

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