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Alice Cruz

Special Rapporteur on the Elimination of Discrimination against Persons Affected by
Leprosy and their Family Members

Excellencies,

Leprosy has been associated with the violation of the human rights of countless women, men and children for thousands of years. Some may argue that such violations resulted from the fact that, for a long time, leprosy was an incurable, disfiguring and disabling disease that spurred an automatic response of fear and rejection. However, this type of functionalist approach does not acknowledge that many societies did not consider leprosy as a transmissible disease. And yet, persons affected by leprosy were systematically labelled as shameful and set apart. Hence, the functionalist approach always ends up by blaming the persons who are stigmatized and discriminated against, while failing to question the persons who stigmatize and discriminate.

Religious and traditional beliefs, harmful cultural practices and misconceptions are the attributing factors that supported the discrimination of persons affected by leprosy in different historical periods and regions. My 2019 thematic report on women and children affected by leprosy shows that both groups suffer from ongoing verbal, physical and sexual violence, as well as institutionalized and interpersonal discrimination. In fact, stigmatization against persons affected by leprosy remains institutionalized at the State's architecture and functioning: there are more than fifty countries in the world that keep hundreds of discriminatory laws against persons affected by leprosy in force.¹ In addition

¹See <https://www.ilepfederation.org/wp-content/uploads/2018/11/Updated-discriminatory-laws-table-Final-1.pdf>

to law and public policies, discrimination is also a reality in the administration of certain States, particularly in health services, education and State benefits.

Early diagnosis is key to prevent leprosy related physical impairments that can lead to discrimination. However, stigma is undoubtedly a social determinant of health and illness. Therefore, in order to ensure early diagnosis, stigma reduction policies must be in place. Not only stigmatization can lead to delay in seeking diagnosis and in adhering to treatment, but it also impairs the availability of material and socioeconomic resources (such as sanitation, housing, work, education), as well as the social relationships that support the livelihoods of persons affected by leprosy. Lack of material resources and substantive equality, as well as of community acceptance and support, play a major role in health inequities. Harmful stereotypes and stigma usually impact the overall life conditions of persons affected, producing multiple and negative outcomes in terms of their social and physical well-being. Until research provides new evidence on the social fabric of leprosy and policy-making addresses its complex social mediator factors, fundamental social causes will continue to reproduce this spiraling of disadvantage that contributes to leprosy's transmission. As Rudolph Virchow brilliantly highlighted in the nineteenth-century, "medicine is a social science, and politics is nothing more than medicine in larger scale".¹⁰

The second decade of the twenty-first century was marked precisely by the acknowledgment that the medicalization of stigmatization (that is to say, the idea that the availability of medical treatment and the dissemination of medical knowledge about the disease would eliminate discrimination) was not enough. In its resolution 35/9, the Human Rights Council established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. I took on this position on 1 November 2017 and on my first thematic report (A/HRC/38/42) I outlined my vision, priorities and working methods.

My vision for my mandate is grounded upon three principles that may be applicable to other NTDs. The first one regards intersectionality and affirmative action. Leprosy-related discrimination is multiple and multilayered and there is sufficient evidence to suggest that leprosy commonly intersects with other marginalized social conditions, such as: gender; ethnicity and/or race; age; disability; migration; and poverty. In practice, this means that leprosy-related discrimination affects in different ways a person according to his or her social status and capital. Intersectionality is key for

analysis, but responses for action must come affirmative action. Affirmative action means creating mechanisms or policies that allow for protecting and supporting specific social groups that dwell in structural disadvantage in order to balance the terms that establish not only opportunities, but also outcomes for those groups, in areas such as education, work or social security.

The second principle is that of vulnerability and intersectorality. The concept of vulnerability refers to the diminished capacity of an individual or group to anticipate, cope with, resist and recover from any hazard. However, vulnerability must be understood as a political, economic, social and cultural condition and not as an ontological feature of a group of persons. That is to say, any analysis of vulnerability must distinguish between the conditions that diminish an individual's or a group's capacity to cope with hazard, from the multiple and creative ways that individuals and groups usually develop to resist it, despite their very limited options and resources. It is mandatory to develop tools to assess vulnerability and the means to tackle it. One important tool is the framework provided by the Sustainable Development Goals. Such a framework may be of great help in developing a multisectoral governance that might avoid duplicity of actions, as well as enhance efficiency, effectiveness and efficacy.

The third principles is that of participation and lay expertise. Participation is key for the long-term elimination of leprosy-related discrimination. Participation in decision-making is not only a right, it is also pivotal for the production of more effective responses to problems. Persons affected by leprosy develop situated knowledge that differs from the knowledge produced by science or the State, and that is particularly helpful in producing new and much needed geographies that might map the complex intersection between leprosy and social factors. Such situated knowledge generates alternative evidence, as demonstrated by popular epidemiology in environmental processes and studies. Situated knowledge is also key to evaluation and accountability. Finally, such participation in public life helps achieving the structural change in which the automatic social response of rejection gives way to an empathic understanding of similarities, that is to the recognition of equality and accompanying elimination of stigma.

The analysis of the more than 600 responses to the consultation I undertook among persons affected, family members, States, National Human Rights Institutions and civil society organizations to my 2019 thematic report, points to the fact that the majority of good practices developed by States fall upon the health sector and that more efforts are

needed to tackle the social, economic, cultural and political dimensions of leprosy. Some diseases are so strongly framed by socioeconomic and cultural factors that the enforcement of the right to the highest attainable standard of health, however critical as it may be, is not sufficient to restore and/or ensure full citizenship to affected persons. Without the recognition de facto that all human rights are inalienable, indivisible, interdependent, and of equal hierarchy, and that they all must be fulfilled on a non-discriminatory basis, alongside a multisectoral strategy that aligns different spheres of governance (such as health, education, work, social security, justice), persons affected by leprosy will surely continue to be left behind.

Research on the intersection of health and human rights of persons affected by leprosy and other NDTs is lacking and urgently needed. I commend the Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and their Family Members as a roadmap for research and action in the field of NDTs. I am currently preparing a set of indicators based upon the Principles and Guidelines that might be of help to map the intersection of NDTs with social, economic, cultural and political factors, but also to assess efforts made by States to eliminate discrimination on their grounds and, as such, to better support them with technical solutions. Here, I propose the following general recommendations for discussion:

- a) Systematically approach, consult and involve in decision-making processes that directly affect their lives, persons affected by leprosy and their representative organizations, with the guarantee of all affirmative measures for ensuring the participation of women, children and men affected by leprosy related impairments and disabilities;
- b) Develop awareness-raising programmes at both the national and subnational levels, with a focus on providing accurate information about leprosy to the general population, as well as on the human rights of persons affected by leprosy. Such programmes should: provide for dialogue with the heterogeneity of all relevant population groups (including those possessing non-scientific knowledge and non-official authorities, such as traditional healers and leaders); involve persons affected by leprosy; and be sensitive to local languages, gender, age and disability;
- c) Improve monitoring systems for leprosy, also comprising disaggregated and equality data that may support anti-discriminatory policies. Monitoring systems should encompass

follow-up of cured cases in order to ensure high-quality care and rehabilitation after bacteriological cure. Leprosy health services should include easy-to-access mechanisms for making complaints of discrimination;

d) Implement a multisectoral governance, and affirmative measures when necessary, in order to tackle the multiple nature of leprosy related discrimination and vulnerability. Multisectorality should also be reflected upon in leprosy health services, guaranteeing accessibility, comprehensive care and peer counselling.