

PERSPECTIVE

Human Rights in the Fourth Decade of the HIV/AIDS Response: An Inspiring Legacy and Urgent Imperative

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Abstract

More than 35 years since the HIV/AIDS pandemic began, HIV continues to cause almost two million new infections each year, and the “end of AIDS” by 2030 remains elusive.¹ Violations of human rights continue to fuel high rates of new infections among key populations and a generalized epidemic in much of sub-Saharan Africa. Meanwhile, as political shifts worldwide threaten not only HIV funding but also progress toward the globalization of human rights, civil society mobilization and advocacy founded firmly on human rights principles have a more vital role to play than ever. Encouragingly, there are numerous examples of successful integration of human rights-based approaches into HIV prevention and treatment initiatives, and evidence increasingly demonstrates that norms enshrining the respect, protection, and fulfillment of human rights can translate into improved public health.² This essay will succinctly trace the historic emergence of human rights as an issue at the heart of the HIV/AIDS response; it will then provide examples of progress and setbacks in recent years and consider the potential for rights promotion to address the structural drivers of HIV. Finally, it will consider how the primacy of human rights in HIV/AIDS has affected other fields of global health and will highlight the continuing imperative to work with civil society to protect and promote human rights to reduce the burden of HIV/AIDS.

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Competing interests: None declared.

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Historical context of human rights in the HIV/AIDS response

The human rights discourse gained prominence in the early days of the epidemic in North America (and soon afterward in Brazil and Western Europe). In the face of authorities' neglect of the epidemic, many people living with HIV (PLHIV) became advocates for their right to health and, in the case of the LGBT+ community, their right to non-discrimination. The initial response by authorities in many countries was to stigmatize groups perceived to be high risk, such as men who have sex with men (MSM) and Haitian immigrants in the United States, and sex workers and truck drivers in India.³ The marginal status and lack of political capital of many of those initially affected by HIV frequently allowed authorities to adopt a "law and order" response limiting individuals' rights—for example, restricting PLHIV from international travel and employment. This climate of fear, blaming, shaming, and isolation led groups most affected by the early HIV epidemic to mobilize against the interlocking stigma of living with HIV and being part of a minority group now associated with disease. Support and advocacy groups formed to demand that governments fund research, explore the potential of experimental treatments, and provide prevention and communication materials. The 1983 Denver Principles, for example, defined rights for "people with AIDS," who refused to be considered "passive" victims or patients.⁴

In the global policy arena, the more formal linkage of health with human rights emerged thanks largely to the efforts of Jonathan Mann, the first director of the World Health Organization's Global Programme on AIDS in the late 1980s.⁵ Mann boldly framed AIDS as an issue of human rights and ethics, taking into account the broader social determinants and structural violence underlying the disease, in contrast to prevailing views of AIDS that focused on individuals' risky or deviant behavior. While legal frameworks and mechanisms had frequently been used to protect the "general public" from the disease, Mann worked innovatively to utilize the law to protect people with the disease from discrimination and exclusion. He ar-

ticulated the epidemiological imperative for human rights, understanding that respecting the rights of PLHIV would improve their engagement with health programs, thereby enhancing HIV surveillance and control. Mann's advocacy work around the respect, protection, and fulfillment of rights for PLHIV helped drive major formal declarations and resolutions, such as the 1996 International Guidelines on HIV/AIDS and Human Rights.⁶

Once HIV infection became a treatable condition, access to antiretroviral therapy came to be framed as a human rights issue. This was amplified by legal disputes involving the governments of Brazil (where the United States had brought a World Trade Organization dispute settlement over TRIPS) and South Africa (where 39 pharmaceutical companies sued the government over changes to the law to expand access to generic drugs). The fight for access to HIV treatment represented a significant advance in the justiciability of the right to health and has provided salutary examples of how social, economic, and cultural rights under the International Covenant on Economic, Social and Cultural Rights can be progressively realized.⁷ In Brazil, thanks in large part to rights-based mobilization and activism, the government passed a law in 1996 to provide free universal access to antiretrovirals, helping realize the government's obligation under the Brazilian Constitution to fulfill the right to health. In South Africa, the 2002 litigation of the Treatment Action Campaign and the AIDS Law Project, regarding the government's failure to provide pregnant women with nevirapine and thus prevent HIV transmission to their children, has become an exemplar of how civil society can hold governments accountable for their obligation to fulfill the right to health.⁸ In countries across the world, PLHIV and human rights activists have used the law and the courts to challenge discriminatory laws and policies in areas such as employment, education, and social services.⁹

When UNAIDS was established, it took special care to listen to rights activists' concerns. Steps were taken to formally involve activists in UNAIDS decision-making processes, such as by including civil society representatives as (non-vot-

ing) members of its Programme Coordinating Board. Further, UNAIDS established the Reference Group on HIV and Human Rights in 2002 to advise the agency on human rights issues relevant to the response. Civil society representatives were also included as (voting) board members of the Global Fund to Fight AIDS, Tuberculosis and Malaria; and the Global Fund's board has since worked to better integrate human rights issues into country coordinating mechanisms and has made the promotion and protection of human rights one of the four major objectives of its 2017–2022 strategy.¹⁰ Despite these positive and pioneering steps, ensuring the genuine, inclusive, and meaningful incorporation of activists, especially those representing key populations, into decision making at the United Nations level remains an urgent priority.¹¹ Addressing this challenge will require organizations leading the HIV/AIDS response to redouble engagement with activists at this pivotal juncture.

It is thanks to the efforts of activists of all stripes that we have, to some extent, seen the propagation of a global “norm cascade,” with states increasingly promulgating laws to protect the rights of PLHIV (although the enforcement of such laws remains uneven). In 2014, 64% of countries reporting to UNAIDS had laws protecting PLHIV from discrimination based on HIV status.¹² There has also been a rapid reduction in the number of countries restricting the entry, stay, or residence of PLHIV, falling from 59 to 35 between 2008 and 2015, demonstrating the speed of improvements in legislation to enhance certain rights of PLHIV.¹³

Persisting and emerging human rights challenges

Nevertheless, many countries still have laws, regulations, and policies hindering effective HIV prevention, treatment, care, and support for key populations, including MSM, intravenous drug users, sex workers, and transgender people. Some 73 countries, nearly 40% of the global total, criminalize same-sex relations.¹⁴ This is in spite of the evidence that criminalization and punitive laws negatively affect HIV transmission by com-

pounding stigma and creating structural barriers to biomedical prevention, health education, and engagement with health services.¹⁵ For example, in Caribbean countries where homosexuality is criminalized, 25% of MSM are reported to be infected with HIV, a significantly higher rate than in countries that do not criminalize homosexuality.¹⁶ Similarly, HIV prevalence among sex workers is generally lower in European countries that have decriminalized aspects of sex work than those where it is criminalized.¹⁷ Alongside evidence from these country-comparison studies, the TRUST cohort study has demonstrated that Nigeria's 2014 Same Sex Marriage Prohibition Act caused a decrease in engagement with HIV services among MSM.¹⁸

These examples serve to remind us that there is no guaranteed “march of progress” toward improved rights for PLHIV or key populations at risk, despite the continuous accumulation of evidence that respecting human rights enhances health. Laws protecting and promoting human rights exist in an unstable, precarious, and politicized equilibrium. For example, in India, home to the world's third-largest HIV epidemic, the high court struck down the Criminal Code provision criminalizing same-sex sexual relations in 2009 before it was reinstated by the Supreme Court in 2013. Today, in 2017, new waves of populist nationalism and a reinvigorated backlash against globalization may threaten hard-won rights gains. Human rights organizations have warned that the postwar international human rights system, founded on the Universal Declaration of Human Rights, is at risk from leaders who frame human rights as a hindrance to state sovereignty or traditional culture.¹⁹ We have already seen President Trump reinstate and expand the Mexico City Policy, or Global Gag Rule, placing restrictions on several agencies (including the United States President's Emergency Plan for AIDS Relief) that may provide information on abortion. This policy is likely to infringe significantly on adolescent girls' and young women's access to contraception and HIV counselling services.²⁰

Currently, HIV infection rates are rising rapidly in countries where there is a limited possibility of holding the government to account regarding its

human rights commitments. A prime example is Russia, where in 2015 in certain cities, one in three intravenous drug users was living with HIV.²¹ Russia has a legal ban on opioid substitution therapy, despite its well-evidenced effectiveness for managing dependency and preventing HIV. Thus, the ban arguably contravenes article 12 (on the right to enjoy the highest standard of health) and article 15 (on the right to enjoy the benefits of scientific progress) of the International Covenant on Economic, Social and Cultural Rights, despite Russia being a party to the convention. Russia's policies have prompted concerns from the United Nations Human Rights Committee, but the onus falls on brave activists to attempt to redress violations through regional or international human rights mechanisms, such as the European Court of Human Rights.²²

Despite these numerous challenges, it is important to highlight recent hard-won successes of HIV activists and human rights defenders who have advanced the rights of PLHIV through combinations of advocacy, activism, and litigation. For example, in England in March 2016, the National Health Service abandoned plans to roll out pre-exposure prophylaxis (PrEP), arguing that the health service was not responsible for preventative health. However, after a successful challenge from advocacy organizations such as the National AIDS Trust, England's Court of Appeal ruled in November 2016 that the National Health Service has the legal power to procure and provide PrEP.²³ A large, three-year implementation trial of PrEP is now set to begin in September 2017, providing PrEP to an estimated 10,000 people at high risk of HIV infection.²⁴ Moreover, in countries such as Ukraine, activists have been a driving force behind AIDS programs and continue to keep AIDS in the spotlight amid the civil conflict.²⁵ Finally, in Zimbabwe, where national policies seem to be moving against the tide of the expansion of human rights, grassroots activist Martha Tholanah has been waging a brave fight against HIV-related and LGBT+ stigma, despite recently facing court charges on the basis of running an "unregistered" organization.²⁶

Perhaps the greatest concern for the future of

the HIV/AIDS response is the largest-ever cohort of adolescents, particularly adolescent girls and young women, living with HIV in sub-Saharan Africa. Deeply entrenched social drivers and structural violence—especially inequality and poverty, symptoms of what Paul Farmer has termed "pathologies of power"—are fueling this epidemic. Vulnerability to HIV continues to be socially conditioned in a context of gender inequality, intimate partner violence, and limited economic and social rights (such as low education and low levels of socioeconomic independence) which undermine women's ability to exercise their sexual and reproductive rights. For example, phylogenetic data from recent research in KwaZulu-Natal, South Africa, shows that age-disparate sex (sex between women under 25 and men on average 8.7 years older), in a context of patriarchy and unequal gender power relations, is a significant driver of the epidemic.²⁷

In countries such as South Africa, the promotion of equality and prevention of unfair discrimination are enshrined in the constitution; however, legal protections for civil and political rights mean little to those who are not in a sufficiently secure socioeconomic situation to exert those rights.²⁸ In such contexts, human rights approaches that reduce discrimination, stigma, and marginalization must also advance social and economic equality and justice, recognizing that poverty and inequality expose individuals to violations of their civil and political rights and thus negatively affect HIV transmission patterns.

The continuing imperative for integrating human rights into HIV/AIDS and global health efforts

Even if the future of the HIV/AIDS response is at risk in the current political climate, the centrality of human rights in HIV/AIDS provides a model for other areas of global health. For example, the fact that antiretroviral therapy was initially rolled out in the face of skepticism and pessimism but has today reached more than 19.5 million people, according to UNAIDS, has inspired advocates in other disease

areas to campaign for more affordable, equitable access to treatment.²⁹ The prominence of rights in the HIV/AIDS response will continue to provide lessons and precedents for our response to other epidemics and evolving health threats. For example, a lawsuit before Brazil's Supreme Court requesting access to information, health services, and safe abortion for victims of Zika builds on the model of litigating the right to health in the context of AIDS in Brazil and many other Latin American countries.³⁰ In addition, the 2013–2016 Ebola outbreak in West Africa brought human rights concerns to the fore, as quarantine and coercive measures were used during the outbreak in a climate of poor messaging, limited treatments, and social and political instability. Today, survivors face stigma, and learning from the HIV/AIDS pandemic may help ensure that they remain free from discrimination as they reintegrate into community life.³¹

Looking forward within the field of HIV and human rights, we increasingly find that legislation is in place but that individuals who might use the law to fulfill their rights do not have the resources, power, or sense of personal security and safety to do so. This is in the context of a “shrinking civil society space” that limits the ability of human rights organizations and defenders to operate, advance rights- and evidence-based responses, and advocate for political, economic, and social change. In a global climate that appears increasingly hostile—or at least indifferent—to human rights, and where competing priorities have a significant impact on AIDS funding, there are challenges ahead in terms of supporting rights-based advocacy and activism for HIV/AIDS.³² In the context of HIV/AIDS, a bold defense of human rights can make the difference between life and death for entire groups of vulnerable people, as seen in the expansion of (and continuing gaps in access to) life-saving antiretroviral drugs. Limited resources and political instability across the world pose serious challenges, but we must do more to support rights-based approaches if we are to make good on our pledge to reduce new HIV infections and end AIDS without leaving anyone behind.

Acknowledgments

We gratefully acknowledge funding support from UNAIDS (grant number ADDEZI70), which covers Jamie Enoch's salary.

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