





EDITORIAL

Realizing the Right to Health: A Long and Winding Road

JOSEPH J. AMON

Introduction

Where are we, in this moment, in our efforts to realize a right to health for all? As I take on the role of editor-in-chief of *Health and Human Rights Journal*, this question preoccupies me. I began thinking about it while reflecting on the legacies of the editors who preceded me—Jonathan Mann, Sofia Gruskin, and Paul Farmer—towering figures, pioneering scholars, and passionate advocates.

The work of each of these former editors still very much resonates. In the third issue of the journal, Mann talked about how the dialogue between public health and human rights can define more clearly the challenges and perspectives of a new approach to public health; however, he presciently warned that this dialogue would not be met with universal acceptance. Resistance to adopting rights as the foundation of public health would come from within the field, he wrote, because addressing root causes requires societal transformation—an approach too radical for most working in public health.¹

Gruskin, in an editorial in 2003, wrote about the need to bring health and human rights together to address violence prevention, highlighting the issue as one that, although a core focus of criminal law, humanitarian law, and human rights law, has only slowly been examined at the intersection of public health and human rights despite complementary values, ideals, and practical applications.²

In his 2008 paper "Challenging Orthodoxies," Farmer questioned the "priority often assigned to civil and political rights over economic and social rights" and exhorted readers to "move beyond crude notions of cost-effectiveness and sustainability and to return to the concept of social justice, which once inspired public health but now seems to embarrass us." Farmer also wrote that he hoped that the journal would focus on "human rights in the doing," writing that conceptual analysis "must be nourished by contact with communities' real needs."

Reflecting on the contributions of Mann, Gruskin, and Farmer is particularly appropriate as we approach the journal's 30th anniversary and consider the progress and the obstacles that face us. For example, public health as a discipline remains more comfortable talking about ethics than rights, and concerns about the boundary between public health and politics abound. When rights are referenced in

JOSEPH J. AMON, PHD, MSPH, is director of the Office of Global Health and a clinical professor at Drexel University Dornsife School of Public Health, Philadelphia, United States, and editor-in-chief of *Health and Human Rights Journal*.







public health journals, they are often referred to in passing, vaguely.⁴ At the same time, social (and political) determinants of health have been widely accepted as an analytical framework, and the use of law—and paralegals—to claim health rights is common.⁵ Gruskin's focus in 2003 on violence prevention could not be more relevant today, as are "the inextricable linkages" she described between the positive and negative impacts of health policies and programs on human rights across areas such as reproductive health, tobacco control, and humanitarian crises.⁶ Farmer's observation of the priority of civil and political rights remains largely true, but more attention is being paid, including in this issue of the journal, to economic inequality.⁷

Furthering this theme of reflecting on "where are we now," Carmel Williams (the journal's executive editor) and I have asked authors of some of the first papers published in the journal to look back—and forward—on the meaning and significance of the issues they raised at the journal's founding and where we are today. From my vantage point, I see many challenges and some hope. But as a human rights activist, I am perhaps predictably drawn to the "glass is half empty" perspective: Why can't more be done?

Finding human rights

My own engagement in health and human rights came about gradually. In college I read *And the Band Played On* by Randy Shilts.⁸ The book is a combination of detective story—featuring the physicians and epidemiologists struggling to figure out the cause of a new "gay plague"—and the very personal stories of activists and individuals living, and dying, with the disease. It is also a scathing review of the ways in which the US government, media, and others failed to take basic steps to recognize the epidemic and to respond to it.

Shilts writes, "The bitter truth was that AIDS did not just happen to America—it was allowed to

happen." The book left me outraged and with a deep and lasting interest in public health. It also gave me a profound respect for the voices of individuals hearing what they have to say and learning from it.

After completing a master's program in public health, I went to Togo as a Peace Corps volunteer. One of the first lessons I learned was the dedication and commitment of my Togolese colleagues. At the time, Togo was undergoing significant political strife, including a workers' strike throughout the southern part of the country, but my colleagues found ways to persevere and to maintain critical public health campaigns. While there, I saw the first wave of HIV cases emerge in the country.

When I returned to the United States, I worked for a large US-based international health organization helping Ministries of Health and nongovernmental organizations (NGOs) design monitoring and evaluation systems and conduct research to better understand the HIV/AIDS epidemic and the impact of their programs. After four years of doing that, and then four more getting a PhD in parasitology, I joined the Centers for Disease Control and Prevention's (CDC) Epidemic Intelligence Service—the same program of "disease detectives" mentioned in the book *And the Band Played On* and the same postdoctoral program where Mann began his career in public health.

I enjoyed working at the CDC. But I was also aware of the limitations of the organization to engage directly in communities and in the advocacy necessary for transformative change. I became frustrated that the underlying causes of the disease outbreaks I investigated were often considered beyond the mandate of the organization. The reasons that people were getting sick—the poor quality of or lack of access to health care, the social marginalization, the desperate poverty, the lack of available and accessible treatment for people who use drugs—were often left out of the epidemiologic analysis or were thought to be too political to include in our recommendations. I didn't feel like we were listen-







ing enough to the people and communities we were trying to help.

My next stop was at Human Rights Watch (HRW). I stayed for a decade, working on health and human rights and starting new programs on the environment and disability rights. I enjoyed being an epidemiologist amidst human rights lawyers and deepening my understanding of how human rights violations impact health.

Although HRW had occasionally worked on economic, social, and cultural rights, the organization's real focus on health and human rights began with the creation of an HIV program in 2000. The program, led by Joanne Csete, partnered with legal and advocacy organizations and produced research reports related to AIDS orphans in Kenya, the harassment of HIV outreach workers in India, women's property rights, and abuses against people who use drugs in Kazakhstan and Russia, among others.9 As the work advanced, HRW's executive director, seeking to present a vision for the work more broadly, wrote and published an article in Human Rights Quarterly presenting a strategy of "naming and shaming" and asserting that international human rights organizations should limit their work on economic, social, and cultural rights to cases (1) where there is a clear violation, violator, and remedy; (2) where the violation is a result of arbitrary or discriminatory action; and (3) where remedies do not require redistributing resources.10 There was considerable pushback against this narrow vision, from both inside the organization and outside of it.11

When I arrived, in 2005, HIV continued to be a major focus within the organization, with research focused on the impact of the criminalization of sex work and drug use on HIV in Ukraine (2006), political repression, user fees, and access to HIV care in Zimbabwe (2006), police violence and access to HIV treatment for people who use drugs in Thailand (2007), access to HIV care for immigrants in detention in the United States (2007), and

more. Later reports included a focus on access to prevention and care for prisoners in Zambia (2010), Uganda (2011), and the United States (2016), and among people living with disabilities in Zambia (2014).¹²

Another major area of work examined harsh, and ineffective, approaches to drug use, including reports focused on the United States, Russia, Thailand, Vietnam, China, Cambodia, and Lao People's Democratic Republic, led by my HRW colleagues Megan McLemore, Jane Cohen, Rebecca Schleifer, and Richard Pearshouse.¹³

In 2008, HRW began to frame the plight of people with advanced or serious illness, most of whom lacked access to palliative care, as a human rights issue. 14 Through a series of reports, led by Diederick Lohman, the organization documented how millions of patients with cancer and other conditions were suffering moderate and severe pain due to a lack of access to inexpensive and effective analgesics. Many patients with cancer pain described their suffering in similar terms as victims of police torture: they said that the suffering was unbearable and that they would do anything to make it stop.

Part of the human rights argument made in these reports was aligned with the approach outlined by HRW's director. Restrictions on the use of morphine were analyzed using an arbitrariness or discrimination test. For example, reports argued that Indian regulations that required hospitals and pharmacies to obtain four or five different licenses from different government departments in order to procure morphine were not reasonable and were therefore arbitrary. But these reports also went far beyond the proposed approach, arguing that governments had an obligation to ensure the adequate availability and accessibility of morphine as part of minimum core obligations under the International Covenant on Economic, Social and Cultural Rights; to ensure that health care workers received training in palliative care; and to ensure that national health strategies, policies, and budgets addressed the need







of patients requiring palliative care.

The advocacy also went well beyond what was outlined.¹⁵ Certainly, naming and shaming was an important part of the advocacy strategy—news coverage often contributed to governments recognizing the need to take steps to address palliative care gaps—but it was not the only or often even the main component of the advocacy approach, which incorporated a combination of public pressure, constructive engagement, capacity building, and epidemiologic research.¹⁶

Throughout my decade at the organization, and under the leadership of Lohman following my departure, there were many other significant impacts stemming from rights documentation and advocacy—on issues such as the detention of hospital patients; drug-resistant tuberculosis; lead and mercury poisoning; the response to cholera, typhoid, SARS, and Ebola outbreaks; and more.¹⁷

Yet in 2018, three years after I left the organization, and not long before the arrival of COVID-19, HRW shut down the division. The explanation given to staff was that health issues could be "mainstreamed" throughout the organization. As with most "mainstreaming" efforts, the result was a sharp drop-off in work. The situation is not much different at Amnesty International, where the organization's website has no mention of health among 20 themes that are presented as defining "what we do." Similarly, the once mighty brain trust and funder of health and human rights work, Open Society Foundations, has largely shuttered its innovative and essential public health program and scattered its expertise to the wind.

Coopting rights

For some organizations, rights are a rallying cry. For others, they are a legal framework or an operational approach. At times the invocation of rights seems to be perfunctory or disingenuous. Certain rights are emphasized while others are ignored or

even denied. In this complex arena of competing human rights claims, how does one evaluate the relevance, force, and effect of these claims? What evidence is marshaled to support claims to rights, and how does this evidence differ from that used by other actors in efforts to shape global health policies?

In 2001, the World Health Organization (WHO) introduced a campaign focused on your "right to know." The campaign promoted the idea that every person has a right to know their HIV serostatus. However, the campaign, coming from an organization that only selectively invoked human rights, was constructed, in part, to counter HIV and human rights activists who advocated for the rights of individuals to informed consent, privacy, and voluntary counseling and testing—advocacy that officials at WHO felt was slowing the acceptance of routine HIV testing services.

Not long after WHO's campaign was launched, UNICEF introduced a "your right to know" campaign as well. In contrast to WHO's campaign, UNICEF's effort focused on the right of adolescents to comprehensive information about HIV prevention. This version of a "right to know" was also contested, this time by governments that sought to limit or deny information about HIV treatment or prevention—either broadly or to specific populations—to promote "abstinence only" approaches or to suppress information for LGBTI communities.

Amidst these battles to define and lay claim to a "right to know," individuals living with HIV campaigned for expanded HIV prevention programs and greater access to affordable antiretroviral drugs. These campaigns sometimes included a rallying cry calling for people living with HIV to "know your rights," emphasizing not only a right to HIV prevention and treatment but also rights to be free from violence and discrimination.

WHO's emphasis on the "right to know" one's serostatus was grounded in the view that individuals vulnerable to HIV infection, or already living







with HIV, are able to realize behavior change unrestricted by structural barriers or factors such as inequality, power, or gender-based violence. The campaign was a part of an effort calling for a return to "traditional" public health methods of case identification and treatment, using a language of rights to mask a return to paternalistic models of medical care.20 Pitting a "rights-based" approach against a "public health" approach, Kevin DeCock, Dorothy Mbori-Ngacha, and Elizabeth Marum claimed in 2002 that the emphasis on human rights in HIV prevention obscured the "essential" nature of public health and social justice. They argued that the emphasis by human rights activists on "Western" approaches, such as anonymous testing with informed consent and pre- and post-test counseling, was discouraging the acceptance of HIV testing.²¹

This argument echoed long-standing criticisms of human rights: that rather than being universal, they are reflective of "Western" values; in other words, too expansive. In Eswatini, one of the countries hardest hit by the HIV epidemic, UNICEF's representative argued that the "Western preoccupation" with the need for informed consent prior to HIV testing and with preserving the confidentiality of test results caused "the ignorance and stigma that grew up around AIDS in the West to make its leap to Africa."²²

Blaming consent and confidentiality around HIV testing for the slow response to the epidemic ignored the kingdom's massive under-investment in health and its severely restricted rights for women. Until constitutional reforms were passed in 2005, women in Eswatini assumed the legal status of a child upon marriage and were not allowed to register property. There were no specific laws criminalizing domestic violence. Rape laws excluded marital rape, and one in three women reported suffering sexual abuse as a child. More fundamentally, the argument that "Western preoccupation" was to blame for the slow response to the HIV epidemic in the country ignored the fact that HIV testing was

not widely available in the country until after HIV prevalence exploded.

Evidence

Whether as a CDC epidemiologist or doing research at HRW, I have always thought a lot about the issue of evidence, how it is defined, what type of evidence is valued (and devalued), the amount of evidence needed for policymaking, and, importantly, how policymaking is done when evidence is sparse.

Frequently, I have found that despite epidemiological treatises about what constitutes high-quality evidence, in practice the amount of evidence required and what constitutes strong evidence is often highly subjective—and reflective of explicit or implicit values conveyed in the different types of training of health workers and in the values—and power—of institutions that are seeking a change in the status quo.²³

One example of two very different approaches to evidence and values arose toward the end of my tenure at the CDC in 2004, when I attended a meeting on HIV. The meeting had two panel discussions, the first on HIV treatment and the second on prevention. During the first, there were a lot of comments by panelists about how "we do not have enough understanding of how to roll out HIV treatment in low-income settings." But the overall message was We have to do something and learn as we go.

By contrast, the second panel discussion on prevention was rife with hesitancy and fear that approaches such as peer education were ineffective. The message was We need large-scale randomized trials to understand what works in HIV prevention, and we should not waste money until we have a better understanding of what works.

The debate betrayed a sense of frustration among the epidemiologists in the room with the complexity of human behavior and a desire for an imagined simplicity of biomedical approaches.







Confident in their ability to prescribe medicines, the absence of evidence was a small barrier. Unconfident in their understanding of behaviors and the determinants of behavior, a desire for evidence far outweighed any consideration of urgency in addressing the clear vulnerability of those at risk.

I saw the same dynamic play out at WHO as it promoted an approach to expanding access to HIV treatment through expanded testing, under the slogan of "test and treat." The intentions were undoubtedly good, but the approach was simplistic, imagining a world where getting an HIV test result would be met with equanimity, with immediate access to care, and without fear, discrimination, or any negative consequences whatsoever.

The promotion of such an overly simplistic approach, because it was coming from the world's public health policymaking organization, could be interpreted in simplistic ways as well. For example, in 2011 a group of researchers led by Lorraine Yap, conducted a study, funded by the Chinese and Australian governments, in three reeducation-through-labor camps for persons who use drugs in China.24 While HIV testing in detention centers was mandatory, the authors found that pre-test education and disclosure was not. Of those testing positive, only 25% received HIV antiretroviral therapy. In a separate paper, the authors reported that nearly half of the male and female detainees over 45 years of age experienced "severe psychological distress," and about 30% said that their health status was "poor." Rather than examining the clear rights violations faced by those detained, the authors concluded that "labor camps provide another opportunity to implement universal treatment ('Test and Treat') to prevent the spread of HIV" and that "forensic mental health services" are needed.25

Four years before the study above was conducted, HRW also conducted research on reeducation-through-labor centers in China. We found a wide range of severe human rights abuses,

including the use of HIV tests, according to one guard, "to know which female inmates they could sleep with without using a condom."26 One former detainee told us, "I started taking antiretroviral drugs before I was put into detox. Then when I was in [detox] I had to stop. I was really worried about my health but there was nothing I could do."27 Another told us, "Lots of people inside drug detention centers have TB [tuberculosis], and lots of people get TB while in detention. There is no treatment and everyone is all together all the time."28 Even the head of the United Nations Office of Drugs and Crime (UNODC) in China agreed that the centers were not a solution, telling the Associated Press that "being detained in these centers not only does not help drug users to recover, as evidenced by the high rates of relapse, but also increases the likelihood that an individual will become infected with HIV."29 UNODC's statement was not in isolation—in 2012, 12 United Nations agencies called for compulsory drug detention centers such as China's reeducation-through-labor camps to be closed down "without delay."30

Yap and colleagues' recommendations for universal testing and treatment were intended, no doubt, to protect the health and well-being of those detained. Yet their research failed to ask the right questions and consequently prescribed the wrong medicine. Expanded HIV treatment and mental health counseling would aid some concerns of some detainees. Closing these centers down and expanding voluntary, community-based substance abuse treatment would advance both public health and human rights.³¹

How can public health researchers narrow their vision so significantly that they fail to see obvious abuses in pursuit of inappropriate solutions? Sadly, I found that this was common. In Cambodia, a detention center for children was funded by UNICEF. Children we interviewed spoke of being given electrical shocks, being beaten, and being forced to dance naked. In Vietnam, our research







on drug rehabilitation centers found that drug users were detained for up to four years without ever being charged or tried, and were routinely beaten, shocked with electric batons, and locked in isolation cells or punishment rooms when they were not being forced to work. Project staff from aid agencies and NGOs visited on a regular basis. The World Bank described its funding of the centers as a humanitarian necessity.³²

If you know nothing about human rights, and you don't ask the right questions, I guess it is easy to believe that what you see is vocational training and rehabilitation. Less charitably, if your focus is on diseases and prevention strategies, it is apparently quite easy to never see the individuals in front of you, who, in addition to being someone you want tested and treated for HIV, may have other pressing needs.

Public health practitioners sometimes render individuals invisible by focusing on "HIV hot spots" or by referring to "hard to reach" populations. Ironically, "hard to reach" populations are often found in "HIV hot spots." So how exactly does one become hard to reach, and why are we blaming them for the failure of our health programs to meet their needs?

When public health practitioners refer to "hard to reach" populations, they are often referring to prisoners, drug users, men who have sex with men, and sex workers. Prisoners by definition are pretty easy to reach. They usually can't go very far. But they can disappear. A colleague of mine at HRW, Kate Todrys, wrote a series of reports on prison health in Africa. During research for one report, she visited the Muinanina Farm Prison in Uganda. Seeing her, 10 prisoners banded together and passed her a letter. It described years behind bars without trial or contact with a magistrate, endless work, and brutal beatings. It concluded, "We feel we are invisible prisoners. If we are invisible, tell us."³³

With or without "hot spot" maps, police don't

have any problem finding people who use drugs, men who have sex with men, or sex workers. And such maps can unintentionally cause backlash, such as police raids, arrests, and sensationalistic media coverage.³⁴ Yet in a deft example of evading liability, the funders and researchers of one hot spot mapping project of "most-at-risk populations" cautioned:

neither Neilsen nor the supporting partners—World Bank, UNAIDS, UNDP [United Nations Development Program], UNODC and USAID [United States Agency for International Development]—conducting or supporting the study on mapping and size estimation ... is liable or can be held responsible or accountable for the misuse of data and information in the reports ... Any legal responsibility resulting through the use of any data or information contained in this report is withdrawn.³⁵

Mapping "hot spots" is ultimately a crude effort to identify risk. More compelling would be mapping human rights violations. For example, public health and human rights professionals could map where HIV peer educators are being arrested for distributing condoms and information on HIV prevention in Senegal.³⁶ HIV donors could commission a mapping of funding levels—identifying inequities by province or district within a country or by key population. They could map stockouts of HIV medicines or the quality of health centers. They could map stigma and sexual violence—including in police stations—and the confiscation of condoms from sex workers.³⁷ In other words, they could map the drivers of HIV transmission.

In my experience, it is often not the individuals at risk of, or living with, HIV infection who are hard to reach. It's the politicians and policy makers who are unavailable. But HIV researchers, too, seem to be hard to reach at times, failing to investigate political determinants of health and the impact of laws, policies, and enforcement on HIV vulnerability and access to care.³⁸







Rights-based interventions

Within the HIV response, attention to human rights and to rights-based interventions has waxed and waned. Currently, organizations such as UN-AIDS are more likely to talk about equity or equality than rights.³⁹ But where do inequalities come from? A number of years ago, I spoke with a senior program officer at a major foundation working on HIV globally who told me, "We don't take a rights-based approach, we take an equity approach." After a bit of back and forth, it became clear that the foundation was uncomfortable with the idea of accountability, a key component of human rights.

Similarly, a keynote address at the American Public Health Association annual meeting, presented by the president and CEO of a large international development agency, spoke about her organization's approach to fighting poverty, emphasizing three core strategies: "embracing a rights-based approach, forging partnerships, and empowering women." She said, "Putting rights at the heart of our work means giving people the tools to create positive change in their lives and to hold themselves and others accountable for making that change happen." Accountability can be framed in a lot of different ways, but I'm pretty sure it's not meant to be about holding marginalized and vulnerable populations accountable for making change happen. The speech said nothing about gender-based violence. Or property and inheritance rights abuses. Or state obligations or those of NGOs.

In contrast, the Global Fund's "Breaking Down Barriers" initiative has funded interventions in 20 countries that seek to ensure that key and vulnerable populations can get access to HIV prevention and treatment. In recent trips to Jamaica and Benin to see these programs in action, I found integrated teams of peer educators, paralegals, social workers, psychologists, lawyers, and HIV specialists working together to ensure that individuals coming to health centers for HIV testing were

able to navigate all of the potential human rights issues they faced—from fears of discrimination and uncertainty about disclosure to the need for protection from domestic abuse or the provision of sexual and reproductive health care. Unlike many HIV programs that engage in a kind of magical thinking that slogans can change deep prejudice, the programs I saw were based on close listening and support—an approach that Farmer championed as "accompaniment," but on steroids.

A recent review found evidence of the impact of these types of human rights programs (singly and combined) on HIV-related outcomes for people living with HIV and key and vulnerable populations, ranging from decreased HIV risk behaviors to increased HIV testing to reduced incidence.40 Yet adequately funded human rights programs addressing discrimination and operating at national scale are rare. More often, "stigma and discrimination" programs emphasize stigma but ignore discriminatory laws, policies, and practices.41 They rely on messaging that calls on everyone to act together to end stigma, while ignoring mechanisms, such as the judiciary, that can identify and hold responsible those who discriminate against others. Making everyone responsible usually means that no one is accountable.

Challenging rights frameworks

In his 2016 report to the Human Rights Council, Philip Alston, the United Nations Special Rapporteur on extreme poverty and human rights, painted a pessimistic portrait of respect for economic and social rights, saying that their acceptance both by states and by "many of the most prominent civil society groups focusing on human rights" remained marginal.⁴²

In 2020, Jonathan Cohen, then at the Open Society Foundations, raised the issue in these pages of whether human rights work is political enough for a moment like this: "By appealing to evidence,







facts, and universal norms, does human rights exempt itself from political struggle and underestimate the reality of power in shaping decisions?"43

Legal scholar Samuel Moyn has argued that "even perfectly realized human rights are compatible with radical inequality." 44 Moyn describes the system of laws and programs to enforce economic and social rights as "a helpless bystander of market fundamentalism"—if not to blame for the neoliberal world order that emerged after the Cold War, then certainly ineffectual in addressing it.

In an article I wrote with my colleague João Biehl, we replied to some of these criticisms, writing that

peoples (let's keep them multiple) live in exhausted worlds. Worlds on the edge of autocracy, of financial collapse, of infrastructural breakdown and environmental tipping points—mediated by extreme populism and state and corporate efforts to dismantle piecemeal, though meaningful, agendas of socioeconomic rights. Violence and deadly health disparities are persistent realities that, time and again, are couched by experts in a rhetoric of recovery even as conditions stagnate or worsen.⁴⁵

Undoubtedly, it's important to engage—indeed, to invite—critiques to how we think and practice health and human rights and to examine questions about whether we are acting forcefully enough to challenge neoliberal policies and ensure that practicing human rights remains a radical praxis and not a comfortable profession.

I am especially thankful for critiques that ask what a more urgent and progressive human rights movement looks like, across all of the spaces and topics on which we work, especially when those critiques come—as Amy Kapczyniski in her article "Right to Medicines in an Age of Neoliberalism" highlights—from "marginal places" at the periphery. 46 In these places, even in the absence of health rights being fulfilled and despite weak mechanisms of redress, there is power in claiming rights, mobi-

lizing, making demands in the courts and on the streets or online, and finding commonalities across rights, communities, health concerns, and government failures.

Human rights paradigms and frameworks can be argued at the global level, but they must never lose their focus on justice locally, on accountability, and on the need to fight within existing political and economic systems to advance, and sustain, rights protections. This is part of the struggle for "decolonization"—of means, priorities, resources, and epistemologies.⁴⁷

Conflict

Threats to the right to health—and the full realization of all rights—are acute whenever countries face, or create, conflict. To highlight just three: Since its invasion of Ukraine in 2022, Russia has committed indiscriminate attacks and the war crimes of torture, rape, and other sexual violence—all resulting in severe and long-term consequences for the physical and mental health of the victims.⁴⁸ The United Nations Office for the Coordination of Humanitarian Affairs has estimated that some 10,000 civilians have been killed since the start of the invasion and that "people's lives are dominated by the constant sound of air raid sirens, as unrelenting air strikes rain down and destroy civilian objects."⁴⁹

The Chinese government's mass arbitrary detention (in so-called vocational education and training centers) of Uyghurs and other Turkic Muslims in Xinjiang—including acts of torture, enforced disappearances, mass surveillance, cultural and religious persecution, separation of families, forced labor, sexual violence, and violations of reproductive rights—was finally recognized by the Office of the United Nations High Commissioner for Human Rights in 2022. The institution said the rights violations "may constitute ... crimes against humanity."⁵⁰







In October 2023, in response to a terrorist attack by Hamas, which included targeted killings and kidnapping of civilians—clear war crimes—Israel has laid siege to Gaza, with devastating consequences for its civilian population. On November 8, the United Nations Special Rapporteur on the right to adequate housing highlighted Israel's targeting of housing and infrastructure in Gaza—rendering an entire city uninhabitable—as a war crime as well.⁵¹ As I write, a tentative cease-fire holds.

In each of these crises, there are both public health and human rights activists engaging—documenting abuses, providing medical and public health care, and challenging intolerance and hate. For example, in Ukraine, the invasion had a major impact on Ukraine's HIV and tuberculosis responses, as health services were diverted to deal with caring for wounded soldiers and civilians. Health care workers faced the difficult choice of staying or fleeing. Hospitals and clinics came under attack. Medical supplies were disrupted, leaving clinics without essential commodities. Patients were afraid to seek care while there was fighting in the streets and the threat of air attacks in the skies. Many were displaced and did not know where to go to get back into care. Thousands of people on antiretroviral and tuberculosis medications were cut off from their treatment. People on opioid substitution treatment, which is banned in Russia, feared that their treatment programs could be discontinued. In occupied territories, Ukrainian health care services ceased altogether.⁵² After a few weeks, though, HIV and tuberculosis programs came back—public health programs adapted, finding and linking people who needed care to services, and finding ways to keep prevention interventions and medicine supply chains running and to continue providing care.

Human rights documentation is critical in crisis settings, whether by international human rights organizations such as HRW and Amnesty International, by local rights groups, or by groups such as Insecurity Insight and the Safeguarding Health in Conflict Coalition (representing nearly 50 NGOs, academic institutions, medical student and health care provider groups, and human rights organizations). The challenge is not only documenting attacks on health workers, facilities, and transport amidst the "fog" of war, but conducting advocacy with governments, including Ministries of Health and Defense, to ensure that humanitarian actors are not harassed.⁵³ Similarly, pressure by medical organizations, such as the International Council of Nurses and the World Medical Association, can amplify and challenge governments that target health providers—or health professionals who participate in rights violations.⁵⁴

This frontline work is not easy, and it is never finished. Humanitarian and human rights organizations sometimes struggle to balance access with their obligation to bear witness. Governments use divisiveness and hatred to suppress dissent. Discrimination, in forms less extreme than arbitrary detention or conflict, is widespread and directly impacts realization of the right to health.55 At the beginning of this editorial, I mentioned my "glass is half empty" approach. But when I am asked how I can sustain work on health and human rights despite all of the challenges and abuses, I reply that I am inspired by those working as rights defenders around the world, in difficult, and almost impossible, settings, doggedly seeking to bring about respect for human rights for all.

Conclusion

This year marks the 75th anniversary of the Universal Declaration of Human Rights, a document that imagined a world vastly different from the one that existed at the time, a world where those most vulnerable among us would be *free and equal in dignity and rights*. This claim, found in the very first article of the declaration, was the subject of Mann's last paper, published in this journal after his untimely







death in 1998, at the age of 51 years. Mann wrote that "from a health and human rights perspective, the possible connections between dignity and health are simultaneously complex, intuitively powerful and difficult to assess." This call to action is still relevant today, and one that needs to be carried into our work on climate change, emerging pathogens, chronic diseases, violence, and on and on.

Amidst all the upheavals of the world today, I am confident that when the public health field focuses on dignity and human rights, we will be better able to restore trust with the communities we serve. But embracing rights as a foundation for public health work will require public health professionals to listen more closely. That will be the easy part. Harder will be the need for public health professionals to understand their work differently.

I am thrilled to take on the job of editor-in-chief, delighted with the role the journal has played in fostering discussion about health and human rights and advancing the field, and excited about working to ensure that the journal remains a robust home for scholars and advocates, public health professionals and human rights activists, to continue the journey of imagining and reimagining, as well as building a world where the right to health is realized for all. Our work is far from complete. I welcome your engagement with the journal in its next chapter.

Acknowledgments

I have many people to thank who have contributed to my education in health and human rights and accompanied me in my work or invited me to participate in theirs. As I step into the role as editor-in-chief, I would especially like to thank Carmel Williams, the journal's exceptional executive editor, and the journal's executive editorial committee: Varun Gauri, Anand Grover, Tlaleng Mofokeng, and Sharifah Sekalala.

References

- 1. J. Mann, "Human Rights and the New Public Health," *Health and Human Rights Journal* 1/3 (1994), p. 229.
- 2. S. Gruskin and A. Butchart, "Violence Prevention: Bringing Health and Human Rights Together," *Health and Human Rights Journal* 6/2 (2002), p. 1.
- 3. P. Farmer, "Challenging Orthodoxies: The Road Ahead for Health and Human Rights," *Health and Human Rights Journal* (2008).
- 4. K Hinman and J. J. Amon, "Human Rights and HIV: Rhetoric or Determinants?," *BMJ Global Health* 8/10 (2023).
- 5. J. J. Amon, "The Political Epidemiology of HIV," *Journal of the International AIDS Society* 17/1 (2014); K. Hinman, N. Sun, and J. J. Amon, "Ensuring Access to Justice: The Need for Community Paralegals to End AIDS by 2030," *Journal of the International AIDS Society* 26/8 (2023).
- 6. S. Gruskin, "Reflections on 25 Years of Health and Human Rights: History, Context, and the Need for Strategic Action," *Health and Human Rights Journal* 22/1 (2020), p. 327.
- 7. G. MacNaughton, A. K. Ahmed, M. McConnell, and S. Aubry, "Economic Inequality and the Right to Health: On Neoliberalism, Corporatization, and Coloniality," *Health and Human Rights Journal* 25/2 (2023).
- 8. R. Shilts, And the Band Played On: Politics, People, and the AIDS Epidemic (New York: St. Martin's Press, 1987).
- 9. Human Rights Watch, Kenya: Government Neglects AIDS Orphans (New York: Human Rights Watch, 2001); Human Rights Watch, Epidemic of Abuse: Police Harassment of HIV/AIDS Outreach Workers in India (New York: Human Rights Watch, 2002); Human Rights Watch, A Dose of Reality: Women's Rights in the Fight against HIV/AIDS (New York: Human Rights Watch, 2005); Human Rights Watch, Fanning the Flames: How Human Rights Abuses Are Fueling the AIDS Epidemic in Kazakhstan (New York: Human Rights Watch, 2003); Human Rights Watch, Lessons Not Learned: Human Rights Abuses and HIV/AIDS in the Russian Federation (New York: Human Rights Watch, 2004).
- 10. K. Roth, "Defending Economic, Social and Cultural Rights: Practical Issues Faced by an International Human Rights Organization," *Human Rights Quarterly* 26/1 (2004).
- 11. L. S. Rubenstein, "How International Human Rights Organizations Can Advance Economic, Social, and Cultural Rights: A Response to Kenneth Roth," *Human Rights Quarterly* 26/4 (2004), p. 845; M. Robinson, "Advancing Economic, Social, and Cultural Rights: The Way Forward," *Human Rights Quarterly* 26/4 (2004).
- 12. See, for example, J. J. Amon and T. Kasambala, "Structural Barriers and Human Rights Related to HIV Pre-







vention and Treatment in Zimbabwe," *Global Public Health* 4/6 (2009); M. Kyoma, K. W. Todrys, and J. J. Amon, "Laws against Sodomy and the HIV Epidemic in African Prisons," *Lancet* 380/9839 (2012); K. Todrys and J. J. Amon, "Health and Human Rights of Women Imprisoned in Zambia," *BMC International Health and Human Rights* 11 (2011); K. Todrys and J. J. Amon, "Human Rights and Health among Juvenile Prisoners in Zambia," *International Journal of Prisoner Health* 7/1 (2011); K. Todrys, J. J. Amon, G. Malembeka, and M. Clayton, "Imprisoned and Imperiled: Access to HIV and TB Prevention and Treatment, and Denial of Human Rights, in Zambian Prisons," *Journal of the International AIDS Society* 14 (2011); K. W. Todrys and J. J. Amon, "Criminal Justice Reform as HIV and TB Prevention in African Prisons," *PLoS Medicine* 9/5 (2012).

- 13. J. J. Amon, R. Pearshouse, J. Cohen, and R. Schleifer, "Compulsory Drug Detention Centers in China, Cambodia, Vietnam, and Laos: Health and Human Rights Abuses," *Health and Human Rights Journal* 15/2 (2013); J. J. Amon, R. Schleifer, R. Pearshouse, and J. E. Cohen, "Compulsory Drug Detention in East and Southeast Asia: Evolving Government, UN and Donor Responses," *International Journal of Drug Policy* 25/1 (2014).
- 14. D. Lohman, R. Schleifer, and J. J. Amon, "Access to Pain Treatment as a Human Right," *BMC Medicine* 8 (2010)
- 15. D. Lohman and J. J. Amon, "Evaluating a Human Rights-Based Advocacy Approach to Expanding Access to Pain Medicines and Palliative Care: Global Advocacy and Case Studies from India, Kenya, and Ukraine," *Health and Human Rights Journal* 17 (2015), p. 149; J. J. Amon, M. Wurth, and M. McLemore, "Evaluating Human Rights Advocacy on Criminal Justice and Sex Work," *Health and Human Rights Journal* 17 (2015), p. 91.
- 16. H. Hamdi, O. Ba, S. Niang, et al., "Palliative Care Need and Availability in Four Referral Hospitals in Senegal: Results from a Multicomponent Assessment," *Journal of Pain and Symptom Management* 55/4 (2018); K. E. Doyle, S. K. El Nakib, M. R. Rajagopal, et al., "Predictors and Prevalence of Pain and its Management in Four Regional Cancer Hospitals in India," *Journal of Global Oncology* 4 (2017).
- 17. J. Kippenberg, J. B. Sahokwasama, and J. J. Amon, "Detention of Insolvent Patients in Burundian Hospitals," *Health Policy and Planning* 23/1 (2008); N. Sun, E. Christie, L. Cabal, and J. J. Amon, "Human Rights in Pandemics: Criminal and Punitive Approaches to COVID-19," *BMJ Global Health* 7/2 (2022); J. J. Amon, F. Girard, and S. Keshavjee, "Limitations on Human Rights in the Context of Drug-Resistant Tuberculosis: A Reply to Boggio et al.," *Health and Human Rights Journal* 11/1 (2009); J. E. Cohen

- and J. J. Amon, "China's Lead Poisoning Crisis," *Health and Human Rights Journal* 14/2 (2012); J. J. Amon, J. Buchanan, J. Cohen, and J. Kippenberg, "Child Labor and Environmental Health: Government Obligations and Human Rights," *International Journal of Pediatrics* (2012); J. Amon, "How Not to Handle Ebola," *CNN* (September 12, 2014).
- 18. Amnesty International, "What We Do," amnesty.org/en/what-we-do/.
- 19. J. J. Amon, "The 'Right to Know' or 'Know Your Rights'? Human Rights and a People-Centered Approach to Health Policy," in J. Biehl and A. Petryna (eds), *When People Come First: Critical Studies in Global Health* (Princeton: Princeton University Press, 2013).
- 20. K. M. De Cock and A. M. Johnson, "From Exceptionalism to Normalization: A Reappraisal of Attitudes and Practice Around HIV Testing," *BMJ* 316 (1998).
- 21. K. M. De Cock, D. Mbori-Ngacha, and E. Marum, "Shadow on the Continent: Public Health and HIV/AIDS in Africa in the 21st Century," *Lancet* 360 (2002).
- 22. A. Brody, "In One Country, AIDS on the Rampage," *New York Times* (August 12, 2006), nytimes.com/2006/08/12/opinion/in-one-country-aids-on-the-rampage.html.
- 23. D. L. Weed. "Weight of Evidence: A Review of Concept and Methods," *Risk Analysis: An International Journal* 25/6 (2005).
- 24. L. Yap, J. Reekie, W. Liu, et al., "HIV Testing in Re-Education through Labour Camps in Guangxi Autonomous Region, China (a Cross-Sectional Survey)," *Sexually Transmitted Infections* 91/6 (2015).
- 25. L. Yap, S. Shu, L. Zhang, et al., "Psychological Distress among Re-Education through Labour Camp Detainees in Guangxi Autonomous Region, China," *Journal of Mental Health* 26/1 (2017).
- 26. J. E. Cohen and J. J. Amon, "Health and Human Rights Concerns of Drug Users in Detention in Guangxi Province, China," *PLoS Medicine* 5/12 (2008).
 - 27. See Amon et al. (2013, see note 13).
- 28. Human Rights Watch, *Where Darkness Knows No Limits* (New York: Human Rights Watch, 2003).
- 29. Associated Press, "Rights Group Slams China's Drug User Detention Centers," *Taipei Times* (January 9, 2010), https://www.taipeitimes.com/News/world/archives/2010/01/09/2003462997.
- 30. United Nations, "Joint Statement on Compulsory Drug Detention and Rehabilitation Centres" (2012), https://www.unaids.org/en/media/unaids/contentassets/documents/document/2012/JC2310_Joint%20Statement-6March12FINAL_en.pdf.
 - 31. International Labour Organization, Joint State-







ment on Compulsory Drug Detention and Rehabilitation Centres: ILO, OHCHR, UNDP, UNESCO, UNFPA, UNHCR, UNICEF, UNODC, UN Women, WFP, WHO and UNAIDS (Geneva: Office of the High Commissioner of Human Rights and World Health Organization, 2012); Global Fund, "Global Fund Calls for End to Compulsory Treatment," International Drug Policy Consortium (November 26, 2014), theglobalfund.org/en/mediacenter/announcements/2014-11-26_Global_Fund_Calls_for End_to_Compulsory_Treatment/.

- 32. Human Rights Watch, "Utterly Irresponsible: Donor Funding in Drug 'Treatment' Centers" (September 14, 2011), hrw.org/news/2011/09/14/utterly-irresponsible.
- 33. K. Todrys, "Invisible Prisoners: The Fight for Human Rights," Jurist (September 4, 2012), jurist.org/commentary/2012/09/katherine-todrys-invisible-prisoners/.
- 34. Global Network of Sex Work Projects, Mapping and Population Size Estimates of Sex Workers: Proceed with Extreme Caution (Scotland: Global Network of Sex Work Projects, 2015).
- 35. Government of Nepal HIV/AIDS and STI Control Board, *Mapping and Size Estimation of Most-at-Risk Population in Nepal: Vol. 2 Injecting Drug Users* (2011), https://www.unodc.org/documents/southasia/reports/IDUs_final_report.pdf.
- 36. M. Carter, "Leading Human Rights Organisation Calls for Release of HIV Workers in Senegal," AIDS Map (January 12, 2009), aidsmap.com/news/jan-2009/leading-human-rights-organisation-calls-release-hiv-workers-senegal.
- 37. J. J. Amon, M. Wurth, and M. McLemore, "Evaluating Human Rights Advocacy: A Case Study on Criminal Justice, HIV and Sex Work," *Health and Human Rights Journal* 17/1 (2015); Human Rights Watch, "Tanzania: Police Abuse, Torture, Impede HIV Services" (June 18, 2013), hrw. org/news/2013/06/18/tanzania-police-abuse-torture-impede-hiv-services.
- 38. J. J. Amon, "The Political Epidemiology of HIV," *Journal of the International AIDS Society* 17/1 (2014).
- 39. UNAIDS, End Inequalities. End AIDS. Global AIDS Strategy 2021–2026 (Geneva: UNAIDS and World Health Organization, 2021).
- 40. A. L. Stangl, D. Singh, M. Windle, et al., "A Systematic Review of Selected Human Rights Programs to Improve HIV-Related Outcomes from 2003 to 2015: What Do We Know?," *BMC Infectious Diseases* 19/1 (2019).
- 41. J. J. Amon, N. Sun, A. Iovita, et al., "Addressing Stigma Is Not Enough," *Health and Human Rights Journal* 24/2 (2022).

- 42. Human Rights Council, Report of the Special Rapporteur on Extreme Poverty and Human Rights, UN Doc. A/HRC/32/31 (2016), para. 11.
- 43. J. Cohen, "Paradigm under Threat: Health and Human Rights Today," *Health and Human Rights Journal* 22/2 (2020).
- 44. S. Moyn, "Do Human Rights Increase Inequality?," *Chronicle of Higher Education* (May 26, 2015).
- 45. J. Biehl and J. J. Amon, "The Right to Remedies: On Human Rights Critiques and Peoples' Resources," Humanity: An International Journal of Human Rights, Humanitarianism, and Development (2019); J. Biehl, M. Socal, and J. J. Amon, "The Judicialization of Health and the Quest for State Accountability: Evidence from 1,262 Lawsuits for Access to Medicines in Southern Brazil," Health and Human Rights Journal 18/1 (2016); M. P. Socal, J. J. Amon, and J. Biehl, "Right-to-Medicines Litigation and Universal Health Coverage: Institutional Determinants of the Judicialization of Health in Brazil," Health and Human Rights Journal 22/1 (2020).
- 46. A. Kapczynski, "The Right to Medicines in an Age of Neoliberalism," *Humanity: An International Journal of Human Rights, Humanitarianism, and Development* 10/1 (2019).
- 47. A. Cerón, "Neocolonial Epidemiology," *Medicine Anthropology Theory* 6/1 (2019).
- 48. United Nations General Assembly, Independent International Commission of Inquiry on Ukraine, UN Doc. A/78/540 (2023).
- 49. United Nations, "'Unceasing Death, Destruction, Suffering' of Russian Federation's War on Ukraine Must End, Senior Humanitarian Affairs Official Tells Security Council" (October 31, 2023), press.un.org/en/2023/sc15476. doc.htm.
- 50. Office of the United Nations High Commissioner for Human Rights, OHCHR Assessment of Human Rights Concerns in the Xinjiang Uyghur Autonomous Region, People's Republic of China (New York: Office of the United Nations High Commissioner for Human Rights, 2022).
- 51. United Nations, "Gaza: Continued Violence is Not the Answer" (October 28, 2023), ohchr.org/en/statements-and-speeches/2023/10/gaza-continued-violence-not-answer.
- 52. D. Lohman, M. Golichenko, and N. Sun, *Ukraine Mid-term Assessment: Global Fund Breaking Down Barriers Initiative* (Geneva: Global Fund to Fight AIDS, TB, and Malaria, 2020).
- 53. L. O. Gostin and L. S. Rubenstein, "Attacks on Health Care in the War in Ukraine: International Law and the Need for Accountability," *JAMA* 327/16 (2022).







- 54. E. Mahase, "Uyghurs: World Medical Association Calls on Chinese Association to Acknowledge Abuse," *BMJ* 383 (2023); L. S. Rubenstein and G. J. Annas, "Medical Ethics at Guantanamo Bay Detention Centre and in the US Military: A Time for Reform," *Lancet* 374/9686 (2009).
- 55. Y. Barhoush and J. J. Amon, "Medical Apartheid in Palestine," *Global Public Health* 18/1 (2023).
- 56. J. Mann, "Dignity and Health: The UDHR's Revolutionary First Article," *Health and Human Rights Journal* 3/2 (1998), p. 8.