

Monthly Progress Report

To Executive Director of Sasakawa Health Foundation

Title of the Report	Monthly Progress Report
Name	Vagavathali Narsappa
Date of Submission	10 July 2020
Reporting Period	June 2020

1. Report on activities of APAL State-Level Bodies and APAL Leaders

- Conducted trial version online board members meeting
- Participated online meeting on Consultation on EDPAL Bill 2015- 2 meetings
- Participated in online National Disability Network Meeting
- President Leprosy Colony Visit
- Foodgrains support associated with The Government, The Leprosy Mission, Lepra Society and Rising Star Outreach to the community affected by leprosy
- Monitoring to visit of the Government authorities in the leprosy colony
- Self-care kits distribution to persons affected by leprosy associated with Lepra Society and Rising Star Outreach.
- Monitoring of regular work in the Hyderabad office for Administration of corresponding mails, finance, and social media.

Trail Version Online Board Members Meeting

Date: 12.06.2020

Place: APAL Head Office

Location: Hyderabad

Topic: Trail version online board members meeting

Introduction: The COVID-19 pandemic has deeply impacted the lives of persons affected by the disease. In response to this upheaval, the Association of People Affected by Leprosy (APAL) conducted a trial version board members' online meeting on 12th June 2020, 11 am to 12 am to address key challenges during the India health crisis and spearhead the leprosy community's emergency response. This online meeting was very useful to us to better understand the challenges of people affected by leprosy from all states of India.



The president of APAL, Mr. Narsappa asked a question to board members at that particular time that, what is the current COVID-19 situation of people affected by the disease of leprosy in all our states of India?

The board members of APAL have raised so many issues consistently, across India, as major concerns for persons affected during the COVID-19 pandemic: In most states, our APAL leaders represented and supported food aid and other key social protection services are reaching some persons affected, but many are unable to benefit from it because of structural barriers, transportation challenges, or information gaps. Persons affected are relying on the safety net of services from the Governments and NGOs, but it is unclear who is receiving what, and difficult to ensure that everyone's needs are being met.

Fundamental goods: Persons affected are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported by some food grains, soaps, and masks to the people affected by leprosy those who are residing in the leprosy colonies.

Health care: Persons affected have specific and ongoing leprosy-related healthcare needs. If persons affected can reach health facilities, they face reductions in services, as facilities transition to exclusively treating COVID-19 patients. MDT is largely still available, but reaction treatment is unobtainable for many persons affected. Unfortunately, in states of Maharashtra and Andhra Pradesh, 5 affected people are infected by Coronavirus and 1 person was dead.

Livelihoods: Persons affected often work in the informal economy. They are surviving only depending on begging, working as daily laborers, or running small shops but they lost all their livelihoods. As a result, many persons affected are unable to work and their ability to meet basic needs is in severe jeopardy.

Information about COVID-19: Health promotion information is reaching some person organization and some local NGOs are working to find alternative ways to get messages to those that need them. Most people haven't smartphones and newspapers also banned.

Intersecting vulnerabilities: Persons affected are not only vulnerable because of their status as a person that is affected by leprosy, but are often vulnerable for other reasons as well. These other factors, like age or gender, compound the challenges faced by persons affected during this time and deserve special attention.

Self-Care Kits distribution-APAL associated with Rising Star& Lepra

Date: 14th June 2020

Place: Harsh Nagar Leprosy Colony

Location: Sendhwa District- Barwani, Madhya Pradesh

Topic: Self- care kits distribution

Introduction: Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported by some food grains, soaps, and masks to the people affected by leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with Lepra society & Rising Star Outreach distributed self- care kits to 80 persons affected by leprosy in Harsh Nagar leprosy colony, Sendhwa, Dist- Barwani, state of Madhya Pradesh. The Self- care kits sponsored by Rising Star Outreach.

The beneficiaries are conveyed their gratitude to APAL, Lepra society and Rising Star Outreach for support self-care kits in the terrible COVID-19 crisis time.

Foodgrains distribution APAL associated with Rising Star

Date: 16th June 2020

Place: Jeevan Jyothi Leprosy Colony

Location: Yadgiri District- Karnataka

Topic: Foodgrains distribution

Introduction: Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported some food grains, soaps and masks to the people affected by leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with Rising Star Outreach distributed food grains 19 members from 10 families, persons affected by leprosy in Jeevan Jyothi leprosy colony, Yadgiri District, state of Karnataka. The food grains are sponsored by Rising Star Outreach.

The beneficiaries are conveyed their gratitude to APAL and Rising Star Outreach for support food grains in the terrible COVID-19crisis time.

Foodgrains distribution APAL associated with The Leprosy Mission

Date: 19th June 2020

Place: Kali Matha Leprosy Colony

Location: Chhattisgarh

Topic: Foodgrains distribution

Introduction: Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported some food grains, soaps and masks to the people affected by leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with The Leprosy Mission distributed food grains 230 families, persons affected by leprosy and their families in Kali Matha leprosy colony state of Chhattisgarh. The food grains are sponsored by The Leprosy Mission Trust India.

The beneficiaries are conveyed their gratitude to APAL and The Leprosy Mission for support food grains in the terrible COVID-19 crisis time.

Foodgrains distribution APAL associated with the Government

Date: 23rd June 2020

Place: Raja Nagar Leprosy Colony

Location: Bhopal- Madhya Pradesh

Topic: Foodgrains distribution by APAL & Government

Introduction: Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported some food grains, soaps and masks to the people affected by leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with the Government distributed food grains 27 families, persons affected by leprosy in Raja Nagar leprosy colony, Bhopal- District, state of Madhya Pradesh. The food grains are sponsored by the Government of Madhya Pradesh distributed by APAL.

The beneficiaries are conveyed their gratitude to APAL and the Government to support food grains in the terrible COVID-19crisis time.

Consultation on EDPAL Bill 2015 online meeting

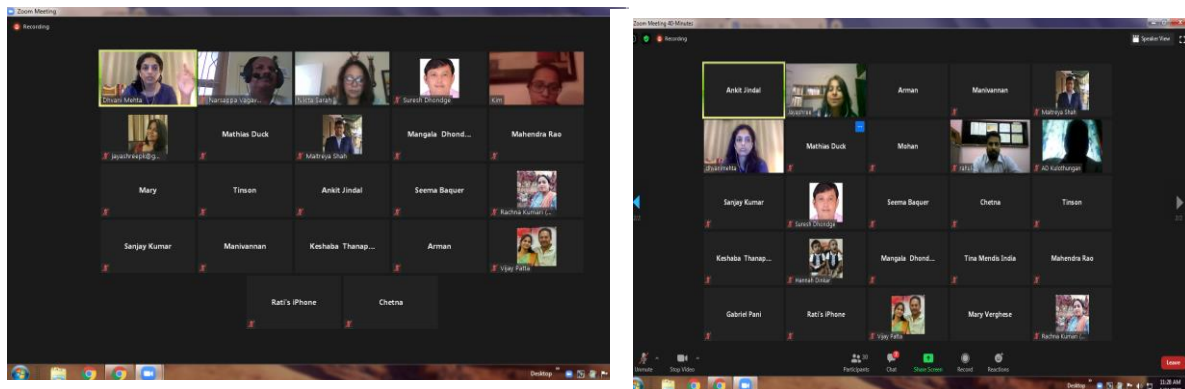
Date: Jun 24, 2020

Time: 11:00 AM to 1 PM

Topic: Stakeholder Consultation

Introduction:

The online meeting conducted for a relook at the previously submitted EDPAL Bill and suggest recommendations for expansion of the scope of the proposed model bill, Elimination of Discrimination Against Persons Affected by Leprosy Bill, 2015 (EDPAL Bill, 2015) Dhvani and Kim from Vidhi Centre for Legal Policy will lead the process of consultation. On behalf of APAL Mr. Narsappa, President of APAL participated and also 40 members are attended from various NGOs and discussions are went on well.



Discussions:

The proposed bill aimed at Elimination Discrimination against Persons Affected by Leprosy and protecting their interests.

This note provides an overview of the points of difference between the draft bill titled 'Eliminating Discrimination Against Persons Affected by Leprosy (EDPAL) Bill, 2015' annexed to the 256th Law Commission Report ("EDPAL Bill"), and the Rights of Persons Affected by Leprosy and Members of their Family (Protection Against Discrimination and Guarantee of Social Welfare) Bill, 2017 ("2017 Bill"). It also contains some suggestions for the expansion of the scope of the EDPAL Bill.

Stated objects of the two Bills:

➤ EDPAL Bill:

- To enact a comprehensive protection regime for persons affected by Leprosy and members of their families;
- To eliminate any discrimination or denial of equal treatment;
- To repeal and amend existing laws that negatively affect persons affected by Leprosy and promote segregation and discrimination; and
- To enable the State to discharge its positive obligations through affirmative action.

➤ **2017 Bill:**

- To protect the human rights of persons affected by leprosy;
- To eliminate discrimination against them and their families;
- To promote their social welfare;
- To take steps for the prevention and control of leprosy;

The meeting went on well with great discussions about the above things and extended to next Friday.

Online Meeting on EDPAL Bill-2

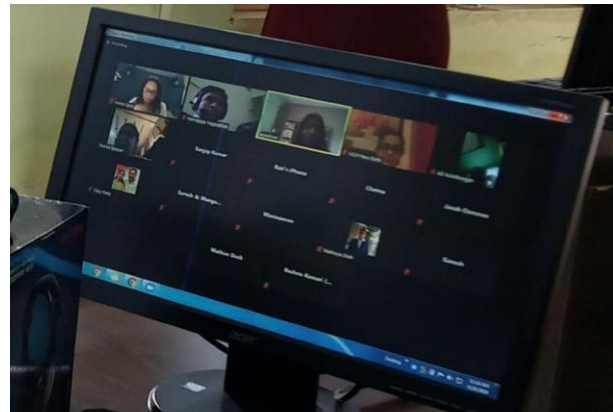
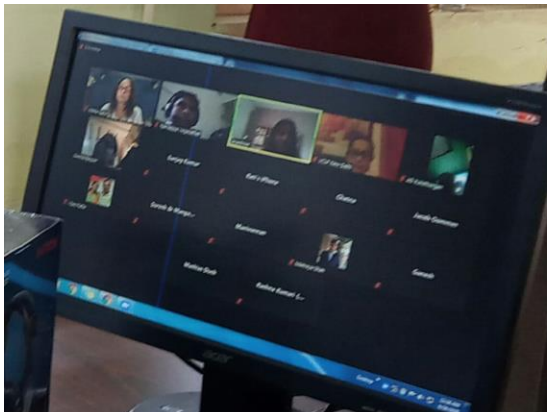
Date: Jun 26, 2020

Time: 11:00 AM to 1 PM

Topic: Stakeholder Consultation

Introduction:

The online meeting conducted for a relook at the previously submitted EDPAL Bill and suggest recommendations for expansion of the scope of the proposed model bill, Elimination of Discrimination Against Persons Affected by Leprosy Bill, 2015 (EDPAL Bill, 2015) Dhvani and Kim from Vidhi Centre for Legal Policy will lead the process of consultation. On behalf of APAL Mr. Narsappa, President of APAL participated and also 33 members are attended from various NGOs and discussions are went on well.



Discussions:

Comparison of the key provisions between EDPAL bill and 2017 bill

1. Background
2. Key Definitions
3. Right to Equality and Non-Discrimination
4. Health Rights
5. Right to Education
6. Socio-Economic Rights

7. Government Obligations
8. Dedicated Authorities
9. Remedies and Penalties

Suggested additions to the EDPAL Bill based on the prayers by the petitioner in *Pankaj Sinha v Union of India*:

- Revising disability pension amounts fixed by States at a regular interval of three years
- Enforceable obligations on the government to take steps to reduce the incidences of Leprosy – requiring periodic surveys to be conducted and published - to determine the prevalence rate, detection rate, and new cases of leprosy
- Organization of regular health camps by the government
- Government to develop a set of uniform guidelines for the coverage of leprosy related medical care under the various health insurance schemes of the Central Government or any other insurance scheme envisaged under the Rights of Persons with Disabilities Act, 2016
- Government to frame guidelines for community-based rehabilitation of persons affected by leprosy in terms of the WHO guidelines
- Government to sponsor research and development and distribution of modified tools and daily use items (such as spoons, toothbrush, etc) for use by persons affected by leprosy with disability in consultation with experts and organizations
- Government to Ensure Leprosy colonies have safe drinking water and maintain cleanliness, disinfection, construction and cleaning of toilets, construction and maintenance of adequate drainage
- Prevent banks from discriminating against persons with leprosy and require them to evolve a system immediately that permits them to own and operate an account without any impairment
- Centre to frame separate rules for the evaluation of disabilities for persons affected by leprosy to issue disability certificate under the RPWD Act.
- Amend the RPWD Act to define 'leprosy cured person' according to the definition under the EDPAL Bill, and to amend the criteria for issuance of disability certificates, accordingly
- Formulate and implement a scheme to assist, preferably every month, to all leprosy affected persons for rehabilitation
- Make void all provisions in other laws that discriminate against persons affected by leprosy

Foodgrains distribution APAL associated with the Government

Date: 24th June 2020

Place: Ram Avatar Leprosy Colony

Location: Alwasa, Bhopal- Madhya Pradesh

Topic: Foodgrains distribution by APAL & Government

Introduction: Persons affected Leprosy are facing difficulty obtaining basic goods, especially food, clean water, and soap, masks which are critical to fighting COVID-19 infection. Lost livelihoods and travel restrictions have made it difficult to obtain food for many persons affected, and many communities of persons affected have not had access to clean water. The Government and local NGOs are supported some food grains, soaps and

masks to the people affected by leprosy those who are residing in the leprosy colonies. In most states, our APAL leaders represented and supported food aid and other key social protection services also.



In response to this upheaval, the Association of People Affected by Leprosy (APAL) associated with the Government distributed food grains 40 families, persons affected by leprosy in Ram Avatar leprosy colony, Alwasa, Bhopal- District, state of Madhya Pradesh. The food grains are sponsored by the Government of Madhya Pradesh distributed by APAL.

The beneficiaries are conveyed their gratitude to APAL and the Government of Madhya Pradesh for support food grains in the terrible COVID-19 crisis time.

President Mr. Narsappa Leprosy Colony Visit

Date: 25th June 2020

Place: Santhi Nagar Leprosy Colony

Location: Mahaboob Nagar District- Telangana

Topic: Awareness on Precaution of COVID-19

Introduction: The COVID-19 pandemic has deeply impacted by the lockdown to the lives of India's thousands of (760 leprosy Colonies all over India) persons affected by leprosy and irrespective of their disability, gender, caste, age or economic background; they are suffering from disability by the disease of Leprosy like Chronic ulcers, reactions and blindness also. They are all most afraid of COVID-19's consequences because of the current terrible crisis lockdown situation may continue.



Mr. Narsappa distributed eggs to colony people

Health promotion information is reaching some persons affected by leprosy, but others are difficult to reach due to travel restrictions and illiteracy. Our APAL organization and some local NGOs are working to find alternative ways to get messages to those that need them. Most people haven't smartphones and newspapers also banned.

In response to this upheaval, Mr. Narsappa Vagavathli, the President of Association of People Affected by Leprosy (APAL) visited Santhi Nagar Leprosy Colony in Mahaboob Nagar District, Telangana and made them well aware on precaution of COVID-19. Also, he distributed eggs to them and said "cook well before eat".

He pointed out following precaution methods

1. Stay at home when you are sick
2. Avoid close contact with people who are sick
3. Wash your hands at least 20 seconds
4. Cover your cough or sneeze with a tissue
5. Don't eat raw food, thoroughly cook meat & egg
6. Avoid touching eyes, nose and mouth with unwashed hands
7. Clean & disinfect frequently touched object & surfaces
8. Avoid crowd places and traveling

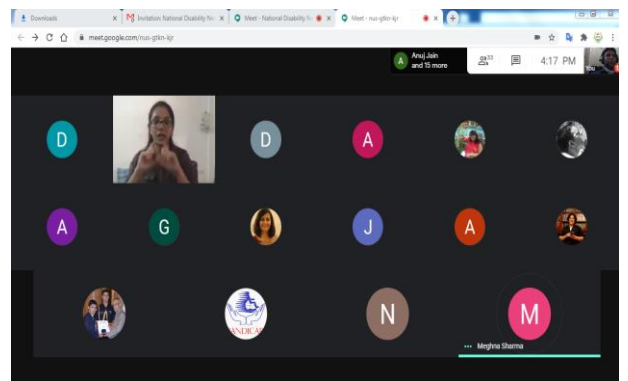
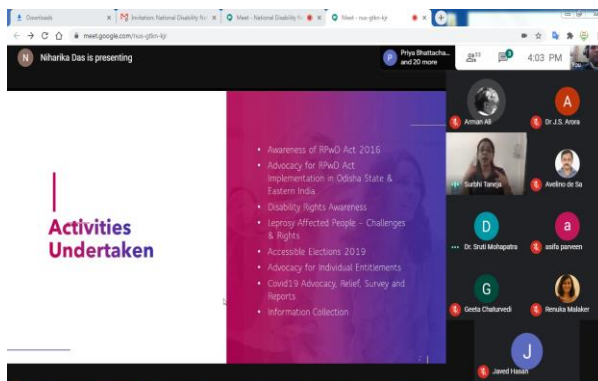
The leprosy colony people expressed their gratitude to Mr. Narsappa and APAL.

NCRPD Online Meeting

NCPEPD as part of its NCRPD meetings held in January and May 2020 had decided to hold a follow-up meeting on 27.06.2020 to identify the thematic areas and form core groups under each of these areas. As a part of the process, each core group would decide on a future advocacy strategy and work towards it and for the same, a meeting has been conducted to take everyone's valuable feedback and input.

Date: 27.06.2020

Venue: Google Meet



Arman Ali welcomed the participants and set the context of the meeting. Building on the discussion in the previous NCRPD meeting held in January and May 2020, he emphasized the need to identify the core thematic areas to work on and form groups under each of the thematic areas to take it forward. Giving an update of the progress made since the previous meeting he spoke of NCPEPD's efforts to highlight issues faced by people with disabilities with Government- NCPEPD submitted a charter of 13 demands to the PMO. These letters were also mailed by all our partners to their MPs and MLAs. Various letters highlighting the plight of persons with disabilities were also written to the Home Minister and Member, National Disaster Management Authority.

Agenda 2: Strategies for better inclusion of PWDs in a post-COVID-19 world

As lockdown eases problems faced by people with disabilities in terms of accessibility in terms of health, education, employment, essential services, etc would largely remain unresolved.

And with the lockdown and closure of economic activities, a lot of the people with disabilities who were previously self-employed, daily-wage earners and others have lost their means of livelihood and are left to fend for themselves.

In addition to the above-mentioned number of gaps in terms of terminologies, non-inclusion of sign language as a Mother Tongue option could be seen in CENSUS which is due next year i.e., 2021. Although the official process of data collection which was due to start from April of this year has been delayed, it opens up scope for civil society

organizations to intervene and advocate. Mr. Aqeel Usmani pointed out that the response to his RTI with MHA states that the questionnaire for the Census is yet to be finalized which allows us to lobby with the RGIs office

Additionally, the diversion of most of the CSR funds to COVID-19 relief adversely impacts the NGOs dependent on these CSR funds. The adverse impact on the funds trickles down to the grass-root level where its impact on the delivery of key essential services and rehabilitation measures would be visible.

Mr. Ankit Jindal pointed out that given the losses faced by companies in current times the CSR spends even in the coming years would be impacted.

As a response to the strategies for better inclusion of people with disabilities in a post-COVID-19 relief, some strategies that were suggested are:

☑ A self-sustaining means of revenue generation for the disability sector wherein the NGOs dependent on the CSR funds would not be negatively impacted

☑ State-level networks need to be strengthened. Disability being a state subject it is imperative for the state networks to monitor the situation at the state and act as pressure groups

☑ At the national level, advocacy needs to be done with the various ministries to seek information and understand the various services made available for people with disabilities.

☑ Regular interaction and coordination mechanisms between the central and state-level networks need to be established.

Discussions:

Based on the discussions on the common and recurring problems faced by people with disabilities, the thematic areas mentioned in the table below have been identified. It may be noted that the members mentioned under the Core Group are not final and are based on the suggestions during the discussion.

1. COVID-19
2. Census
3. Disaster Management
4. Education
5. Accessibility of services
6. Health and Rehabilitation
7. Employment

Members of the NCRPD are requested to add their names to the Core Groups they would like to be involved with.

Monitoring implementation of DEPwD Guidelines of Safety and Protection of Persons with Disabilities in the COVID pandemic:

The DEPwD had issued letters to all Chief Secretaries asking information on a series of questions related to the implementation of the Guidelines and few others. The letter has been mailed to all members with a request to try to access the response from each state for us to prepare and submit a report to the Government on the gaps in implementation. Ms. Nakhro has also offered to write to all State Commissioners to ask for these responses

Concluding Remarks & Way Forward

As a way forward, it has been decided that to avoid confusion the Core Groups under the various thematic areas would be formed and finalized after the meeting via email and shared with all. Following the formation of the groups, separate meetings would be conducted under each of the thematic areas and an advocacy strategy would be formulated for the future course of action based on a mutually agreed timeline by all the groups and the finds will be shared accordingly

2. Report on activities of the Indian Central Government and States/UTs related to leprosy control that you have learned about while conducting duties as APAL President Mr. Narsappa.

In June 2020 there is no activity in Central/ State Government programs.

3. Key findings which are important for SHF work

- a. To be Concentrated Advocacy on RPWD Act and Supreme Court should be expanded to some more states.
- b. APAL to organizing more coordinated activities with other disabled sectors like DPI & NCPEDP.
- c. The regular meeting of youth leader & women empowerment programs should be budgeted and organized.
- d. To form women empowerment among colony women

4. Difficulties/Challenges you faced during the period

Difficulties: In most states, our APAL leaders represented and supported food aid and other key social protection services. The services reaching some persons affected, but many are unable to benefit from it because of structural barriers, transportation challenges, or information gaps. Persons affected are relying on the safety net of services from the Governments and NGOs, but it is unclear who is receiving what, and difficult to ensure that everyone's needs are being met

Challenges:

- We started office work slowly because of India Ministry of Home Affairs released new guidelines called "Unlock 1.0" that allow the opening of Private Offices, malls, restaurants and religious places in all areas except the containment zones
- We are conducting and participating in online meetings by ZOOM and Google meet
- Mostly using social media platforms
- We pray for those who are working in the hospital, Doctors, Nurses and paramedical staff

V. Narsappa.