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FOREWORD

Embodying Law and Embedding Public Health with the Voices of Those Affected: Ending NTDs by 2030

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In the mid-nineteenth century, when public health was establishing itself as a scientific field, the great physician-scientist Rudolph Virchow wrote, "Medicine is a social science, and politics is nothing more than medicine on a larger scale."[1] With this statement, Virchow highlighted the interplay between human health and society.

A century and a half later, the looping effect—that is, the fundamental relationship between society and health, between culture and biology—remains inadequately addressed.[2] The difficulty lies in what Bruno Latour refers to as the modern cut of the Gordian Knot tying the different elements that make up the world; this cut drove the separation of science and knowledge from politics and power.[3] Hence, science became responsible for representing nature, and law for representing citizens. Accordingly, medicine and law grew apart as the modern state's organizational structure became progressively bureaucratized and its intervention increasingly sectoral. Yet there have been significant attempts to combine medicine and legal theory. These include the notion that non-discriminatory access to health is fundamental to the right to the highest attainable standard of health, the social determinants of health, and civic participation in public health strategies.

I welcome this special section on neglected tropical diseases (NTDs) and human rights. It comes at a critical moment, soon after the Sustainable Development Goals (SDGs) were agreed on by 193 United Nations member states in 2015. I would like to highlight SDG 3.3, which calls for ending NTDs by 2030. But I also wish to draw attention to SDG 17, which calls for strengthening global multi-stakeholder partnerships for sustainable development. Goal 17 reminds us of the interrelatedness among many of the SDGs and the fact that multisectoral coordination and action will be required to reach every one of them. Thus, goal 3.3 is closely linked to the SDGs on eliminating poverty and hunger, realizing health and well-being, and achieving quality education, gender equality, clean water and sanitation, decent work and economic growth, and sustainable cities and communities.

This special section is also timely because it coincides with United Nations Resolution 35/9, issued in 2017, which calls for the elimination of leprosy-related discrimination. As Special Rapporteur for the elimination of discrimination against persons affected by leprosy and their family members, I accepted this challenge on November 1, 2017.

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The establishment of this mandate acknowledges the fact that diseases are not reducible to isolated biomedical categories. Indeed, some diseases are so strongly framed by socioeconomic and cultural factors that enforcement of the right to health, however critical it may be, is inadequate to restore and ensure full citizenship to affected persons. Some diseases, particularly those that affect populations subjected to structural violence, are complex biosocial phenomena that require a rights-based approach. Such an approach recognizes that all human rights are inalienable, indivisible, interdependent, and of equal hierarchy, and that they must be fulfilled on a non-discriminatory basis in agreement with the provisions of the Universal Declaration of Human Rights and other human rights instruments.[4]

As many persons affected by leprosy have noted, curing infection is not the same as healing. For the majority of affected women and men, healing is dependent not only on access to medical treatment and bacteriological cure but also on the quality of care, rehabilitation, and social inclusion and participation. For persons affected by leprosy, the Gordian Knot between biology, society, culture, and history is vividly tied, and so are their civil, political, social, economic, and cultural rights.

As Special Rapporteur, I welcome all NTDs into this position's mandate. Despite the structural invisibility of leprosy—which nourishes its social representation as a disease of the past—leprosy is probably one of the most well-known NTDs due to its history. Many of the factors that systematically result in negative outcomes for persons affected by leprosy are also active for other NTDs. Leprosy exemplifies the historically thick barriers to health that also exist for other NTDs, such as widespread stigma and institutionalized and multilayered discrimination. However, stigma and discriminatory laws, jurisprudence, and public policies (in the case of leprosy, there are still discriminatory laws in more than 20 countries, covering the topics of segregation, immigration, marriage, voting rights, public transportation, employment, and housing) are not the only reasons for the exclusion of persons affected by leprosy.[5] These persons also face discrimination in the administration of public goods and services—and even when their rights are recognized, they are not effectively implemented. Access to rights, including the right to health, depends on extra-institutional factors, such as education, inclusion in the formal work market, gender equity, and racial non-discrimination. Given the generalized lack of material equality and prevalent conditions of vulnerability faced by persons affected by leprosy and other NTDs, the gap between the laws on the books and the laws in action is massive, with a correspondingly large impact on these persons' health and well-being.

Taking further the example of leprosy to address NTDs from a human rights perspective, I would like to draw attention to the insufficiency of a medicalized and pharmaceuticalized approach to leprosy.[6] While the groundbreaking role of multidrug therapy cannot be dismissed—there has been an impressive decrease in the number of cases since multidrug therapy's introduction three decades ago (from over 5 million cases in the mid-1980s to fewer than 200,000 cases at the end of 2016), as well as improvements in the lives of persons affected by leprosy and in the public's image of the disease—there is still (1) considerable incidence and ongoing transmission, (2) a high proportion of late diagnoses, (3) under-notification of the disease by physicians and governments, (4) the emergence of new challenges, such as the increase in foreign-born cases in countries that no longer have expertise in diagnosing and treating leprosy, resulting in increased transmission, and (5) persistent stigma and discrimination.[7]

Of the 214,783 new cases reported to the World Health Organization in 2016, 12,437 occurred in persons with grade 2 disabilities—that is, visible impairments.[8] Such impairments are preventable. When they occur, they indicate a delay in access to diagnosis and high-quality treatment. Moreover, of the 12,437 new cases reported in 2016 with grade 2 disabilities, 281 were among children, a shamefully high figure, and the overall detection among children was nearly 9% of the 214,783 new cases. Additionally, the overall underreporting of women affected by leprosy reflects their vulnerability and lack of access to health services in many settings, especially in poorer communities.[9] The epidemiology of leprosy is linked to the continuous violation of the human rights of vulnerable groups worldwide and within countries.

In recent decades, it has become increasingly obvious that reducing the incidence of leprosy will require more than just a medical approach. Yet the belief that the availability of medical treatment and dissemination of medical knowledge about leprosy will eliminate stigma and discrimination remains strong, despite the historically, socially, politically, economically, and culturally entrenched discrimination against persons affected by leprosy. In fact, stigma and discrimination hinder people from being diagnosed and treated, as well as from fully enjoying their civil, political, economic, social, and cultural rights.

For these reasons, in 2010 the United Nations approved Resolution 65/215 on the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members and the accompanying Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members.

Research on the intersection of health and human rights with regard to persons affected by leprosy and other NTDs is nevertheless lacking and urgently needed. I commend these principles and guidelines as a roadmap for research and action in the field of NTDs.

The commitment to leaving no one behind seems to draw inspiration from Virchow's statement, and it highlights the need to retie the Gordian Knot between science and politics, between health and human rights. This means reuniting the ethics upon which human rights are built with the soteriological concern of the practice of medicine, which places compassion at the center of public health efforts.[10] But this also means *embodying* law—that is, making law relevant to the individual body, where, as Eleanor Roosevelt noted decades ago, all human rights should begin.[11] Further, it means increasingly embedding public health with the human voices of those whose rights have been violated. We must listen to the human voice and respect the knowledge of persons affected and of civil society if we wish to achieve positive outcomes in public health. Taking Virchow seriously means restoring an experiential body to the law and an experiential voice to public health. Both movements are critical for the fulfillment of the 2030 agenda and, particularly, for ending NTDs.

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