

Persons Affected by Leprosy and the COVID-19 Global Health Crisis

Working Group 2 Consultative Calls Report

Introduction

The COVID-19 pandemic has deeply impacted leprosy control and prevention and the lives of persons affected by the disease. In response to this upheaval, the Global Partnership for Zero Leprosy (GPZL) established three working groups in April 2020 to address key challenges during the global health crisis and spearhead the leprosy community's emergency response. The first working group was established to better understand challenges faced by and provide support to National Leprosy Programmes, the second to advocate for the needs of persons affected by leprosy, and the third to prepare the Global Partnership for the post-pandemic global health landscape. The second group's work to date identifying needs and specific challenges persons affected by leprosy are facing during the pandemic will be explored in this interim report.

Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members; Amar Timalina, President of IDEA Nepal; Mathias Duck, Chair of ILEP Panel of Persons Affected by Leprosy; and Andie Tucker, Project Manager for the Global Partnership for Zero Leprosy, came together to form Emergency Response Working Group Two. More information about this group can be found in the TOR in [Appendix 2](#). Working Group Two initiated their efforts to identify needs and challenges faced by persons affected by setting up regional calls for persons affected and representative organizations. These conversations were preceded by the establishment of a regular call for persons affected around the world hosted by the International Association for Integration, Dignity and Economic Advancement (IDEA), an international persons affected organization. These calls, as well as work done by Alice Cruz, UN Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, to initiate conversations with persons affected organizations on the topic of COVID-19, laid the groundwork for our discussions.

This report would not have been possible without the generous contributions of time and insight from the call participants. Data compiled in this report reflects their contributions and their work of gathering information from their colleagues and friends. Working Group Two is grateful for their assistance in creating this work, and acknowledges the persons affected that participated in the regional calls as its creators. A full list of the persons affected organizations that contributed to these calls can be found in [Appendix 3](#).

Summary of Key Findings

The goal of Working Group Two's consultative calls with persons affected was to identify specific needs and challenges that persons affected are facing in light of the COVID-19 pandemic. Conversations with persons affected revealed regional specificity, but many challenges and needs were common among

persons affected and their families from all regions. The following issues were raised on a consistent basis, across geographies, as major concerns for persons affected during the COVID-19 pandemic:

- [Access to health care](#): persons affected have specific and ongoing leprosy-related healthcare needs. Access to healthcare is currently limited by transportation bans that prevent persons affected from reaching health facilities: persons affected are either banned from travel, or cannot reach health facilities because public transportation is not operational due to travel bans. If persons affected are able to 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.
- [Access to fundamental goods](#): persons affected are facing difficulty obtaining basic goods, especially food, clean water, and soap, 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 and settlements of persons affected have not had access to clean water prior to the pandemic— a preexisting vulnerability that has been exacerbated by the current crisis.
- [Access to government support](#): in most countries represented on the calls, food aid, income support, 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 a patchwork safety net of services from governments and NGOs, but it is unclear who is receiving what, and difficult to ensure that everyone's needs are being met.
- [Access to stable livelihoods](#): persons affected often work in the informal economy, working as day laborers or running small shops, occupying jobs that are particularly vulnerable to economic instability. As a result, many persons affected are unable to work and their ability to meet basic needs is in severe jeopardy.
- [Access to information about COVID-19](#): health promotion information is reaching some persons affected, but others are difficult to reach due to travel restrictions, geography, or illiteracy. Persons affected organizations and NGOs are working to find alternative ways to get messages to those that need them.
- [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.

Methods

GPZL's Emergency Response Working Group Two conducted seven consultative calls with persons affected individuals and organizations from April – May 2020, speaking with over 100 individuals from more than 25 organizations from 22 different countries. The first six calls were conducted based on geographical region, including: Latin America, Africa, Asia, and the Pacific. The final call was for women affected by leprosy. These women represented a variety of organizations and countries, and were asked to participate in this call to increase representation of women's voices in the gathered data. A set of guiding questions was written to shape the calls (available in [Appendix 1](#)), but the conversations were conducted loosely, allowing participants to answer the questions that were most relevant for them, and

include other pertinent information. Each call was conducted on Zoom and was facilitated by a person affected. After each call, notes were compiled, and the data gathered from all the calls has been distilled into this report.

Key Findings

Access to health services related to leprosy during the pandemic:

A key topic discussed in the consultative calls was access to health services related to leprosy during the pandemic. A few major themes surfaced:

Access to health facilities and medical care:

Issues with the accessibility of health facilities was referenced by almost all call participants. 89% of countries represented on the call reported being under lockdown, which is preventing persons affected from being able to travel to hospitals, limiting their access to care. In 79% of countries represented on the calls, health centers and hospitals have transitioned to COVID-19 centers and are turning away persons affected seeking treatment for leprosy-related health problems. The main leprosy treatment facility in Myanmar has discharged the vast majority of its leprosy patients, leaving only a handful of leprosy patients, to create room for COVID-19 patients. A concerning consequence of leprosy treatment facilities becoming COVID-19 facilities is that leprosy patients are, in Brazil for example, being treated alongside COVID-19 patients. As an immunosuppressed population, this is putting persons affected at great risk of infection. This issue will be explored further in the later section on vulnerabilities.

In Indonesia doctors are trying to use telemedicine to treat leprosy patients that cannot come to leprosy treatment facilities that have been converted to COVID-19 facilities, but patient advocates reported that this technology is difficult for persons affected with limited education to use. In Papua New Guinea, organizational partners reported that they are trying to increase field work and community health provision to combat the unavailability of leprosy-related health services at facilities and the transportation lockdown, but there are leprosy control activities that are the purview of the Ministry of Health that they are not empowered to implement, so their impact is limited. In Timor Leste, organizational partners are not empowered to prescribe MDT, despite having doctors on staff, leading to gaps in MDT provision while government health facilities are shut down.

The consequence of health centers being closed to leprosy patients, or inaccessible to them, is that diagnosis of suspected leprosy cases is not happening in many places, patients are sometimes not getting the medications they need, and wound care and support for self-care of wounds is hampered.

Wound care:

A pressing need discussed by almost every call participant was the need for continued medical care for persons affected by leprosy, especially for leprosy-related wounds, reactions, and disabilities. Persons affected by leprosy that live in communities without access to clean water rely on health facilities for help cleaning wounds and bandages. These services are currently unavailable, and care for more complex wounds or ulcers is also unavailable in places where health facilities are focusing exclusively on COVID-19 patients. This has long-term impacts on the health of persons affected, and could lead to an increase in leprosy-related disability.

Drug provision (MDT and reaction treatment medication):

National Leprosy Programmes in many of the countries represented on the consultative calls are distributing three months of Multi Drug Therapy (MDT) to patients at a time, instead of a single month, to prevent patients from frequently coming to health facilities to collect medication. In some countries represented on the calls, the 'last mile' of MDT distribution is handled by NGOs, which have continued MDT distribution, sometimes with great difficulty because of travel restrictions, but there was less certainty about patients that collect medication at government health facilities. Closure of government health facilities to leprosy patients is likely preventing some patients from receiving the MDT they need.

None of the call attendees reported that reaction treatment drugs were available for more than a month at a time for patients under reaction management, and reaction treatment was cited as a major concern for a handful of the call participants. A representative from India reported that she was unable to reach the health facility to obtain reaction treatment medication for her mother, and that she was also unable to find the drug in the market. In other countries reaction treatment medication can only be prescribed by a physician. Persons affected that are currently being treated for reactions are struggling to obtain medications because normal pharmaceutical services are not available. Those that are not already being treated are likely going without help while medical services are unavailable.

Access to social protection services for persons affected:

Access to government resources and social protection services spanned a spectrum from no available government assistance, to some assistance from government and some assistance from NGOs, to assistance being made available by the government, but inaccessible for persons affected, and finally, all the way to fully available and utilized social protection services.

In Bangladesh there is some COVID-19 relief available from the government, but there is limited access for persons affected that might be eligible because of travel restrictions. In Ethiopia, persons affected with disabilities are normally eligible for government food aid, but under current travel restrictions are unable to travel to distribution centers, cutting them off from a resource that is usually available to them. In a few countries, like Nigeria, there is some food aid being provided from the government and some is being provided by NGOs, but a concern that a patchwork approach is not adequately reaching everyone was raised by multiple call participants about the same issue in their respective contexts. In Indonesia the government is providing basic food resources, but only to those with identity cards, which is a major barrier to aid for persons affected, who often do not have government identification. Persons affected organizations within the country are working to obtain government IDs for their peers, but the high distribution of persons affected in rural areas further complicates this effort and prevents them from reaching distribution centers, even when they do have proper identification for participation in the food aid programme. One of the call participants Indonesia made the point that most persons affected are not well connected to powerful government officials, and as a consequence, are often excluded from participation in government resource distribution.

An allowance to provide COVID-19 relief has been set up in Brazil, but persons affected are not currently eligible to receive it. MORHAN, a persons affected organization in Brazil, is advocating with the government for the inclusion of persons affected in this programme. In some countries, Myanmar being an example, there are COVID-19 government relief schemes that are open to persons affected because participation is income based, so there are some that qualify. There are some countries that offer regular social protection services to persons affected that have continued, but some service has been interrupted during this time. India offers regular support, through a pension to those with disabilities, but travel restrictions have made it difficult for qualifying persons affected to obtain their

disbursements. Ghana also offers persons affected with leprosy-related disabilities an allowance from the government and many receive the benefit. Unlike India, this has not been compromised by the COVID-19 pandemic.

Access to fundamental goods and items:

After access to medical care, access to fundamental goods was the concern most often cited by call participants. This issue is deeply tied to livelihoods, which is further explored after this section. Food access was first discussed and was a major concern for 79% of countries represented on the consultative calls. In countries with extreme travel restrictions or public transportation closures, persons affected are unable to leave their homes to go to the market to purchase food. In other countries, like Timor Leste, markets are closed and it is challenging to find food to purchase. In places where markets are open and travel is permissible, persons affected are still sometimes excluding themselves from participation for fear of being infected by COVID-19, as an especially vulnerable population. These barriers have led to significant food insecurity for persons affected, especially in cities. Persons affected organizations in Kenya, India, and Nepal are attempting to address this food insecurity in their communities through disbursement of relief packages and food aid, although not all households are being reached. Food inaccessibility for persons affected living in poverty in rural areas was discussed, but call participants from Kenya and Papua New Guinea mentioned that persons affected in rural areas that grow their own food have a more stable food supply, and thus were facing less food insecurity.

In addition to food, the need for clean water and hygiene materials was discussed. The lack of clean water access for persons affected was cited as a primary concern in 58% of countries. Access to clean water is critical for COVID-19 disease control, and many persons affected lack adequate clean water sources to hand wash regularly. In India and Papua New Guinea, NGOs are teaching persons affected to make a solution of heavily diluted bleach to clean hands and surfaces, because it requires less water. However, access to soap and cleaning agents was also cited as a concern, and many organizations of persons affected, like MORHAN in Brazil, are focusing relief efforts on soap and face mask distribution for persons affected. These preventive measures are especially critical among persons affected, because of increased vulnerability to COVID-19.

Livelihoods

Access to stable, dignified employment has historically been a challenge for persons affected in many countries, but even more so during the COVID-19 pandemic. Persons affected are often on the lowest rungs of the socioeconomic ladder because of disability, stigma and discrimination, and the isolation of the disease. They are commonly employed in the informal economy, in jobs that are especially vulnerable to instability. Many call participants reported that persons affected in their communities work as day laborers, and with transportation bans and social distancing regulations these work opportunities have dried up. This has a direct impact on access to fundamental goods, especially food, because persons affected that work as day laborers use their daily wages to buy food and often do not have a surplus of income or food to rely on in times when they are unable to work.

Those that are more formally employed have also faced economic instability. A partner in India that runs a sustainable livelihood programme for women reported that 140 of her programme participants had lost their livelihoods. These women worked in shops, in agriculture, in fishing, or in providing meals to school children. Other partners in Nepal and Papua New Guinea reported that persons affected that have market stalls are unable to work because markets have been broken up and disbanded by the police, and new markets are not yet able to open. In Papua New Guinea persons affected that ran

market stalls are attempting to sell their wares in their front yards, but transportation restrictions and the lack of a centralized market for buying makes it difficult for customers to find these vendors and purchase their goods.

Another means of income generation for persons affected in some communities is begging. This too has been impacted by transportation restrictions in many countries. Call participants reported that in India, Senegal, Nigeria, and Kenya, venues for begging like temples, city centers, and markets, have been closed. These closures, as well as a reduction in foot traffic from transportation restrictions, has eliminated begging as an alternative source of income for those that are unemployed because of the pandemic. Begging and charity offered by religious institutions, like free meals, is a final safety net for persons affected, and the elimination of those sources of support has a significant impact on persons affected by leprosy.

Intersecting or compounded vulnerabilities

A number of intersecting vulnerabilities for persons affected came to light during the calls. 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, and the intersections of these vulnerabilities are key considerations that should inform the way support for persons affected during the COVID-19 pandemic is approached.

Age:

Age was referenced multiple times as a compounding vulnerability for persons affected during the COVID-19 pandemic. In many countries, like Indonesia and Japan, the majority of persons affected are elderly. Their age puts them at greater risk to infection of COVID-19, but it also prevents them from accessing important supportive care services and goods, in some cases. In Indonesia, elderly persons affected often do not have identity cards, so they are not eligible to receive government food aid, and telehealth resources that are available to those suffering from reactions are often inaccessible to this population because of technology and educational barriers.

Gender:

“Women and children are bearing the brunt of this crisis,” reported a woman affected from Nigeria on the call with women affected. Gender was discussed at length on the call, and many women expressed their concern that the burdens of health protection, education promotion, and the maintenance of family life were falling heavily on women affected during this crisis. Concern was expressed that women, who already work the ‘double shift’ of employment outside the home and employment in the home, were being forced to bear even more responsibilities during the pandemic because of the cancelation of supportive care services, like school, daycare for children, and help with domestic responsibilities. Concern for women’s increased responsibility for income generation was also expressed. With husbands out of work, call participants felt that women affected were now being asked to find ways to generate more household income, increasing the scope of their responsibilities and pressure to keep the family afloat. In addition to these issues, concern was expressed about an increase in domestic violence being reported with families spending more time together in their homes because of travel restrictions. Call participants from Nepal, where women have limited autonomy, expressed concern that women’s limited power is being further restricted by the lockdown and the crisis. Brazilian women affected on the call reported a significant increase in the reports of domestic violence their organization receives and expressed deep concern for the safety of women affected in their homes.

Race:

Race was discussed by one call member as a compounding vulnerability in Brazil during the COVID-19 pandemic. The point was made that black people are already particularly vulnerable in Brazil due to racial stigma and discrimination, resulting in the worst health outcomes of any group in the country for leprosy care. There are many barriers to proper treatment, and disability rates are higher among the black population. Persons affected that are in a racial minority are even more vulnerable to negative health outcomes related to leprosy, and to the impacts of this pandemic.

Health-related stigma:

Health-related stigma was discussed by almost every one of the 100+ call participants. Persons affected by leprosy face extreme health-related stigma, impacting the way they receive services and assistance during the pandemic. Persons affected on the calls from Nepal reported that because leprosy affected people are so stigmatized and discriminated against, that in instances when they are seeking aid related to the pandemic (medical help, food aid, etc.), they often receive less assistance than those that have not been diagnosed with leprosy. One call participant from Nepal said, “They run away from us, spitting.” In Indonesia there is not only stigma against persons affected to contend with, there is also increasing stigma against people affected by COVID-19, and especially against surviving families after a family member has died from the COVID-19. If a person affected were to contract COVID-19 the compounded stigma may prevent them or their family from receiving needed assistance.

Mental health challenges:

Another commonly explored topic was the stress the COVID-19 pandemic has placed on the mental health of persons affected by leprosy. Persons affected on every call articulated that they have deep personal experience with quarantining, with losing livelihoods, with worrying that one’s family might become sick, and with isolation. Some call participants described the trauma of reliving their experience of being isolated because of leprosy. One call participant from Brazil said, “I’ve experienced isolation before [when I had leprosy], and now, when I leave my house, those feelings came back. The feeling is the same.” Others expressed the pain of not being able to see, touch, and support their friends that are persons affected. Worry about loneliness, especially the loneliness of elderly persons affected in isolation, was commonly expressed.

Some persons affected on the calls expressed solidarity with a world that is experiencing difficulties and pains associated with isolation and vulnerability that persons affected have all experienced. They expressed a feeling of being understood, or having their experiences related to leprosy made visible, maybe for the first time. They concluded that persons affected have strength and personal experience to share with the world that is valuable during this crisis.

Persons affected organizations and their partners are leading the response to the mental health challenges that have arisen in the global community of persons affected. MORHAN in Brazil is hosting Facebook live events to discuss key issues and raise awareness about the particular needs and challenges facing persons affected during the pandemic. Many organizations, like FELEHANSEN in Columbia, are calling community members to offer peer counseling and support over the phone. Persons affected are suffering because of this crisis, but they are also leading the work to bring support and healing to the community.

Government inattention to the particular health vulnerabilities of persons affected:

A systemic vulnerability that was discussed on the calls is the action of governments in protecting or endangering the health of persons affected during the pandemic. In some countries, governments are bolstering the isolation of settlements or communities of persons affected to keep them insulated from COVID-19 cases. In some cases, this has caused increased mental health risks because of heightened isolation, but is a measure taken to guard the physical health of persons affected because immunocompromised persons affected are more susceptible to COVID-19 infection. In other countries, governments are placing persons affected at greater risk of COVID-19 infection by using leprosy health facilities for COVID-19 treatment. In some countries, like the Philippines and Malaysia, the COVID-19 patients are treated in the same facilities, but are kept away from persons affected. There are three leprosy sanatoriums in the Philippines that are currently being used as isolation facilities for COVID-19 cases. Persons affected are not being treated in those facilities right now, but many persons affected live in the neighborhood surrounding the facilities, putting them in close proximity to COVID-19 cases. In other countries, like Brazil, COVID-19 patients are being treated alongside persons affected by leprosy, putting persons affected at increased risk of COVID-19 infection.

Leprosy settlements

Not all countries have leprosy settlements, but representative on the calls from those that do spoke about the conditions in the settlements during the pandemic. In some countries, like Japan, leprosy sanatoriums have been isolated from the public, to prevent COVID-19 from entering. This has had an impact on the mental health of the persons affected living there, but residents are being cared for by the sanatorium staff and their physical health seems protected and stable. In leprosy settlements in India there have been some reported COVID-19 cases in some settlements, and none reported in others. Settlements are being supported by a patchwork of aid from the government, NGOs, and private donors, but it's sometimes unclear who has received what, and that all needs are being met. In Ethiopia, there haven't been cases of COVID-19 reported in leprosy settlements, but living conditions in the settlements is poor, with limited access to power and clean water. There is concern that if COVID-19 makes it to these settlements, it will be difficult to mitigate.

Access to information about COVID-19

Access to information about the risks of COVID-19 and health promotion activities is uneven, and there are significant barriers to reaching persons affected. In many places, like India, Bangladesh, and Kenya, many persons affected live in rural areas that are difficult to reach with information about COVID-19. NGOs and persons affected organizations have started creative projects to respond to the lack of information in rural areas, like the Leprosy Mission Trust India's community health information challenges. In Bangladesh, partners reported difficulty in distributing information to those in rural areas that do not have TVs because of travel restrictions. In Myanmar, information has been disseminated by the government, but this is not useful for persons affected that cannot read. To combat this, the Leprosy Mission Myanmar has employed community representatives to walk through communities multiple times a day to spread information about hygiene and social distancing. Similarly, in Indonesia and Columbia, persons affected organizational representatives are calling other persons affected to spread health promotion messages.

Conclusion

Working Group Two's consultative calls with persons affected intended to identify specific needs and challenges that persons affected are facing in light of the COVID-19 pandemic. The issues explored during the consultative calls and in this report are not exhaustive, but highlight the particular vulnerability of persons affected during the COVID-19 pandemic, and raise key issues that should be promptly addressed by the members of GPZL, NGOs leaders, inter-governmental agencies, and government leaders.

Appendix 1

Guiding Questions for consultative calls with persons affected:

1. Access to the services of the State:
 - 1.1. How is the access to health services related to Hansen's disease's care under this crisis?
 - 1.2. How is the access to social protection services related to Hansen's disease and disability's benefits under this crisis?
2. Access to fundamental goods and items
 - 2.1. How is access to food, clean water and basic hygiene means for preventing Covid-19?
3. Are there groups, such as women, children, persons with disabilities, older people, immigrants, refugees, within the overall population of persons affected and their families that are more vulnerable to the impact of Covid-19?
4. What is the situation of Hansen's disease's settlements in terms of health, hygiene and access to fundamental goods?
5. Are persons affected and their families being informed about the risks and preventions measures related to Covid-19?
6. Can you please suggest what would be the most effective strategies of communication with the population on the ground and between the organizations?
7. Please share any information you may find relevant in the context of this crisis.

Appendix 2

Terms of Reference

Working Group 2: Emergency Advocacy

Introduction

The Global Partnership for Zero Leprosy (GPZL) was launched in January 2018 to facilitate alignment of the leprosy community and accelerate effective collaborative action towards zero leprosy. The COVID-19 pandemic has strongly impacted leprosy control and prevention, and as a result, GPZL's Leadership Team has worked to identify the leprosy community's key challenges and outline an emergency response plan for 2020. This plan will ensure that the GPZL's substantial expertise and network is focused on the urgent situation being faced by National Leprosy Programmes and persons affected by leprosy and their families. It will also help to prepare for 2021 onward, including the likely consequences of the pandemic around the world and the impact on the GPZL's planned country partnerships. GPZL's three objectives for COVID-19 response in 2020 are:

- Chronicle and provide support for the urgent needs of national programs, particularly for access to MDT and follow-up care.
- Advocate for access to comprehensive healthcare, social protection services and humanitarian measures for persons affected and their families.
- Be prepared post-pandemic.

To achieve these objectives, three new term-limited working groups that correlate with these objectives have been created to mobilize the expertise and authority of the Leadership Team and key organizational experts.

Objective and tasks of Working Group 2

The objectives of Working Group 2 are: to advocate for access to comprehensive healthcare, social protection services and humanitarian measures for persons affected and their families.; advocate for the need to minimize the negative impact of this health crisis on the mental health and well-being of persons affected and their families; and give visibility to, and strengthen, already implemented strategies by a variety of civil society organizations to reduce the impact of this crisis. To do this, Working Group 2 will connect and distribute information to and from persons affected, and to other key audiences (policy makers, funders, NGO leaders), with a view to provide information in a quick, targeted and efficient way and enhance action that can respond to the needs of persons affected and their families.

This objective will be operationalized through a number of tasks to be conducted by the working group. In 2020, Working Group 2 anticipates conducting the following:

1. Creating a collaborative network of organizations of persons affected that can gather and disseminate information through teleconference meetings and other communications platforms.
2. Gathering information about the needs of persons affected during the COVID-19 pandemic by creating and distributing a questionnaire.
3. Collecting and distributing helpful information or guidance to persons affected and key stakeholders.
4. Elevating stories of persons affected and affiliated groups that are working to improve conditions for persons affected.
5. Sharing potential solutions for challenges faced by persons affected with key stakeholders.

General considerations

General considerations for the group are, firstly, that key voices in this conversation are persons affected and the organizations representing them, and their contributions should be acknowledged and appreciated. Data shared with the Working Group will only be used with due authorization and acknowledgment of the organization or individuals that have provided it. This is not only the work of GPZL, but is the collective work of many organizations, and the contributions of others are invaluable to the success of this working group. Secondly, the products of this group need to be sensitive to context. Guidance that comes from this group should be contextualizable and flexible, and should acknowledge that each setting is different. Finally, all communications should be as accessible as possible for all parties. This may include using communications tools that are most appropriate for the audience, keeping language as accessible as possible, and keeping recommendations as brief and clear as possible.

Structure and Membership

Working Group 2 is comprised of two GPZL Leadership Team Members that serve as co-chairs, and two staff members from GPZL and ILEP. Working Group 2 will heavily rely on our partners from organizations of persons affected, persons affected who are unaffiliated with an organization, and from IDEA to help facilitate the information sharing role of this group.

Contacts

Co-Chairs:

1. **Alice Cruz**, UN Special Rapporteur
2. **Amar Timalina**, President, IDEA Nepal

Staff:

1. **Mathias Duck**, Chair of ILEP Panel of Persons Affected by Leprosy
2. **Andie Tucker**, Project Manager, Global Partnership for Zero Leprosy

Appendix 3

Organizations of persons affected consulted via regional calls and written submissions:

- APAL
- ASOCIACIÓN PACIENTES CON MAL DE HANSEN DE LORETO
- ASOHANVIDA (Asociación de Personas Afectadas por Hansen Luz y Vida)
- Coalition of Leprosy Advocates of the Philippines (CLAP)
- ENAPAL
- Felehansen
- Global Leprosy Champions
- HANDA
- IDEA Ghana
- IDEA India
- IDEA Nepal
- KKM
- MAPAL
- MORHAN
- NAPAL Sierra Leone
- PerMaTa

- Président de L'association Sénégalaise de Lutte Contre la Lèpre et les Maladies Tropicales Négligées (ASCL/MTN)
- Purple Hope Initiative Nigeria
- Rengesõ no Kai
- Sungai Buloh's community

Partner organizations consulted:

- The Leprosy Mission International's headquarters and regional offices in Myanmar, Bangladesh, India, Papua New Guinea, and Timor Leste
- The Leprosy Mission England and Wales
- The Leprosy Mission Trust India

Persons Affected by Leprosy and the COVID-19 Global Health Crisis: Recommendations for NGO and Government Leaders

Recommendations

To address the needs and challenges faced by persons affected during the COVID-19 crisis, NGO and government leaders should:

1. Implement swiftly and in a sustained manner relief actions in response to the humanitarian crisis faced by persons affected and their families worldwide.
2. Develop and put in place a participatory framework for humanitarian aid that links relief to development. [Access an example of this kind of framework, “Participation by Crisis-Affected Populations in Humanitarian Action A Handbook for Practitioners”.](#)
3. Support grassroots organizations of persons affected with funding and capacity building, and liaise with them to share information about COVID-19, existing national social schemes, and information for persons in the community about accessing fundamental rights.
4. Support coalitions among grassroots organizations of persons affected with a view of elevating their joint voice at the international level and improve decision making, advocacy, and human rights enforcement.
5. After mapping the disproportionate impact of COVID-19, map available solutions and resources. Such information needs to be available and accessible to persons affected and their representative organizations.
6. Ensure ethical standards in the use of images and information employed in fundraising strategies, including: ensuring informed consent; using positive images; presenting persons affected in a dignified manner that depicts them as agents, instead of passive beneficiaries.
7. Implement a gender approach to humanitarian aid that empowers women affected.
8. Give due consideration to the social determinants of leprosy in the design of responses to the crisis, in order to ensure access to healthcare. Extra-institutional barriers, such as lack of transportation to healthcare services, lack of income or dependency on third party authorization in the case of women, should also be taken into consideration.
9. Liaise with and support National Leprosy Programmes to ensure access to the continuum of care for persons affected, including access to leprosy reaction treatment, and the resumption of wound care services and self-care groups as soon as possible.
10. Monitor the situation of former colonies and settlements and leprosy hospitals where COVID-19 patients are being treated in close proximity to elderly persons affected.

Mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members

22 May 2020

Open letter on COVID-19 and leprosy to the UN Member States

Excellency,

I have the honour to address you in my capacity as Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members pursuant to Human Rights Council resolution 35/9.

The Covid-19 pandemic threatens all countries and citizens on the globe, with greater impact on vulnerable social groups. Furthermore, most of the public responses to the pandemic have missed taking into account the structural inequalities that determine who is in a position to protect oneself from the virus and its economic and social consequences and who is not. In order to implement prevention measures (isolation, social distance, frequent hand washing, space cleaning and the use of masks), it is necessary to have, at least, decent housing, access to clean water and soap, income security with which to ensure subsistence during the quarantine, as well as to purchase masks and other hygiene and protection items. However, the percentage of the world population without access to the aforementioned goods is unacceptably high and includes the majority of persons affected by leprosy and their families. The former are, in fact, among the furthest behind and are currently experiencing the disproportionate impact of the crisis generated by the Covid-19 pandemic.

The current global crisis calls upon us to develop short, medium and long term action plans. In the specific case of leprosy, the progress of the past decades cannot be jeopardized by the loss of financial and human resources to the fight against Covid-19. Moreover, this crisis and its impact on persons affected by leprosy urges us to identify the social determinants of leprosy and develop a preventive strategy to stop transmission that can act on its root causes. Now more than ever substantive discrimination against persons affected by leprosy and their family members must be tackled in order to ensure their survival. It is with such aim in view that I have the great privilege to share with you information and advice based on evidence. Importantly, I have gathered detailed information on specific regions and countries, which I will not mention here. Needless to say that I put myself at your entire disposal for any bilateral dialogue on the specific situation of particular countries.

As the crisis generated by the Covid-19 pandemic unfolded, I received individual reports on how persons affected by leprosy were at a greater risk of the effects of Covid-19 and of the disproportionate impact of the crisis thus generated. The emergence of a humanitarian crisis among people and communities affected by leprosy became rapidly obvious. Being aware of the structural barriers faced by the vast majority of persons

affected by leprosy to elevate their voices to decision-making organs, I opted to develop a joint action with the main stakeholders in the field of leprosy with the goal of promoting swift responses to such humanitarian crisis. The Global Partnership for Zero Leprosy (a coalition that includes the World Health Organization, the Novartis Foundation, the International Federation of Anti-Leprosy Associations, the Sasakawa Health Foundation and the International Association for Integration, Dignity and Economic Advancement), in which I participate as a member of the leadership team, produced, together with the World Health Organization, key recommendations on diagnosis and clinical management of leprosy patients, on public health aspects of leprosy in the context of the COVID-19 pandemic, and for services for persons living with disabilities and/or psychosocial consequences of leprosy, herewith attached.

Together with the Global Partnership for Zero Leprosy, I held several consultations to individuals affected by leprosy, their representative organizations and non-governmental organizations around the world. We consulted leprosy priority countries from the Global South, reached out to more than 25 organizations and collected testimonies from 70 persons affected. This cooperative work made it possible to identify global trends in the impact of Covid-19 on this population, summarized as follows:

1. With regard to the barriers in the access to healthcare, most are institutional, such as:
 - a) loss of financial and human resources from national leprosy programs with the re-direction of leprosy funds and staff to the fight against Covid-19, which is leading to a substantive reduction on leprosy related initiatives;
 - b) interruption of key activities for early diagnosis and concomitant prevention of physical impairments (such as active case detection and chemoprophylaxis);
 - c) non-availability of leprosy care in health services, which in some cases have even refused to attend people suspecting of having leprosy;
 - d) sporadic difficulties in the provision of multidrug therapy;
 - e) generalized difficulties in the treatment and clinical management of leprosy reactions, aggravated by the lack of monitoring necessary for an highly complex medical treatment, but also by the lack of steroids for treating leprosy reactions in some countries;
 - f) deferral of complementary care essential for the prevention of physical and psychosocial disabilities, such as wound care or self-care groups. Extra-institutional barriers, related to the lack of sufficient income and transportation for travelling to healthcare services, are widespread among endemic countries. The continuum of care for persons affected by leprosy is seriously threatened and we may see a setback in the interruption of transmission and early diagnosis in the near future. Of particular importance is the fact that the number of leprosy cases in children, but also the number of cases in children diagnosed with irreversible physical impairments, is expected to increase in this context.
2. In what concerns access to social protection, recognized as a right in international law, there is a generalized lack of a State response that can guarantee a minimum

standard of protection to the more vulnerable populations in the context of the crisis. The guarantee of income security, through social security schemes that allow individuals and families to acquire minimum healthcare, basic shelter and housing, clean water and food, is urgent and glaring. However, in the cases where States have implemented cash transfer programs to ensure a minimum standard of living for vulnerable populations during the crisis, such benefits are largely inaccessible to persons affected by leprosy for different reasons. It may be due to eligibility criteria, either because they do not recognize the additional costs of disability, or because they rely on administrative services or bureaucratic procedures that are inaccessible to illiterate populations or those poorly educated and also to those living in remote areas. In addition, there are cases where persons affected by leprosy are excluded from these programmes because they do not own identity cards, which is a clear violation of their civil and political rights. With regard to regular social protection schemes prior to the crisis, there are cases in which the shutdown of the public administration has led to the non-availability of these subsidies and other cases in which the aforementioned lack of means of transportation also acts as a barrier in the access to social protection. To conclude, it is vital to mention the structural and widespread barriers in the access by persons affected by leprosy with invisible physical impairments to disability benefits as a result of eligibility criteria based on a very limited medical assessment, alongside the non-recognition of invisible impairments, such as loss of sensitivity and chronic pain, which is contrary to provisions of the Convention on the Rights of Persons with Disabilities.

3. Access to fundamental goods, such as food, energy for cooking, clean water, soap, masks and other protective items, is lacking for the majority of persons affected by leprosy and their families, and results from shortcomings related to the systematic discrimination against this group. The impossibility of many persons affected by leprosy, who are structurally excluded from the formal labor market, to guarantee any income, together with the loss of safety nets essential for their survival, in the context of the quarantine and other exceptional measures enacted by the States, has determined that many persons affected by leprosy and their families are left to extreme poverty. Non-governmental organizations and civil society organizations are making a huge effort, while striving to cope with a dramatic concern over the decrease in institutional funding and in development aid by governments, to provide humanitarian aid. Importantly, civil society organizations play a key role in healthcare delivery, community-based rehabilitation, formation of associative, self-help and self-care groups of persons affected by leprosy and the decrease in funding will undoubtedly increase the burden of disease, disability and stigmatization among persons affected by leprosy. Still, such humanitarian aid is more effective in reaching former leprosy colonies and leprosy villages than affected persons living in the society at large. Moreover, such humanitarian aid may sometimes rely on fundraising strategies that can lead to a setback in the struggle for the dignity of persons affected by leprosy. In order to respond to this humanitarian crisis, States should put forward unconditional cash transfer programmes in a timely manner.
4. In the case of the more vulnerable groups within the overall population affected by leprosy, older people living in former leprosy colonies are at higher risk of contracting Covid-19 and their right to life may be menaced by inadequate policies. Regarding former leprosy colonies and villages (there are still up to two thousands of leprosy settlements active in the world today), there is a great number of issues of concern: a) institutional neglect leading to lack of food, clean

water and hygiene and protective items; b) public administration that has turned parts of these former colonies into field hospitals for Covid-19 patients, putting the elderly population at a great risk. An even more disproportionate impact of the current crisis within the population affected by leprosy is found among women, refugees, persons with disabilities, people living in remote areas, in which children are of the greatest concern. Moreover, the disproportionate impact of Covid-19 is being felt in ongoing demands against institutionalized and interpersonal discrimination, which are blocked by the quarantine and the barriers it raises to freedom of assembly and organization and access to justice. Lastly, information for the prevention of Covid-19 is, to a large extent, not accessible to a considerable part of this population.

I conclude with the presentation of five key principles that should guide responses to the consequences of the crisis in the medium and long term:

1. Health systems should be strengthened and the efforts of national leprosy-related programmes sustained. The right to a continuum of medical and psychosocial care that encompasses the full spectrum of prevention, timely access to multidrug-therapy, proper management of leprosy reactions, complementary care, such as wound care, physiotherapy, rehabilitation, reconstructive surgery, should be guaranteed, alongside service delivery at the community level. A rights-based strategy for leprosy within health-care systems must be people-centred, having as a priority the well-being of persons, communities and populations, and must ensure: availability, as well as physical and economic accessibility of health-care services.
2. The scope of national leprosy-related programmes should be expanded to include a targeted action on the social determinants of leprosy. Such targeted action should be based on a comprehensive multisectoral policy that puts into practice the principles of the indivisibility, interdependence and universality of rights through coordinated interventions between the different sectors of government. National leprosy programmes should also endeavor to ensure the right of persons affected by leprosy to the highest attainable standard of mental health, with an approach that is ethically respectful, culturally appropriate, gender-sensitive and empowering to individuals, and that makes use of peer support as an integral part of recovery-based services.
3. Given the interlinkage of leprosy and poverty, the right to an adequate standard of living may not be accomplished without the prior granting of social benefits under a rights-based comprehensive social protection policy. Such a policy must be implemented through administrative services and bureaucratic procedures that can guarantee full accessibility to illiterate or poorly educated populations, as well as to populations living in remote areas. Furthermore, social benefits, such as unconditional cash transfers, should take into consideration the real needs of the target population, including the additional costs of disability. Such a comprehensive social protection policy should also target active citizenship by promoting training opportunities and formal employment. policies for the inclusion of persons affected in the formal labor market and should be grounded on the provisions of the Convention for People with Disabilities. They may require, in some cases, affirmative measures.
4. Relevant and accessible information on Covid-19 prevention should reach the entire population affected by leprosy. In order to achieve public health

education's goals, the participation of grassroots organizations of persons affected by leprosy is critical for ensuring that relevant information reaches all people. Such key participation should be supported with proper funding. Such organizations play a key role in mainstreaming good practices, fulfilling institutional gaps and providing support services. Meaningful participation of the organizations of persons affected in policy-making, monitoring and evaluation is essential to ensure an inclusive response to the crisis. By the same token, building autonomy through empowerment, is vital for marginalized persons or persons in disadvantaged situations to achieve greater control over their lives and further their democratic engagement. The 2030 Agenda for Sustainable Development is built upon the recognition that development is not only transforming the material conditions of people in disadvantaged circumstances, but also implies providing them with a voice and choice. The empowerment of individuals affected by leprosy and their representative organizations is essential for long-term responses to the current crisis.

5. International cooperation is key to supporting the elimination of leprosy and the right to the highest standard of physical and mental health of persons affected by leprosy and to promoting leprosy related human rights policies in low-income countries. Considering the global prevalence of leprosy, necessary resources from Member States would be modest, whereas the return on the investment would be of great value for the promotion of the human rights of extremely vulnerable groups, especially within the context of the realization of the 2030 Agenda for Sustainable Development.

As independent human rights expert, I would like to reiterate my willingness to engage with your authorities in a dialogue on this issue in my relevant fields of expertise, including how to implement the Guidelines effectively during and after the pandemic. I sincerely look forward to working together towards a world in which nobody is left behind.



Alice Cruz

Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members