

## EDITORIAL

# “Equipping Practitioners”: Linking Neglected Tropical Diseases and Human Rights

JOSEPH J. AMON AND DAVID G. ADDISS

In 2007, Paul Hunt, the United Nations Special Rapporteur on the right to health, and colleagues published a report entitled *Neglected Diseases: A Human Rights Analysis*. In introducing the report, the authors wrote:

*The human rights implications of neglected diseases, and the contribution that human rights can make to addressing neglected diseases, have not been given the attention they deserve. This report aims to equip practitioners with an understanding of human rights, how human rights abuses cause and result from neglected diseases, and how a human rights approach can contribute to the fight against neglected diseases.<sup>1</sup>*

More than a decade later, the human rights implications of neglected tropical diseases (NTDs) are still only infrequently addressed, and there remains a need to “equip practitioners”—in both the NTD and the human rights fields—and to ensure that rights-based principles and approaches are examined and integrated into NTD programs. Seeking to expand this attention, the call for articles for this special issue of *Health and Human Rights Journal* asked NTD scholars and practitioners to share examples of how rights interact with NTDs and how current NTD programs respect, protect, and promote human rights.

The four articles in this issue respond to this call from different vantage points. Nina Sun and Joseph J. Amon present an overview that looks at how human rights intersect with NTD control and elimination efforts and focus on how rights-based interventions and advocacy can accelerate progress toward global goals. Jibril Abdulmalik and colleagues examine mental health status among persons with lymphatic filariasis (LF) in Plateau State, Nigeria, and how stigma, discrimination, and social exclusion toward people with LF result in significant and often unaddressed morbidity. Hunter Keys and colleagues describe how in the Dominican Republic, an LF program has managed to overcome discriminatory government policies to reach at-risk individuals, protecting their health, building greater trust in government health activities, and reducing the effects of social exclusion. Finally, Arianne Shahvisi, Enguday Meskele, and Gail Davey look at the human rights violations that cause, and are caused by, podoconiosis in Ethiopia, focusing on access to prevention (shoes), education, and affordable and accessible health care. Together, these articles describe some positive steps to integrate human rights into the response to NTDs. But they also highlight how

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despite more than a billion treatments provided and hundreds of millions of people no longer at risk of infection, tens of millions of people are still left behind, and how NTD programs neglect opportunities to advance broader health and human rights concerns among the world's poorest populations.

### “What gets counted gets done” versus “not everything that counts can be counted”

In their overview of human rights and NTD issues, Sun and Amon recount how, before international advocacy helped establish the goal of Guinea worm eradication, Nigeria reported about 5,000 cases of the disease to the World Health Organization (WHO) annually. After the goal was set, nationwide village-by-village searches found over 650,000 cases, some in communities previously unknown to government officials. Quantification of the disease burden provided a basis for accountability and for international donor funding toward eradication. From an estimated 3.5 million cases in 21 countries in Africa and Asia in 1986 at the start of eradication efforts, so far in 2018 only three cases have been reported worldwide. The expression “what gets counted gets done” can be understood in this context as not dissimilar from the first steps of human rights advocacy strategies, which include building coalitions, raising awareness, identifying government obligations, and securing commitments.<sup>2</sup>

However, public health programs generally, and NTD programs specifically, often follow an approach that seems closer to the philosophy of “what is easiest to count is counted.” As seen in the article by Abdulmalik and colleagues, mass drug administration programs often fail to address the large burden of mental health morbidity associated with NTDs. In their study, nearly all the respondents with LF revealed personal experiences of stigma and discrimination, frequently in the form of being shunned. They also reported that social interactions—including the ability to find marital partners, the quality of marital relationships, and participation in community social events—were negatively affected. And this experience is not lim-

ited to Nigeria: A recent paper estimated that the global burden of mental illness associated with LF was more than five million disability-adjusted life years (DALYs)—nearly twice as high as the DALYs directly attributed to the disease itself.<sup>3</sup>

Although mass drug administration programs may succeed at breaking LF transmission, can we declare victory when some 40 million people will continue to suffer lymphedema? What does it say about what we value in global health that funding for NTD morbidity management is a small fraction of what is allocated for mass drug administration programs? After transmission interruption goals are met, donor funding will undoubtedly become even more scarce. Even more striking is that this underfunding is happening even though WHO's LF elimination criteria stipulate that programs must assess LF disease burden and include morbidity management within health systems. As NTD (and polio) programs claim success in reaching their goals of interrupting transmission, it seems likely that the communities they served will once again fall off the radar of government health services.

Shahvisi, Meskele, and Davey highlight another disease often overlooked by traditional NTD programs despite occurring alongside other NTDs. Podoconiosis is a debilitating disease marked by chronic swelling of the foot and lower leg, and it is caused by long-term exposure to irritant red volcanic clay soil in highland regions of Africa, Central America, and India. It is so neglected that it is not even officially recognized by WHO as a neglected tropical disease.

In their case study from Ethiopia, the authors describe rights-based programs for podoconiosis and outline government obligations to address the disease. They highlight how civil society advocacy helped spur podoconiosis's integration into the National Master Plan for NTDs, with improved staff training and lymphedema management services at government clinics. In theory, this should promote sustainability. Yet funding remains insufficient and reliant on external donations. The authors also point out that government health care facilities do not serve all endemic rural populations and less

than 5% of Ethiopia's gross domestic product is spent on health care.

In contrast to the focus on diseases left out, Keys and colleagues examine people left out, by law if not always by practice. The authors describe how LF elimination efforts in the Dominican Republic have had to navigate between constitutional protections that guarantee that *toda persona*—every person—has the right to “integral health” and a law passed in 2013 that strips individuals of Haitian descent of their citizenship and rights, including access to health care.

The authors describe how extending LF treatment to individuals of Haitian descent required building trust and evolving from a centralized, vertical program to one grounded in the local health care system that mobilizes local primary care staff, neighborhood associations, and community volunteers. Post-elimination, can this trust, and the provision of care, be sustained? Or will the contribution of individuals of Haitian descent toward ridding the country of LF be rewarded with a return to discrimination and exclusion? Absent political reform, the status of individuals of Haitian descent in the Dominican Republic is unlikely to stabilize through disease-specific initiatives. While LF elimination may be sustained, inclusion and recognition by the public health sector may not.

### Finding a way to count what counts

In all four articles, there is a broadening of the lens to explore how NTD elimination efforts can intersect with universal health coverage goals and the promotion of the right to health, non-discrimination, and human dignity. While NTD donors and practitioners have often defined the goal of transmission interruption as the most important priority, the authors and programs highlighted in this issue show how incorporating a rights perspective can not only strengthen health outcomes (beyond breaking transmission) but also accelerate the achievement of NTD elimination goals.

Collectively, the articles can be read as a call for more attention to (and creativity in defining) indi-

cators that measure the capacity and sustainability of governments to fulfill the right to health in terms of NTD morbidity and mental health, as well as structural determinants of vulnerability to NTDs. Our challenge is to find new ways to count what we dismiss too easily as uncountable. To a large extent, social justice and health equity have served (only) as a rallying cry for advocacy for NTD programs. Rights are recognized implicitly, as NTD programs are intended to be “pro-poor.” But if we pursue NTD elimination because we recognize the extent to which these diseases both cause and result from injustice and inequity, then we must be sure that our efforts and means of achieving elimination address this underlying concern and advance equality and promote human dignity. Measuring reductions in stigma and discrimination and improvements in mental health and gender equity should be an essential part of NTD program evaluation.

In addition to the topics addressed by the four papers included in this special issue, NTDs engage with and pose many other challenges to human rights. For example, in Brazil, persons with Chagas disease face discrimination in securing employment and remaining employed.<sup>4</sup> As Alice Cruz states in her foreword to this special section, laws and policies that discriminate against persons affected by leprosy remain on the books in many countries, and affected persons and their families continue to experience stigmatization. Ongoing transmission of Zika virus, although not (yet) recognized by WHO as an NTD, highlights challenges to reproductive rights, as well as failures to collect or report data on Zika.<sup>5</sup> Massive dam-building schemes in areas endemic for schistosomiasis can both infringe on the human rights of persons living in these areas and increase communities' risk of contracting the disease.<sup>6</sup>

On a broader scale, a human rights approach can be valuable in addressing complex issues of intellectual property and the development of low-cost generic drugs for NTDs.<sup>7</sup> Recent examples of rogue companies purchasing the rights to license NTD drugs in the United States and then jacking up the price to astronomical levels highlight the fact that

access to safe and effective NTD drugs is not simply an issue for developing countries.<sup>8</sup> In addition, the inextricable link between NTDs and human rights violations makes it difficult, yet essential, to address them in refugee settings and areas of conflict.<sup>9</sup>

## Human rights and the future of NTD control and elimination

The 2012 London Declaration on Neglected Tropical Diseases mobilized substantial resources and attracted international attention to 10 NTDs in an effort to achieve the 2020 WHO targets for their control or elimination. Our laser-like focus on these targets, which are related largely to transmission, has yielded impressive results. Donated NTD drugs from pharmaceutical companies were used in mass drug administration programs to treat more than one billion persons in 2016. Since 2012, 20 countries have stopped mass drug administration for LF, either having received WHO validation or having passed their transmission assessment surveys.<sup>10</sup> Five countries have been recognized by WHO as having eliminated trachoma as a public health problem, including, most recently, Nepal and Malawi.<sup>11</sup>

However, although transmission has been significantly reduced, and in some cases nearly eliminated, for many NTDs the public health problem remains. Our focus on transmission has also had the negative effect of constricting our notion of what an NTD program is. NTD programs have been conceived of as vertical, military-like assaults on implicated pathogens, rather than as providing care for affected persons. Thus, chronic NTD morbidity, together with its accompanying stigma and mental health problems, has been viewed as falling largely outside the purview of NTD programs—as have the underlying causes of NTDs, such as poverty, inequity, and inadequate sanitation. Consequently, despite the NTD mantra of “integration” with broader health initiatives, NTD programs have remained relatively isolated within ministries of health. An important early justification for NTD programs was that they would extend and strengthen health systems. Yet our restricted notion of what NTD programs are

has limited their potential to relieve suffering and strengthen health systems.

Calls to expand the scope and vision of NTD programs—whether to address chronic morbidity, mental health, or health systems strengthening—have mostly been met with shrugs of resignation from donors, governments, and nongovernmental partners alike. At a recent international meeting on NTDs, the representative of a prominent donor, replying to a comment on the challenge of reaching geographically isolated (but affected) communities, said matter-of-factly that NTD programs had to consider indicators measuring the cost per person reached, which might lead to focusing on achieving elimination targets through high treatment coverage of populations living close to health facilities. Such an attitude is opposed to the spirit and the fundamental intent of the Sustainable Development Goals (SDGs). Given the radical and far-reaching vision of the SDGs, it is time to reflect on whether our current “donate to eliminate” approach to NTDs, which appeals primarily to the goals of eliminating specific diseases and advancing economic development, can carry us much further.

We suggest two major complementary shifts in approach that can both broaden and deepen NTD programs and equip them for realizing the SDGs. First, as we have outlined above and as the articles in this special issue detail, a human rights approach is needed to build on the successes of the NTD effort to date and expand progress to new areas. Second, in keeping with intent of the SDGs to “leave no one behind,” NTD programs must commit to caregiving for affected *persons* in addition to engaging the battle against infectious organisms.

Addressing the challenge of NTDs at the global level necessarily requires massive systems, partnerships, and bureaucracies. In the process, we tend to lose sight of the importance of providing care to affected individuals, and the human dimension of our efforts withers.<sup>12</sup> In recognition of this tendency, the WHO Global Learning Laboratory recently named compassion as a key component of high-quality universal health coverage and has issued a co-development call to better understand how to harness the essential human aspects required for quality health

care. For global health and NTD control programs to realize their full potential, they must simultaneously embrace and be informed by both human rights and human dignity.

In his 1935 book on typhus, entitled *Rats, Lice and History*, Hans Zinsser wrote that “however secure and well-regulated civilized life may become, bacteria, protozoa, viruses, infected fleas, lice, ticks, mosquitoes, and bedbugs will always lurk in the shadows ready to pounce when neglect, poverty, famine, or war lets down the defenses. And even in normal times they prey on the weak, the very young and the very old, living along with us, in mysterious obscurity waiting their opportunities.”<sup>3</sup> But those opportunities—at least for LF, trachoma, Guinea worm, and onchocerciasis—are waning because of the heroic work of NTD campaigns to map NTD prevalence and deliver effective drugs on a massive scale. These successes represent major victories for public health. But as the articles in this issue highlight, the chronic manifestations and public health burden of many NTDs remain—and with them, stigma, exclusion, and lack of access to care still lurk and lie waiting.

The SDGs, with their renewed emphasis on universal health coverage, underscore the need to turn our attention and shift our global health priorities from vertical programs targeting specific pathogens to programs aimed at strengthening systems of care. In support of this new perspective, the human rights approach is well positioned to inform, guide, and catalyze efforts to realize national and global goals for NTD control and elimination. To date, human rights principles and approaches have emphasized, to varying degrees, participation and transparency, in terms of community engagement and public accounting of NTD prevalence and progress toward elimination and control. But non-discrimination and accountability (including for greater country financial investment) have been less emphasized. Sun and Amon note three specific areas where rights-based approaches to NTDs can be expanded: addressing inequity and populations at risk of being left behind; combatting stigma and discrimination and ensuring attention to mental health needs among people living with NTDs; and

promoting patients’ rights and non-discrimination in health care settings. These three areas represent concrete starting points for NTD practitioners seeking to integrate rights into their work.

As Paul Hunt noted more than a decade ago, if fully deployed, human rights can help NTD programs—and the governments that run them—deliver on their fundamental promise of health equity and more effectively advance their unfinished “pro-poor” agenda. Building on Hunt’s call to action, the four articles in this issue begin to explore the opportunities and need for an enhanced collaboration between NTD programs and human rights principles and approaches. What is to be gained is not just the elimination of specific pathogens but more equitable communities and healthier populations.

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