility is the worsening of conditions of those patients who were undergoing treatment for complicated ulcers and reactions. When the lockdown was eased, the TLM hospital saw ulcer patients coming with cauliflower growth (ulcer turning malignant), with maggots and with bone damage, which happens due to prolonged absence of treatment and care.

The situation in Delhi’s Tahirpur—one of the largest leprosy colonies in India—was not very different. “Every day, we see between 100-150 patients who come for ulcer care. They are mostly leprosy patients. During the lockdown, only 50% of the patients could visit us. People who got stranded elsewhere, could not come for their regular care,” said Pramod, member of Samarpan Foundation Trust, a non-profit organisation involved in management of ulcers & complications through its clinic at Tahirpur. What must have happened to these people who couldn’t come for treatment for months? He does not know.

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Pramod is concerned over the fact that some of the healthcare organisations dedicated to leprosy decided to stop functioning during the first wave of COVID-19. “This should not have happened. Except for the first month (of the 77 first wave of COVID-19), we remained open and continued to work without PPE kits for days. Come what may, leprosy care should not stop,” he argued. To prevent a repeat of what happened, he has an appeal for the Delhi government: ensure that government dispensaries and Mohalla clinics provide ulcer care and other leprosy-related services so that no person affected by leprosy remains untreated.

Access to MDT and other leprosy-related treatment

In her submission to the Human Rights Council in July 2021, Alice Cruz, the UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy highlighted the complaints received from 10 countries from mid-2020 to the beginning of 2021, about the shortage of MDT.

MDT is provided free to the patients, in accordance with the WHO and through their agreement with Novartis, a pharmaceutical company. The drugs are manufactured in India and the WHO oversees the delivery and supply chain. During the COVID-19 pandemic, there had been a lack of information on delivery of drugs to new and existing leprosy patients.

Some of the leprosy hospitals in the country, especially in Tamil Nadu, reported interrupted supply of MDT and steroids. As these hospitals did not get usual supply of MDT from the government since March 2020, they had to buy the medicine. Those patients, who did not get their MDT from the primary health care centre, came to TLM hospital to collect it.

In the neighbouring states as well, the stocks at the block level did not always reach the Primary Health Centres (PHCs) on time. Frontline health workers (ASHAs) were engaged in COVID-19 work and there had been some delay in delivering MDT to the people. But what led to this scramble for MDT? What could be the long-term implications?

Media reports confirmed that the lockdown measures interrupted key transport routes needed by the Novartis to manufacture and supply MDT, thereby putting patients' access to MDT at risk. The reports suggested that in March 2020, manufacturing and supplying MDT became a challenge for Novartis as COVID-19 spread and India ordered a nationwide lockdown, including the partial closure of air and sea routes.⁸ Back in June 2020, the WHO had alerted us: it is crucial that MDT stocks are properly managed, distribution of MDT continues and that MDT orders are placed on time.

Among communicable diseases, leprosy is the leading cause of disability in the world. When patients do not take MDT regularly or adhere to treatment compliance, not only does healing get delayed or incomplete, but the disease activity also progresses, and the patient may develop serious disabilities and deformities. Moreover, these patients will become a source of infection to the community, in addition to perpetuating stigma generated by the sight of the deformities. What is even more concerning is that if the irregularity is selective to one or the other drug in MDT, there is a possibility of drug resistance to multiple drugs.

This does not augur well for leprosy patients, more so because they are already vulnerable to COVID-19. According to Dr Barbara De Barros, clinical research fellow and doctor of infectious disease at the London School of Hygiene and Tropical Medicine, COVID-19 could have a potentially devastating impact on those suffering from leprosy reactions. "The corticosteroids used to treat leprosy reactions significantly alter the immune system. These people are at high risk of developing severe COVID-19 because of this."⁹

The challenge was not the interrupted supply of drugs alone. According to Vijay Prathap—a Public Health Consultant with the Hind Kusht Nivaran Sangh (HKNS)—hospitals in Delhi-NCR that offer leprosy treatment were mostly out of bounds for people affected by leprosy. "Most of the hospitals, including the nearby GTB hospital, stopped giving leprosy medicine as they were converted into COVID-19 centres. People with other medical needs were prohibited from entering the hospital. When I started receiving distress calls from patients

about not getting MDT, a centre was opened at the Lal Bahadur Shastri Hospital, especially to provide leprosy medicine, with the support of the State Leprosy Officer,” said Vijay.

Vijay is responsible for collecting data on patients in Delhi-NCR and doing door-to-door patient visits to see if they are complying with the treatment. He identifies defaulters and then again gets them back to the treatment regime. “There were already issues of migrant workers getting MDT in one state for a few months and then stopping medicine after going back home, thinking they have been cured,” he added.

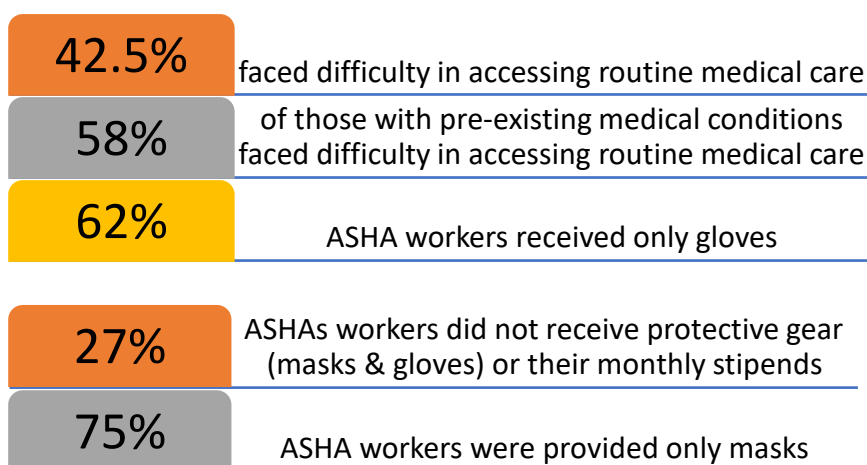
“During lockdown, patients called me to enquire how they will get access to ulcer care. We reached out to NLR India to collect materials for dressing, but then not everyone knew how to dress deep ulcers. While the government dispensaries provide dressing materials, they do not provide dressing services,” Vijay expressed concern.

Access to Disability Management Services

The challenge in accessing healthcare service was not limited to leprosy, as it had a stonewalling effect on people with other disabilities as well. According to a collaborative research study¹⁰ by CBM India Trust, Indian Institute of Public Health, and Humanity & Inclusion, done across 14 states, 70.7% of the respondents believed that the government has not given any special considerations to persons with disability during the lockdown, especially in terms of access to vital information and rehabilitation /therapy support.

Two out of every five people (42.5%) with disability reported that lockdown had made it difficult for them to access routine medical care. Among those with pre-existing medical conditions (12.7%). Moreover, 58% reported having faced difficulty in accessing routine medical care. It means, PwDs with antecedent medical problems suffered significantly more than those who did not have an antecedent health condition. While 75% found it difficult to access rehabilitation services, nearly 25% reported difficulty in getting medications, and 28% reported postponing scheduled medical appointments because of lockdown.

Impact of lockdown on PWDs in 14 states



Source: CBM India Trust, Indian Institute of Public Health, and Humanity & Inclusion

People undergoing leprosy treatment need to visit hospitals regularly for their routine medical needs such as blood pressure monitoring, ulcer dressing, medicines (MDT blister packs and steroids), and MCR footwear. With public transport becoming out of bounds because of nationwide lockdown, the scope for getting healthcare and disability management services in institutional setup reduced. There were growing concerns over conditions getting worse for people with anaesthetic feet and feet ulcer, and people with leprosy developing contractures, all due to non-availability of service.

COVID-19 lockdown exposed another layer of challenge that PwDs face. Physical therapists and other allied healthcare professionals are predominantly available at the district or state level in urban areas. For patients in remote areas, accessing these specialists at district centres regularly is not feasible. For example, in two districts of Tamil Nadu—Cuddalore and Villupuram—the therapy service was available only in the district hospitals located between 70km and 120km away from the target communities, respectively. The therapy services in these districts lack technical expertise to manage leprosy-related disabilities. Economic hardship prevents these communities from accessing therapy services in private clinics.

Due to the deeply entrenched stigma of leprosy in the communities, leprosy patients already have a limited social network to depend on. COVID safety protocols like social distancing made it harder for them to tap into that network to seek help. Under such circumstances, reaching out to the last-mile person in far-flung areas is crucial. The Leprosy Mission Trust India took a step in that direction and started operating its mobile therapy clinic in three districts of Tamil Nadu—Cuddalore, Villupuram and Kallakurichi. All the services one expects in a fully functional hospital, are squeezed into a well-equipped van.

A team of physiotherapists, occupational therapists, prosthetic and orthotic technicians, community health workers and community volunteers, with the help of the mobile clinic, reached out to communities. People affected by leprosy with plantar ulcer underwent ulcer dressing and callus debridement in the mobile clinic. People with below-knee amputation underwent stump management and pre-ambulatory training. Measurements for Plaster of Paris (PoP) moulds were taken for making below-knee prosthesis (artificial limbs) and the appliances were delivered in the follow-up camps.

The mobile clinic also provided teleconsultation services on ulcer care, ophthalmology and services related to reconstructive surgeries. Patients in hard-to-reach areas were able to consult medical experts. This intervention made it possible to reach the most vulnerable with the most advanced care, most importantly, at a time when most other health care facilities were focussing only on treating COVID-19 patients.

2c. Impact of COVID-19 on livelihood

Persons with disabilities are less likely than others to be employed; and when employed, they are more likely to be employed in the informal sector. The irregular nature of their work makes them vulnerable. They have less access to social protection and productive assets as compared to others, which decreases their economic resilience in the times of contingencies, especially COVID-19. As a part of the informal economy workforce, they either survive on a meagre income or live in poverty. Their vulnerability stems from how they are perceived by society.

According to the International Committee of the Red Cross (ICRC), “For persons with physical disabilities, the ability to achieve economic security and independence has very often been a goal kept out of reach by a variety of societal assumptions about their ability—or inability—to reliably fulfil professional requirements, their perceived increased rate of health-related absences or a host of other preconceptions.”¹¹

The PwDs have already started proving these assumptions wrong, but with the COVID-19-led lockdown and working from home becoming the norm, they found themselves amid another challenge. Most of them face increased risks of losing their job and income as they could not continue working from home due to the absence of equipment and support, which are available in their workplaces. The COVID-19 measures indirectly affected PwDs and prevented breadwinners of their household from working, affecting overall income of the household.

This lack of income, according to the UN Office of the High Commissioner for Human Rights, represents a disproportionate burden on PwDs and their households, which generally face extra costs and expenditures related to disability (accessible housing & equipment, assistive devices, specific goods, and services, etc.), pulling them more rapidly into poverty.¹²

“People with disabilities, who mostly have entry-level jobs in different sectors, have suffered massive job losses during the COVID-19 crisis. Many of them are the only bread earners in their families. The emotional cost of being unemployed is high as a lot of them are considered a burden by their own families,” says Arman Ali, Executive Director, National Centre for Promotion of Employment for Disabled People (NCPEDP). The NCPEDP study titled, ‘Locked Down and Left Behind,’ claims that 73% of the people surveyed (1,067) had faced severe hardship and challenges during the pandemic and 57% reported facing an employment-related financial crisis.

People with disabilities, who mostly have entry-level jobs in different sectors, have suffered massive job losses during the COVID-19 crisis. Many of them are the only bread earners in their families. The emotional cost of being unemployed is high as a lot of them are considered a burden by their own families. - Arman Ali, NCPEDP

People had to dip into their savings and were forced to take loans from local money lenders. A survey by Centre for Advocacy and Research (CFAR) suggests that more than 70% of the respondents have borrowed money from moneylenders to manage household expenditure. While some pledged their jewellery; others took support from extended family; a few took loans from Self Help Groups, even as they struggled to pay for household expenses like rent and electricity.

Shyamla, a 32-year-old woman affected by leprosy, hails from Vizianagaram district in Andhra Pradesh. Her story is a common refrain across the entire spectrum of people with disabilities. “After I got trained in dress making at the TLM vocational training centre for 1 year, the organisation provided me with a sewing machine so that I can start my business. However, the pandemic made it too hard for us to survive. No one was willing to give us clothes for making dresses. My health also started deteriorating, and I was unable to go to hospital for a check-up. As my husband was not willing to take care of me, I stayed with my parents. No one is willing to help us. My financial condition has been deteriorating day by day. I have a daughter, and I am struggling to raise her,” said Shyamla.

Not far away, Satyavathi was also struggling in silence. She is a dressmaker by training and a person affected by leprosy. “After completing my training in dressmaking from the TLM Vocational Training Centre, I rented a shop in my village and started my business. Because of the lockdown, the shop had to be closed. I used to stay with my father, who was suffering from kidney problems due to which he could not go out and work. During the second wave of the pandemic, my father contracted COVID-19. We both struggled but were not able to reach out for help. After a few days, my father expired. When I also tested positive for COVID-19, I isolated myself in one room for a month and I felt very low. No one helped me during that time.”

Like Shyamla and Satyavathi, the “city-makers” like the daily wage workers (seasonal and circular), street vendors, auto or rickshaw drivers, construction and utility workers found it onerous to survive amid no work and lack of social protection. While there was an acknowledgement of the need for social distancing and self-isolation, there were growing concerns over adding to the severity of economic and social impact that the lockdown would have on the country.¹³

People affected by leprosy and disabilities were forced to slip into the very seclusion from which they have been trying to come out of for many years. Just as they have begun to find the first tiny openings in their ability to access education or gain regular employment, the isolation necessitated by the pandemic threatens to slam those doors closed once again.

Question of survival

While the plight of migrant workers was reported widely in the media, and justifiably so, there are others whose stories were never really heard. People affected by leprosy and other disabilities were one among them. According to Mr. Ghasiram Bhoi, President of the State Leprosy Rehabilitation Committee of Chhattisgarh, residents within and outside the 34 leprosy colonies in the state have been affected due to prolonged and frequent lockdowns. “While a significant number of these people are still into begging, others have been trying to

do something on their own by setting up small shops and getting into weaving and other semi-skilled and informal work. Lockdown disrupted their small businesses and prevented people from going out for work. Hence, their survival was dependent on relief work of the government and NGOs,” he said.

Ghasiram feels that people affected by leprosy and disability do not have the resources to rebuild their small enterprises, which might again push them to begging, which is already a huge concern. “We need to focus more on transitioning these people from begging to a dignified livelihood, which builds their resilience,” added Ghasiram.

In neighbouring Madhya Pradesh, the situation is reportedly grim as well. In response to the rise in infections, the state went under lockdown to curb the spread of the virus. Hence, villagers, who are mostly daily-wage workers or street vendors in nearby towns, have lost their livelihoods. “While remittances from family members working in big cities were relied upon to boost the income of rural households, the rise in cases in the urban areas beginning in early February led to another exodus of migrant workers from those cities, like what occurred in 2020 during the first wave and nationwide lockdown. Rural households suffered losses in household incomes as a result, pushing many to deeper indebtedness and worse hunger,” noted a report from the Observer Research Foundation.

A joint statement issued by the ILO, FAO, IFAD and WHO on October 13, 2020, warned about the impending crisis of mass starvation. “Without the means to earn an income during lockdowns, many are unable to feed themselves and their families. For most, no income means no food, or, at best, less food and less nutritious food.”¹⁴ More worryingly, it is poor nutrition that leads to increased susceptibility to some of the chronic infectious diseases, especially leprosy.

About two-thirds of nearly 4,000 people interviewed by Hunger Watch—a collective of social groups and movements—reported that the quantity of food they consumed in October 2020 had either “decreased somewhat” or “decreased a lot” compared to the pre-lockdown period. “Even more calamitous than this was the impact of the lockdown on socially vulnerable groups, such as households headed by single women, households with people having disabilities, transgendered people, and old persons without caregivers. In our survey, 58% of older people without caregivers had to sometimes sleep at night without a meal. This was also the case with 56% of single women-headed households, and 44% of households with persons with disabilities,” Harsh Mander noted in the preface of the report.¹⁵

Even more calamitous was the impact of the lockdown on socially vulnerable groups, such as households headed by single women, households with people having disabilities, transgendered people, and old persons without caregivers. – Harsh Mander

Among the economically and socially vulnerable groups surveyed by Hunger Watch, there is evidence of a sharp fall in the consumption of food grains, pulses, vegetables, eggs, and meat, as compared to the pre-lockdown period. The collective observed that a direct rise in

unemployment has led to a serious decline in incomes, and in food access and consumption. In fact, many sustained themselves on the grocery and dry rations provided by the state governments, NGOs and socially concerned individuals.

While the situation was similar across the country, it was different in Tahirpur leprosy colony in Delhi. The Community Intervention Unit (CIU) of The Leprosy Mission Trust India's (TLMTI) hospital, in Shahdara, has been working in 29 leprosy clusters in Tahirpur and had formed 29 Self-Help Groups (SHGs) with 452 members, including people affected by leprosy and other disabilities. Long before the lockdown happened, TLMTI had trained them on various home-based businesses like production of phenyl, petroleum jelly, and incense sticks to help them move towards social and economic empowerment. With the lockdown, their daily wages snapped, and their savings depleted.

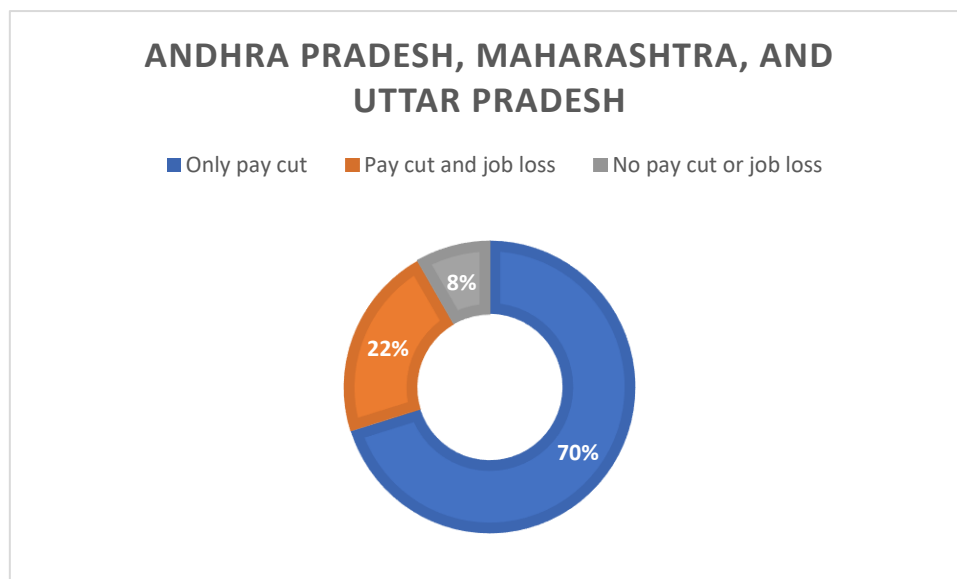
To navigate through the crisis, the members were encouraged to take loans from their respective SHGs and start businesses that supply essentials. While some of them took loan and started selling vegetables and fruits on carts to sustain their families, others started stitching face masks and bags from locally available clothes for helping COVID 19-relief and response work, like distribution of groceries and hygiene kits. "When our income dried up because of the lockdown, we were left in the lurch. With our SHGs supporting us, we could tide over the crisis," said one of the SHG members.

Not everyone, however, had access to such support systems. According to a *pradhan* (Head) of the Shanti Samiti of the leprosy colony, there are some 600 people from the colony who work as sweepers under the MCD (Municipal Corporation of Delhi). They had got the job under the 4% quota for PwDs. Rest all are either looking for jobs or earning their living as small vendors. "I also work as a MCD sweeper in the morning and put up this food stall in the second-half of the day for some additional income. But there are people in the colony who have serious deformities. Begging is the only livelihood they know. Their children, however, are educated and capable of doing a job, but they are not getting any. My daughter, who speaks English and knows how to operate a computer, lost her job because of the lockdown. Young and educated people are now earning their living as small vendors or rickshaw-pullers," he rued.

Impact on Youth with Leprosy and Other Disabilities

The outbreak of COVID-19 and the ensuing economic shutdown was a setback for the young, skilled, and job-ready population. Findings of an online and telephonic survey of graduates who passed out from vocational training centres across three states point to a concerning trend.

Out of the 181 individuals surveyed across Andhra Pradesh, Maharashtra, and Uttar Pradesh, 166 (92%) reported that COVID-19 pandemic not only affected their job prospects, but they also had to receive pay cuts in their existing jobs. About 24% (39) of them first received pay cuts and then lost their jobs. Most of these individuals either have a background of leprosy, other disabilities or they belong to marginalised communities.



Source: The Leprosy Mission Trust India

These numbers don't really explain the struggle. Prajwal Prakashan Dondalkar, a trained mechanic for motor vehicles in Maharashtra and a graduate of 2018 is worried about his future, "My condition is bad; I lost my work due to the pandemic. This led to a major cut back on my household earnings. I don't know how long things can go on this way," said Dondalkar, whose concern resonates among skilled and market-ready youth, especially those in resource-poor settings.

Jayesh Lokhande, a diesel mechanic, had launched his business before the lockdown. "Because of the decline in business activity, it has become difficult to even get my monthly expenses covered," he said. "I did not receive a salary for a few months. I had to borrow money to pay for my food and room rent," said Suraj Dadaji Randaye, who graduated as computer operator and programming assistant in 2020. Dhamma Jamnik, a diesel mechanic by profession, received only 60% of his salary for six months—May 2020 to November 2020.

Impact on Women with Disabilities

Like many others, for women with disabilities, access to work and livelihood have been adversely affected due to lockdown. Loss of livelihood is not just an economic setback for them as their economic empowerment is linked to their position in the households. No financial contribution to the family results in abuse and marginalisation.

According to the Survey of Persons with Disabilities conducted by the National Statistical Office (NSO) India in December 2018, Labour Force Participation Rate among women with disabilities was 8% as against 36.8% for men with disabilities. Most women with disabilities find that self-employment and working in the unorganised sector are often the only options left with them. COVID-19 did not leave them with these options as well.

A study initiated by Rising Flame,¹⁶ in collaboration with Sightsavers, during the first wave of COVID-19 in 2020 points to that. A total of 82 women with disabilities across 19 states and

nine self-identified disability groups participated in the study. Half of the respondents reported facing challenges in getting access to work and livelihood. Losing livelihoods and jobs was the most common concern that all the women respondents had.

The study revealed how 25 women with locomotor disabilities, who are residents of rural Rajasthan, Bihar, Jharkhand, Chhattisgarh, Madhya Pradesh, Maharashtra, and Odisha, reported not having computers and good internet connection at home. Ever since the lockdown was announced, they have been struggling to perform official tasks on their smartphones with intermittent internet connectivity. The respondents felt that there would be downsizing of staff and within that, women with disabilities would be the ones to be laid off first. Losing jobs, declining income, uncertainty about the rebound of the economy: all lead to loss of the sense of pride and dignity that came with financially supporting the family. Most respondents expressed concern about it.

2d. Impact on Access to Education

While the pandemic has been hard for all communities, a section of demography that has been hanging by the thread is school students. With COVID-19-led restrictions making digital and online space the only option, the education sector suffered a jolt. Teaching has not been the only issue; learning through virtual means and assessment have been hard for the students to get used to as well. More so when the students have some form of disability.

According to the State of the Education Report 2019 for Children with Disabilities by UNESCO ¹⁷ based on Census 2011, there are 7,864,636 children with disabilities (CwDs) (up to 19 years) in India, which makes up 1.7% of the country's total child population. Of them, 5,572,336 were up to 14 years old at the time of the Census.

The report demonstrated low education rates among CwDs: Of the total 6,572,999 children in the 5-19 age group, only 61.18% (4,021,301) have attended any educational institution. This was well below the national average of 70.97% for children in all categories.

About 26.68% (1,753,737) of CwDs have never attended any educational institute as compared to the national average of 17.21%. About 12.14% (797,961) attended one but dropped out later.

It is evident from the report that CwDs are already less likely than others to complete education, and more likely to be excluded altogether from schooling. Moreover, they are more likely to belong to socio-economically worse-off households as compared to other children. Hence, inaccessibility of education for many CwDs is, thus, also a function of poverty.

Because of COVID-19, most states temporarily closed education institutions. To reduce the impact of disruption in education, some states adopted remote learning practices. This proved an additional barrier for students with disabilities owing to the absence of required equipment, poor access to internet and other accessible materials and support necessary for them to follow online classes. Furthermore, students with disabilities were also affected by other dimensions of school closures, including access to school meals and opportunities to play and interact with their peers.

As students were left with no choice but to accustom themselves to the "new normal" of online schooling, pre-existing learning inequalities were magnified. These gaps, brought about by socio-economic differences, manifested themselves in educational access, participation rates, and learning outcomes. With online and remote learning being far less effective than the teacher-driven, physical classroom mode, students have suffered, what a report by Azim Premji University called, 'regression in learning'. According to the report, the experience is shared across India's vast socio-economic spectrum. ¹⁸

With online and remote learning being far less effective than the teacher-driven, physical classroom mode, students have suffered regression in learning. – Report by Azim Premji University

Infrastructure deficit

A two-month study (Sep-oct 2020) ¹⁹ by Vidhi Legal Policy across four states—Andhra Pradesh, Karnataka, Kerala, and Tamil Nadu—suggested that the allocation of resources between children in a household was affected by the disruptions in delivery of entitlements under government support schemes, which their parents and caregivers depended on. With households facing job losses and increased debts, it is not surprising that digital devices and high-speed internet became out of reach.

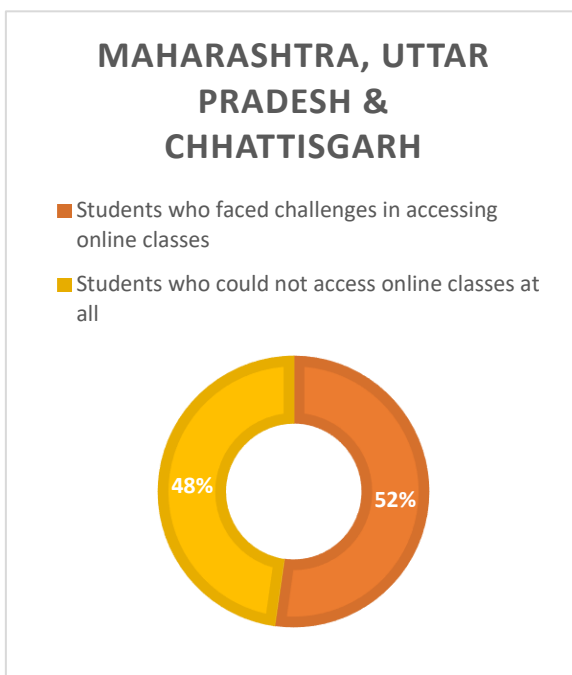
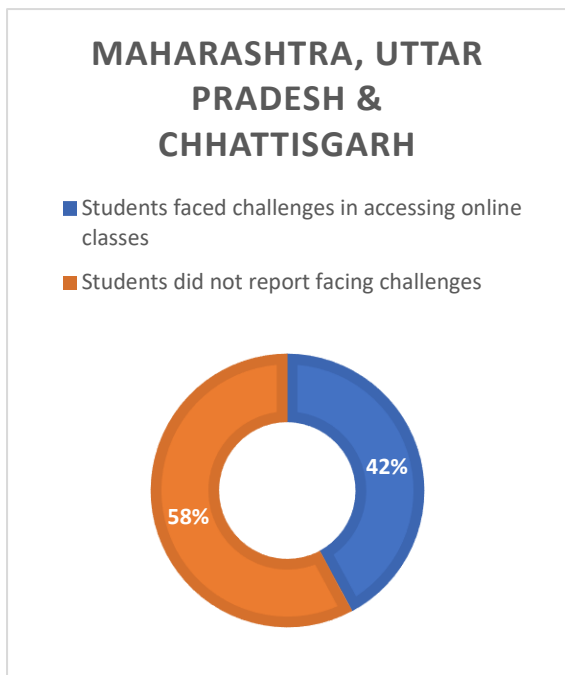
P. Lokesh from Vizianagaram in Andhra Pradesh shares his experience of carrying on with education in these difficult times. He hails from a poor household and his mother is the sole breadwinner after his father passed away. “I don't have a smartphone to attend online classes, and my family was not able to bear the extra cost. During lockdown, we barely survived. My interest in education made me go to my friend's house who used to write notes after online classes. I used to take notes and prepare for myself and attend exams.

Unlike him, not everyone has access to the social capital—helpful neighbours and friends, etc. Zakir, a 13-year-old from Barabanki in Uttar Pradesh, is one such example. “Because of my leprosy, friends stopped talking to me. I was left alone and unable to study. I was told that there will be online classes due to COVID-19 lockdown. My friends, who had smartphones, could attend the classes, but I was unable to visit them because of leprosy. My father struggles to feed us. He did not have enough money to provide me Smartphone for online classes. I suffered from all possible ways,” said Zakir.

Job losses and consequential losses of income directly affected a family's ability to pay rent, school fees; meet day-to-day expenses; and for many, it became difficult to even manage the basic needs such as food. Take the example of Yashoda Sahu from Chhattisgarh. She is doing a diploma in medical lab technician from a vocational training centre. During COVID-19, her grandfather passed away, and because of that her mother had to leave her job to take care of the household. It led to a significant decline in their household income.

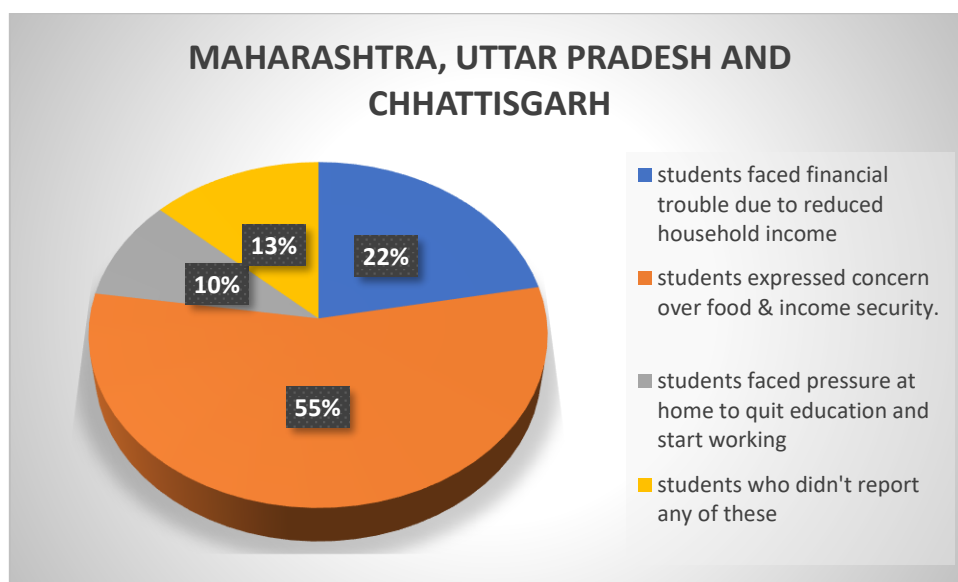
Like Yashoda, around 700 other students get trained at The Leprosy Mission's Vocational Training Centres (VTCs), which provide skilling to students affected by leprosy, other disabilities and are from marginalised sections of the society. A mix of online and a telephonic survey of 280 students in our vocational training centres across four states—Uttar Pradesh (24), Andhra Pradesh (121), Chhattisgarh (69), and Maharashtra (66)—reveals quite a few concerns.

While 67 (42%) out of 159 students across three states—Maharashtra, Uttar Pradesh, and Chhattisgarh—reported facing challenges in accessing online classes, 32 (48%) out of those 67 said they could not access online education at all.



Source: The Leprosy Mission Trust India

Worryingly enough, 15 students (9.5%) admitted to the pressure they had received at home to drop out of school and start working. More than 22% of the students (159 across 3 states) reported experiencing financial trouble due to reduced household income: between 50% and 80% in some cases. This perhaps explains why more than 55% of students expressed concern over food and income security.



Source: The Leprosy Mission Trust India

Out of 280 students across four states, 112 (40%) students felt that their job prospects have dimmed due to the closing down of organisations during the pandemic.

Low technological literacy and other issues

While lack of infrastructure has been an issue, low digital literacy further prevented students from accessing online education. A study by Vidhi Legal Policy revealed that most CwfDs faced challenges in navigating online modes of instruction, largely due to the lack of technological know-how among their parents. Even the teachers faced similar difficulties. Poor technology literacy confronts both parents and students because most of them rely on basic phones. According to a 2020 Goldman Sachs report, “India Internet: A Closer Look Into the Future”, only 42% of all mobile phone owners in the country had a smartphone in FY2020.

Most of the students surveyed in the study by Vidhi Legal Policy reported having difficulty in understanding lessons and completing assignments, even those who could access classes regularly. Students having visual and hearing impairments reported unique issues with accessibility of the learning materials, such as lack of subtitles or sign language interpreters for audio-visual lessons.

Moreover, children with disabilities require routine and emotional support as well as therapy and personal attention for their overall development. Physically attending schools help them learn effectively. More than just education, schools offer them a social environment of normalcy and acceptance. Traditional classroom education offers the benefit of face-to-face interactions with peers, which are typically moderated by a teacher. It provides children with a stable environment for social interactions.

Much of this is not possible in online classes. “E-learning platforms cannot replicate the various dialects, varied contexts and different life experiences that are brought together by physical classrooms,” argue experts.²⁰ Moreover, online learning calls for significant investment in mobile phones, computers, internet, etc. This is a burden on the family of students with disabilities. For a household having a child affected by leprosy, trips to healthcare facilities for treatment and follow-ups is itself an expensive affair. Additional expenditure for pursuing online education might discourage many from carrying on.

COVID-19 and resultant lockdown may have compelled the education system to quickly devise and apply different modes of remote learning (radio, TV, and different online tools), but they also brought to the fore the growing inequality of access to education technology and hence, educational opportunity.

Recommendations

The impact of COVID-19-led lockdown on people affected by leprosy and other disabilities has been layered. It reduced their chances of getting early diagnosis, limited their access to treatment, disrupted their livelihoods and put a question mark on their education. Since April 2020, individual experts and organisations recommended a slew of changes, and sometimes, a complete overhaul of existing structures, to protect and better address the needs of the already vulnerable group if the next contingency hits us.

Here's a list of recommendations that we have curated based on our secondary research and one-on-one interviews with our staff and partners.

On early diagnosis and treatment

- The Indian Association of Dermatologists Venereologists and Leprologists (IADVL) Special Interest Group (SIG) on leprosy,²¹ recommends advising health centres to dispense MDT blister packs and other treatments to all leprosy patients who approach them, even if they are registered with other centres or the private sector, till the time a contingency situation doesn't ease up.
- The Union Ministry of Health should be requested to inform state and district health centres to make provision for extra quantity of MDT blister packs and medicines to provide for three months of MDT for all registered patients, old and new, in case of similar contingencies.
- ASHA workers or other healthcare workers in each region should be able to send SMS in local languages to the patients regarding collection and continuation of the MDT. The Leprosy Mission Trust India introduced tele-counselling services²² for people affected by leprosy and other disabilities across states.
- Leprosy patients, who develop acute signs and symptoms of lepra reaction/new nerve function impairment/neuritis during regular treatment or any drug allergy or adverse effects, should be able to report immediately to the closest functioning leprosy treatment facility/general health centre for assessment and treatment. As an alternative, they should be able to use teleconsultation through WhatsApp/SMS.
- Enhanced emphasis should be placed on self-care techniques. Patients should be educated on active and passive home-based physiotherapy and wound care and prevention of disability services, including the use of splints and supports.
- The government needs to ensure that Section 8 of the RPWD Act 2016, which stipulates that PwDs shall have equal protection and safety in situations of risk, armed conflict, humanitarian emergencies and natural disasters, is followed.²³
- Counselling and peer support networks should be made available online. A database may be created in consultation with disability rights organisations from the panchayat level upwards for providing counselling services to PwDs.

On Livelihood

- According to Govindarajulu Srinivas, Head of Department of Epidemiology, The Tamil Nadu Dr. M.G.R. Medical University, and his co-researchers, “There is an absolute need for addressing underlying social structures that translate into food insecurity, housing insecurity, lack of education, living in poor sanitary conditions, malnutrition, or poorly nutritional diets, and living lives with more dignity.” The solution, according to him, is not a vaccine but social improvements in the lives of those affected with leprosy or at risk of becoming infected.²⁴
- State authorities should ensure home delivery of all essential services, including groceries medicine, blood supply and oxygen cylinders for persons with disabilities.
- Social media platforms need to be leveraged to provide psycho-social counselling for people facing increased stigma, discrimination, and depression from job loss.
- Skill development programmes run by the public and private sector which are now moving online must also comply with accessibility requirements and be designed to address barriers faced by PwDs in accessing training.
- Schemes for creation of employment, including those run by the Ministry of Micro, Small & Medium Enterprises, Ministry of Labour & Employment, Ministry of Rural Development and Ministry of Housing & Urban Affairs, should focus on creation of a range of home-based work options for PwDs.

On Education

- Consult with children with disabilities (CwDs) and their parents to assess modes of instruction used during the pandemic for accessibility, quality, and engagement of children.
- Identify and track children at high risk of dropping out, or who have discontinued education during the pandemic.
- Use multiple modes of communication to be more inclusive, interactive, and efficient.
- Provide pre-recorded videos or television lessons, rather than live classes to minimise issues of accessibility due to power cuts, poor internet, sound quality, etc.
- Enable two-way interaction between students and teachers, through home visits, follow-ups on calls or messaging applications.
- Minimise reliance on personal devices and high-speed internet, by using blended modes of instruction such as physical delivery of learning materials, and home visits where possible.
- Assess the possibility of providing devices/ internet to vulnerable households where possible.
- Support access to regular learning opportunities at home for children with disabilities and low-socio-economic-status households.²⁵ This will address the inequality in learning caused due to the COVID-19 school closures.

- Set up a dedicated office or centre in public and private universities for smooth transition of students with disabilities, their integration into the social environment of the campus, and access to course material and technologies for improved academic experience.²⁶
- Reorient pedagogical practices towards teaching children at their level rather than completing syllabus; different syllabi could be provided to reduce stress on children with intellectual disability.
- Special educators need to be inducted in mainstream schools and as resource persons in underserved regions.

The experts also recommended removing all barriers to transportation of caretakers, attendants, and support staff for PwDs, so that the latter are not left to fend for themselves. They also called for including the State Commissioner for Persons with Disabilities during disaster response/management. These commissioners, according to them, should oversee all disability-related issues and act at the State Nodal Authority to ensure inter-Ministry interactions.

References

1. Thevar S, *Leprosy detection drive in Pune hit by Covid cases overload*, Hindustan Times, Nov 8, 2020, www.hindustantimes.com/cities/leprosy-detection-drive-in-pune-hit-by-covid-cases-overload/story-N2Yv5L3xShgsGUCfvx6QXK.html
2. Rout H, *Virus blow to leprosy screening, special drive from January 18 in Odisha*, The New Indian Express, Dec 26, 2020, www.newindianexpress.com/states/odisha/2020/dec/26/virus-blow-to-leprosy-screening-specialdrive-from-january-18-in-odisha-2241370.html
3. Robert de Arquer G, et al. *COVID-19 and leprosy new case detection in India*, Leprosy Review, March 2021, Volume 92 (Issue 1), page 88-91 <https://leprosyreview.org/article/92/1/20-21008>
4. Singh A, *Early leprosy detection helping in preventing grade two disability in Indore*, The Times of India, Sep 4, 2021, www.timesofindia.indiatimes.com/city/indore/early-leprosy-detection-helping-in-preventing-grade-two-disability-in-indore/articleshow/85923700.cms
5. ENS, *Odisha doorstep survey finds high cases of TB, leprosy*, The New Indian Express, Sep 8, 2021, www.newindianexpress.com/states/odisha/2021/sep/08/doorstep-survey-finds-high-cases-of-tb-leprosy-2355767.html
6. Chakraborty M & Suri S, *Winning the COVID-19 Battle in Rural India: A Blueprint for Action*, Observer Research Foundation, June 2021, www.orfonline.org/research/winning-the-covid-19-battle-in-rural-india-a-blueprint-for-action/
7. NLR Annual Report 2020, <https://nlrinternational.org/app/uploads/2021/06/NLR-Annual-Report-2020-FINAL.pdf>
8. *Novartis Kalwe Site Associates Live On-Site during COVID-19 Lockdown to Maintain Multi-Drug Therapy Supply Chain for WHO Donation Program*, Global Partnership for Zero Leprosy, Aug 6, 2020, <https://zeroleprosy.org/novartis-kalwe-site-associates-mdt-covid19/>
9. *COVID-19: India's most vulnerable battle two infectious diseases at once as total countrywide lockdown continues*, Lepra, [www.lepra.org.uk/pr/COVID19 India's most vulnerable battle two infectious diseases at once as total countrywide lockdown continues.pdf](http://www.lepra.org.uk/pr/COVID19%20India%E2%80%99s%20most%20vulnerable%20battle%20two%20infectious%20diseases%20at%20once%20as%20total%20countrywide%20lockdown%20continues.pdf)
10. Murthy GVS, Kamalakannan S, et.al, *A Strategic Analysis of Impact of COVID-19 on persons with disabilities in India*, August 2020, CBM and Humanity & Inclusion (HI) and Indian Institute of Public Health Hyderabad (IIPH-H), Public Health Foundation of India (PHFI), https://images.hindustantimes.com/images/app-images/2021/7/covid-impact-final-report-iiph-to-cbm-hi_02122020.pdf
11. Markt J, *COVID-19 and its Impact on Persons with Disabilities*, International Committee of The Red Cross, Aug 26, 2020, <https://blogs.icrc.org/new-delhi/2020/08/26/covid-19-and-its-impact-on-persons-with-disabilities/>
12. *COVID-19 AND THE RIGHTS OF PERSONS WITH DISABILITIES: GUIDANCE*, United Nations Human Rights Office of the High Commissioner, Apr 29,2020, [www.ohchr.org/Documents/Issues/Disability/COVID-19 and The Rights of Persons with Disabilities.pdf](http://www.ohchr.org/Documents/Issues/Disability/COVID-19%20and%20The%20Rights%20of%20Persons%20with%20Disabilities.pdf)
13. Mehta BS et al. *Covid-19 Impact: Lockdown and Livelihood in the Lurch*, EPW Engage, Feb 20, 2021 Vol. 56 (Issue No. 8), www.epw.in/engage/article/covid-19-impact-lockdown-and-livelihood-lurch
14. Joint statement by ILO, FAO, IFAD and WHO, *Impact of COVID-19 on people's livelihoods, their health and our food systems*, WHO, Oct 13, 2020 www.who.int/news/item/13-10-2020-impact-of-covid-19-on-people-s-livelihoods-their-health-and-our-food-systems

15. Mander H, *Harsh Mander: A lesson in how to end the mass suffering unleashed by India's first lockdown*, Scroll.in, May 14, 2021 <https://scroll.in/article/994378/harsh-mander-a-lesson-in-how-to-end-the-mass-suffering-unleashed-by-indias-first-lockdown>
16. *Neglected and Forgotten: Women With Disabilities During the COVID Crisis in India*, Rising Flame and Sightsavers, Jul 14, 2020 https://risingflame.org/wp-content/uploads/2020/07/NeglectedAndForgotten_RFandSS.pdf
17. *N for Nose: State of the Education Report for India 2019 : Children with disabilities*, UNESCO, Jul 12, 2019, <https://en.unesco.org/news/n-nose-state-education-report-india-2019-children-disabilities>
18. Kalra M & Jolad S, *Regression in Learning: The High Cost of COVID-19 for India's Children*, ORF Online, Aug 2, 2021, www.orfonline.org/research/regression-in-learning/?amp
19. *COVID-19 and Exclusion of Children with Disabilities in Education | Insights from four states*, Vidhi Centre for Legal Policy, Dec 2020, https://vidhilegalpolicy.in/wp-content/uploads/2020/12/Executive-Summary_English-Version.pdf
20. Modi S & Postaria R, *How COVID-19 deepens the digital education divide in India*, World Economic Forum, Oct 5, 2020, www.weforum.org/agenda/2020/10/how-covid-19-deepens-the-digital-education-divide-in-india/
21. Rathod S et al, *Management of leprosy in the context of COVID-19 pandemic: Recommendations by SIG leprosy (IADVL academy)*, Indian Dermatology Online Journal, Vol 11 (Issue 3), page 345-348, www.idoj.in/article.asp?issn=2229-5178;year=2020;volume=11;issue=3;spage=345;epage=348;aulast=Rathod
22. *For leprosy patients, help was just a call away during COVID-19 lockdown*, The Economic Times, July 22, 2020, <https://economictimes.indiatimes.com/tlmti/viruspevijay/for-leprosy-patients-help-was-just-a-call-away-during-covid-19-lockdown/articleshow/77109572.cms?from=mdr>
23. *Impact of COVID-19 on Persons with Disabilities, India*, FICCI, Apr 2, 2020, <https://ficci.in/SEDocument/20501/ficci-recommendation-apr2-2.pdf>
24. Srinivas G et al. *Risk of disability among adult leprosy cases and determinants of delay in diagnosis in five states of India: A case-control study*, PLOS Neglected Tropical Diseases, June 27, 2019, <https://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0007495>
25. Vegas E, Lee S and Shrestha U, *How has education technology impacted student learning in India during COVID-19?* Brookings.edu, Aug 23, 2021, www.brookings.edu/blog/education-plus-development/2021/08/23/how-has-education-technology-impacted-student-learning-in-india-during-covid-19/
26. Gupta R, *Re-imagine learning for students with disabilities*, The Hindu, May 1, 2021, www.thehindu.com/education/re-imagine-learning/article34456695.ece

“Every day, we see between 100-150 patients who come for ulcer care. They are mostly leprosy patients. During the lockdown, only 50% of the patients could visit us. People who got stranded elsewhere, could not come for their regular care.” - Pramod, Samarpan Foundation Trust

“I did not have sanitisers and gloves to keep myself protected during a door-to-door survey in the time of COVID-19. I used to feel scared. While touching patients for screening of leprosy, I used to have this fear at the back of my mind that I might be putting my family at risk. I have two small children.” - ASHA worker

“People with disabilities, who mostly have entry-level jobs in different sectors, have suffered massive job losses during the COVID-19 crisis. Many of them are the only bread earners in their families. The emotional cost of being unemployed is high as a lot of them are considered a burden by their own families.” - Arman Ali, NCPEDP

“Even more calamitous was the impact of the lockdown on socially vulnerable groups, such as households headed by single women, households with people having disabilities, transgendered people, and old persons without caregivers.” – Harsh Mander

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