

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

Global consultation with NLP managers, partners and affected persons on Global Leprosy Strategy 2021–2030

I thank the Global Leprosy Programme for the opportunity to comment the draft Global Leprosy Strategy. As the United Nations Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, I support the Global Leprosy Strategy. I also call upon governments to implement it with proper budget allocation at the national and subnational levels, as well as with the full participation of national organizations of persons affected by leprosy. In times of COVID-19, I make an appeal to all the Global Leprosy Programme's partners to advocate for the sustenance of national efforts in leprosy activities and control.

I would like to start by congratulating the Global Leprosy Programme on progress regarding Pillar 4 "combat stigma and ensure human rights are respected". If it is true that all the pillars of the strategy are interrelated, goals related to pillars 1, 2 and 3 will not be reachable without the full implementation of pillar 4. Among the many examples that clearly show the interaction between biology, culture and society, I would like to highlight how apparently simple things can have powerful effects. It is widely known that the gender of the healthcare workforce can act as a barrier in the access of women to diagnosis and treatment in many endemic regions. It is also widely known how physically demanding labour, which is the daily reality of livelihoods' sustenance among many persons affected by leprosy, can aggravate physical impairments related to nerve damage. In order to be effective, public health strategies need to be comprehensive and act on the social determinants of health and illness. As I will focus my intervention on pillar 4, I trust that the Global Leprosy Programme will take due consideration of the excellent

recommendations made by persons affected by leprosy regarding all the pillars of the strategy, given the fact that they are, as Mr. Yohei Sasakawa has very appropriately called them, the primary stakeholders.

In order to proceed to pillar 4, allow me to start by clarifying the concept of discrimination. Now, more than ever, we need to make an effort to move beyond the medical and charity models that have dominated both public and private interventions on leprosy and leprosy related stigmatization and truly embrace a human rights approach that recognizes persons affected by leprosy as right holders. Discrimination encompasses much more than interpersonal stigmatization at the micro level of the community, which has been the primary focus of the majority of stigma reduction strategies. Discrimination can be direct or indirect and usually leads to loss of opportunities, material deprivation, structural disadvantage, stigmatization and poor access to State's goods and services. My 2019's report to the Human Rights Council,¹ which was informed by more than 600 contributions from civil society organizations and governments, maps ongoing human rights violations, providing a clear picture on how leprosy continues to be at the root of wrongful stereotyping, interpersonal, institutional and structural violence, as well as of the worst form of dehumanization, which is the internalization of stigma. Reason for which pillar 4 of the global strategy is of the greatest importance.

While I commend the global strategy for the reference made to the Principles and Guidelines on the elimination of discrimination against persons affected by leprosy and their family members, I would like to present concrete recommendations in this regard:

First, the strategy should acknowledge the status of the Principles and Guidelines. By underpinning the normative integration of several international human rights instruments, the Principles and Guidelines interpret and translate legally binding norms in connection with the conditions and needs of persons affected by leprosy and their family members. They are, as such, a road map for States to enforce international human rights law, which States are obliged to comply with.

¹ A/HRC/41/47.

Second, the Principles and Guidelines put forward the need for a rights-based policy framework. The global strategy should, as such, advise States to consider the policy framework for rights-based action plans developed by my mandate² and which is based upon an in-depth study on the relation between the Principles and Guidelines and legally binding international human rights instruments, as well as on the examination of good and best practices. Such policy framework is structured upon four main axes, as follows: (a) adequate standard of living and economic autonomy, which includes social protection, work and training opportunities and access to health systems; (b) non-discrimination, independent living and inclusion in the community, which includes anti-discrimination principles, accessibility and independent living; (c) elimination of stereotypes and the right to truth and memory, which includes awareness-raising and capacity-building, reparation and the preservation of history; (d) empowerment, with a focus on vulnerable groups, which includes education, participation and access to justice.

Third, the implementation of the Principles and Guidelines cannot be expected to be undertaken by National Leprosy Programmes alone, but requires mainstreaming leprosy into government bodies other than the Ministries of Health, such as the ones regarding education, work, justice, but also those created for protecting the rights of more vulnerable groups, like women, children, older people, people with disabilities.

Fourth, in order to eliminate discrimination on the grounds of leprosy, collection of data and monitoring of discrimination requires significant improvement, for which the following is recommended: clear targets, indicators and benchmarks need to be developed; systematic data collection should include disaggregation not only by demographic and socioeconomic variables, but also by the various grounds of discrimination recognized in international human rights law (such as gender, age, race, disability, among others), and must respect the principles of participation and privacy; monitoring and accountability mechanisms with transparent sharing of information to primary stakeholders should be put in place; provision of accessible mechanisms for filing complaints on the violation of human rights should be developed, implemented and

² A/HRC/44/46.

followed-up with the participation of the organizations of persons affected by leprosy, since they will need to adjust to distinct local and national realities.

Fifth, in order to implement the above recommendation, it is mandatory to put in place a robust human rights education strategy directed at different groups. By the one hand, the healthcare workforce should be trained in not only clinical, but also structural competency that can foster in-depth understanding of the root causes of discrimination and emotional distress experienced by users within the context of their culture and life. By the other hand, promotion of human rights education for persons affected by leprosy, as well as delivery of legal advice, are a key component of any human rights monitoring and complaints' mechanism.

Sixth, regarding the overall global strategy, while acknowledging the difficulties faced by many health systems in endemic countries, goals need to aim at people-centred health systems, which should ensure: availability, as well as physical and economic accessibility of healthcare services; active and informed participation of users; gender-sensitive and culturally sensitive strategies, as well as childfriendly services; accountability of the healthcare workforce, with indicators that facilitate monitoring. Healthcare systems should empower community engagement and participation, by including social support, increased patient-provider communication, psychosocial individual and family counselling, selfcare and self-help groups, peer support and peer health promoters and outreach activities within partnerships between health services and organizations of persons affected by leprosy. In the same way, a holistic strategy needs to include a rights-based approach to mental health, which should be ethically respectful, culturally appropriate, gender-sensitive and empowering to individuals, making use of peer support as an integral part of recovery-based services.

Seventh, as it is widely acknowledged, challenges will be mostly felt at the level of national implementation. As such, pillar 1, particularly in what concerns “political commitment with adequate resources for leprosy in integrated context” is key. In order to ensure political commitment, not only advocacy, but especially accountability needs to be strengthened. In order to make effective the principle of accountability, strategies aimed at empowerment and meaningful participation of persons affected by leprosy must be put in place. Common elements

to empowerment are: it has a dimension of collective involvement; it involves active participation, critical reflection, and understanding; it involves access and control over important decisions and resources. Common elements to meaningful and not tokenistic participation are: it requires full involvement in decision-making; it must respect the principles of autonomy, representativity through the democratic appointment of people's representatives by their own constituents, horizontal relationships between different partners and freedom of expression. Moreover, in order to ensure meaningful and barrier-free participation of groups historically discriminated against, special measures that can address the several barriers to participation (such as illiteracy and low educational qualifications, inaccessibility of administrative procedures, inaccessibility of the information being provided, gender-based discrimination) need to be put forward.

To conclude, I recommend the Global Leprosy Programme to include an explicit reference to guideline 14 of the Principles and Guidelines on "development, implementation and follow-up to States' activities", guiding States to designate a committee to address activities relating to the human rights of persons affected by leprosy and their family members, which should include representatives of organizations of persons affected by leprosy. I also make an appeal to private actors, such as Non-Governmental Organizations to implement guideline 14, in strict respect of the principles of autonomy and democracy.