

EDITORIAL

Thirty Years of Scholarship and Debate: Advancing the Right to Health

JOSEPH J. AMON AND CARMEL WILLIAMS

Last year marked the 75th anniversary of the Universal Declaration of Human Rights. As anniversaries go, it was kind of a quiet one, with global conflicts and crises calling into question whether human rights are mere aspirations or truly fundamental—and useful—tools for advancing human dignity and equality.

The idea of a right to health, however, predates the Universal Declaration of Human Rights, having been included two years earlier in the 1946 Constitution of the World Health Organization (WHO), whose preamble says that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition,” and today the right is now included in over 115 national constitutions.¹

Almost immediately, however, the right to health was contested, caught up in Cold War tensions between civil and political rights versus economic and social ones, and WHO, after a change in leadership, stepped away from its promotion of a right to health—and, more broadly, social medicine—toward a more technocratic and biomedical orientation.²

Reflecting these lingering tensions some 45 years later in the first issue of *Health and Human Rights*, Jonathan Mann, the journal’s founding editor, wrote:

*We have created this new journal, Health and Human Rights, to inform and expand the space within which ideas about the intersection between health and human rights can venture forth into the world, to be cited and criticized, debated and discussed, torn down and built up.*³

This “new beginning,” now 30 years old, and this goal, continue to drive the journal forward.

In the spirit of informing and expanding debate and understanding of the intersection between health and human rights, we asked a number of authors of early articles published by the journal to look back and reflect on the issues raised and what progress—or regress—has occurred since their publication. We also invited members of our Executive Editorial Committee to contribute their views on any paper from the first volume to consider how far we have come or otherwise.

Each of these contributions tells part of the story of the development of the journal and of the field more generally—and often, as is the case with the contributions by Sofia Gruskin and Stephen Marks, of

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*.

CARMEL WILLIAMS, PhD, is executive editor of *Health and Human Rights*.

personal journeys alongside the development of a journal and a discipline.⁴

Sofia Gruskin's contribution reflects on the foundational article from the first issue that she coauthored with Jonathan Mann, Lawrence Gostin, Troyen Brennan, Zita Lazzarini, and Harvey V. Fineberg, entitled simply "Health and Human Rights."⁵ She highlights how the ground has since shifted from discussions of "why link health and human rights" to "how to do it? What does it mean to do so in practice?"⁶ On rereading the foundational article, Gruskin finds that it not only is a piece of history but remains a living document.

Stephen Marks attended the first two health and human rights conferences organized and reported on by the journal and found his life transformed by them.⁷ The enthusiasm of conference participants resulted in the completion of five tasks set at the first conference, one of which contributed to the launch of *Health and Human Rights*. He concludes that "ideas do change the world, and the linkage of human rights and health work is one of those ideas."⁸

Lawrence Gostin and Eric Friedman reexamine Gostin and Mann's article on health and human rights impact assessment, also from the first issue, which combines a personal history and historical perspective of the influence of the global HIV/AIDS pandemic on the emerging health and human rights field.⁹ The impact assessment approach described in the original article laid out a view of health and human rights as a pragmatic tool, speaking in a language and a "checklist" orientation familiar to public health practitioners, emphasizing such steps as evaluating policy effectiveness and assessing the necessity for coerciveness. Thirty years later, they believe that impact assessments remain necessary but could be even more forceful with increased emphasis on equity, participation, and accountability.

Sharifah Sekalala and Kene Esom also reflect on HIV, and risks that arise from overlooking structural inequalities and the indivisibility of all human rights. They focus on Mark Heywood and Morna Cornell's paper "Human Rights and AIDS in South Africa: From Right Margin to Left Margin," which examined South Africa's apartheid

struggle and asserted that despite efforts to develop a bold national HIV/AIDS policy, the failure to integrate social and economic rights would render its response ineffective.¹⁰ Sekalala and Esom note the remarkable progress South Africa has made in the fight against HIV/AIDS, but they highlight that deep inequalities remain and that the absence of a human rights-based response with the rights of structurally marginalized groups at the center leaves South Africa grappling to address other health challenges and pandemics.

Finally, the current United Nations (UN) Special Rapporteur on the right to health, Tlaleng Mofokeng, examines Lynn Freedman's 1995 article "Reflections on Emerging Frameworks of Health and Human Rights."¹¹ Like many of the articles in the first volume of the journal, Freedman emphasized how the "analytical tools of public health can be used in conjunction with emerging theories of human rights" to advance women's reproductive health and rights.¹² Mofokeng expounds on Freedman's belief in using advocacy as an inherently subversive tool to challenge sociopolitical norms that both produce and sustain ill health. She explains that in her UN mandate, she uses anti-racist, anti-colonial analyses and employs intersectional frameworks to advocate for substantive equality to fulfill health rights.

Collectively, these commentaries speak both to progress and to ongoing struggles in the effort to expand understanding and realization of the right to health. Thirty years on, there are still those who stubbornly debate that health (and other social and economic rights) does not deserve a full seat at the rights table alongside civil and political rights.¹³ They argue that negative rights—restrictions on governments' actions—which relate to, for example, the prohibition of torture, arbitrary detention, and other civil and political rights abuses, are fundamentally different from positive rights, which promote the progressive realization of rights such as the rights to health, education, and shelter.

Since the founding of the journal, health and human rights scholars and activists have challenged this contention. In each issue, articles have pointed to the indivisibility of civil, political,

economic, social, and cultural rights. Irrespective of which specific health issue an author is addressing, achieving progress in preventing or treating it requires the understanding that all human rights must be respected. Scholars published in the journal were examining the “underlying” determinants of health long before they became more mainstream with WHO’s world report in 2008 on the social determinants of health.¹⁴ Over the past 30 years, the journal has published multiple articles on the environment, tuberculosis, compulsory drug dependency treatment, COVID-19, reproductive rights, disability rights, and more that have illustrated how both sets of rights influence health. In each case, recognizing this indivisibility strengthens efforts to uphold the right to health and protect vulnerable and marginalized communities.

For example, in the second volume, published in 1997, Alistair Iles wrote that “linkages between health and the environment are increasingly recognized, but human rights law still does not provide an adequate framework for dealing with those connections.”¹⁵ Today, there is a UN Special Rapporteur on human rights and the environment, who, along with organizations such as the Center for International Environmental Law and Human Rights Watch, recognizes the deep connections between human rights and health and the importance of addressing all civil, political, economic, and social rights in their research and advocacy.¹⁶ Ten years ago, the journal assembled a special section on climate justice and the right to health, linking it to issues related to children’s rights, racism, and social justice, and in 2021 there were two special sections on both the climate crisis and ecological justice, which examined not just the indivisibility of human rights but also humanity and its interdependence with nature.¹⁷

Articles on multidrug-resistant tuberculosis in the journal have addressed permissible and impermissible rights restrictions—including quarantine—as well as the importance, from a rights perspective and from a public health perspective, of community-based alternatives.¹⁸ These analyses, which insist on the indivisibility of all human rights, have proved equally important during the

Ebola and COVID-19 outbreaks.¹⁹ Similarly, articles on compulsory drug detention, and on drug policy generally, including with regard to access to palliative care, have highlighted the inescapable indivisibility of all human rights.²⁰

Yet the challenges outlined by Mann in another editorial, “Human Rights and the New Public Health,” remain.²¹ In that editorial, Mann anticipated that public health professionals will resist a reframing of public health to recognize human rights as fundamental determinants of health, both because of a lack of familiarity with human rights and an unease with engaging beyond narrow, biomedical approaches.²²

Nonetheless, the journal’s archives show increasing confidence among contributors in developing human rights-based approaches and analyses. The term itself first appeared in the title of an article in the journal in 1998, “Human Rights Approaches to an Expanded Response to Address Women’s Vulnerability to HIV/AIDS,” which sought to identify effective strategies to address multiple components of vulnerability in addition to providing adequate health services.²³ Thereafter, “rights-based approaches” became more frequent, and in her final article as editor in 2006, Gruskin wrote, “Human rights are now understood to offer a framework for action and for programming, even as they provide a compelling argument for government responsibility—both to provide health services and to alter the conditions that create, exacerbate, and perpetuate poverty, deprivation, marginalization, and discrimination.”²⁴

In 2008, with Paul Farmer as the new editor-in-chief, a section explored what rights-based approaches mean, with the frequently cited Leslie London paper “What Is a Human Rights-Based Approach to Health and Does It Matter?” and Alicia Ely Yamin’s “Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care.”²⁵ In 2015, guest editors Paul Hunt, Yamin, and Flavia Bustreo presented an entire issue on evidence showing the impact of human rights-based approaches to health.²⁶

But in practice, the record is mixed. Orga-

nizations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria have recognized the importance of rights-based approaches to remove barriers to access, uptake, and retention in prevention and treatment programs.²⁷ WHO highlights rights violations related to the detention of hospital patients for being unable to pay their bill; violence against women, including abuses during childbirth and pregnancy and female genital mutilation; “conversion” therapy; and the denial of sexuality education, among other abuses, as critical to address in order to achieve a right to health for all.²⁸ WHO also promotes rights-based approaches to health services, recently seen in its QualityRights training materials for people working in mental health and in its guidance on mental health services.²⁹

Other global health donors and actors are more reticent in recognizing the importance of rights and the need to overturn harmful laws, policies, and practices that impede the realization of the right to health. They may prefer to talk more broadly about “equity” than “rights,” failing to recognize linkages between the two—or intentionally avoiding the discussion of rights and questions of obligation.³⁰ The concept of accountability can also be a challenge for UN agencies, donors, and other global health actors to accept—both in holding themselves accountable and in holding governments to account.³¹

The journal’s archives, covering 30 years of articles, present an extraordinary range of topics. The journal has provided a platform for scholars, health and legal practitioners, and activists to address health concerns that especially affect marginalized and disadvantaged communities, along with the underlying inequalities and discrimination that leave communities so vulnerable to ill health and multiple rights violations. As Mofokeng expresses in her commentary, “We have to be committed to ending the systems of oppression that create those situations. This can be done only through an unwavering commitment to social justice, reproductive justice, economic justice, and racial justice. And the tools we have to get to justice are human rights.”³²

We invite you to contribute commentaries

with your own reflections on the current state of the right to health and how far—or how little—we have advanced since our early volumes on the recognition of the right to health; on the integration of the right to health among bilateral and multilateral donor agencies; and on how the right to health is operationalized by community-based organizations worldwide. As always, we welcome critical and lively debate—or as Mann suggested, tearing down and building up.³³

References

1. J. Morsink, *The Universal Declaration of Human Rights: Origins, Drafting and Intent* (Philadelphia: University of Pennsylvania Press, 1999); Office of the United Nations High Commissioner for Human Rights and World Health Organization, *The Right to Health: Fact Sheet No. 31* (June 2008), <https://www.ohchr.org/sites/default/files/Documents/Publications/Factsheet31.pdf>.
2. B. M. Meier, “Global Health Governance and the Contentious Politics of Human Rights: Mainstreaming the Right to Health for Public Health Advancement,” *Stanford Journal of International Law* 46/1 (2010); P. Alston, “The United Nations’ Specialized Agencies and Implementation of the International Covenant on Economic, Social and Cultural Rights,” *Columbia Journal of Transnational Law* 18 (1979).
3. J. Mann, “A New Journal: A New Beginning,” *Health and Human Rights Journal* 1/1 (1994).
4. S. Marks, “A Personal Commentary on the Two Conferences on Health and Human Rights,” *Health and Human Rights Journal* 26/1 (2024); S. Gruskin, “Health and Human Rights: What Relevance Now?,” *Health and Human Rights Journal* 26/1 (2024).
5. J. Mann, L. O. Gostin, S. Gruskin, et al., “Health and Human Rights,” *Health and Human Rights Journal* 1/1 (1994).
6. Gruskin (see note 4).
7. “Conference Report: First International Conference on Health and Human Rights,” *Health and Human Rights Journal* 1/2 (1994); J. M. Mann and S. Gruskin, “The 2nd International Conference on Health and Human Rights: Bridge to the Future,” *Health and Human Rights Journal* 2/3 (1997).
8. Marks (see note 4).
9. L. O. Gostin and E. A. Friedman, “The Health and Human Rights Impact Assessment: The Preeminent Value of Equity,” *Health and Human Rights Journal* 26/1 (2024).
10. M. Heywood and M. Cornell, “Human Rights and AIDS in South Africa: From Right Margin to Left Margin,” *Health and Human Rights Journal* 2/4 (1998)
11. L. P. Freedman, “Reflections on Emerging Frameworks of Health and Human Rights,” *Health and Human*

Rights Journal 1/3 (1995).

12. T. Mofokeng, "Freedom Dreaming: On Emerging Frameworks of Health and Human Rights," *Health and Human Rights Journal* 26/1 (2024).

13. A. Neier, "Differentiating Fundamental Rights and Economic Goals," in B. Fassbender and K. Traisbach (eds), *The Limits of Human Rights* (Oxford: Oxford University Press, 2019).

14. Commission on the Social Determinants of Health, *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health* (Geneva: World Health Organization, 2008).

15. A. T. Iles, "Health and the Environment: A Human Rights Agenda for the Future," *Health and Human Rights Journal* 2/2 (1997).

16. See, for example, UN Special Rapporteur on Human Rights and the Environment, "Thematic Reports," <https://srenvironment.org/thematic-reports>; Human Rights Watch, "'They Destroyed Everything': Mining and Human Rights in Malawi" (September 27, 2016), <https://www.hrw.org/report/2016/09/27/they-destroyed-everything/mining-and-human-rights-malawi>; Center for International Environmental Law, "Chilean Communities' Responses and Recommendations to Accountability Mechanisms of Development Banks Regarding the Alto Maipo Hydroelectric Project (June 2023)" (June 28, 2023), <https://www.ciel.org/reports/chilean-communities-responses-and-recommendations-to-accountability-mechanisms-of-development-banks-regarding-the-alto-maipo-hydroelectric-project-june-2023/>.

17. See *Health and Human Rights Journal* 16/1 (2014), Climate Justice and the Right to Health: A Special Issue; *Health and Human Rights Journal* 23/2 (2021), Special Section: Ecological Justice and the Right to Health and Health Rights and the Urgency of the Climate Crisis.

18. 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* (October 7, 2009), <https://www.hhrjournal.org/2009/10/limitations-on-human-rights-in-the-context-of-drug-resistant-tuberculosis-a-reply-to-boggio-et-al/>.

19. Human Rights Watch, "West Africa: Respect Rights in Ebola Response" (September 15, 2014), <https://www.hrw.org/news/2014/09/15/west-africa-respect-rights-ebola-response>; 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).

20. R. Elliott, J. Csete, E. Wood, and T. Kerr, "Harm Reduction, HIV/AIDS, and the Human Rights Challenge to Global Drug Control Policy," in M. Gordin, D. Tarantola, G. Annas, and S. Gruskin (eds), *Health and Human Rights in a Changing World* (New York: Routledge, 2013); M. Golichenko and A. Sarang, "Atmospheric Pressure: Russian Drug Policy

as a Driver for Violations of the UN Convention against Torture and the International Covenant on Economic, Social and Cultural Rights," *Health and Human Rights Journal* 15/1 (2013); 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* 17/2 (2015).

21. J. Mann, "Human Rights and the New Public Health," *Health and Human Rights Journal* 1/3 (1995).

22. Ibid.

23. D. Whelan, "Human Rights Approaches to an Expanded Response to Address Women's Vulnerability to HIV/AIDS," *Health and Human Rights Journal* 3/1 (1998).

24. S. Gruskin, "Rights-Based Approaches to Health: Something for Everyone," *Health and Human Rights Journal* 9/2 (2006).

25. L. London, "What Is a Human Rights-Based Approach to Health and Does It Matter?," *Health and Human Rights Journal* 10/1 (2008); A. E. Yamin, "Will We Take Suffering Seriously? Reflections on What Applying a Human Rights Framework to Health Means and Why We Should Care," *Health and Human Rights Journal* 10/1 (2008).

26. P. Hunt, A. E. Yamin, and F. Bustreo, "Editorial: Making the Case: What Is the Evidence of Impact of Applying Human Rights-Based Approaches to Health?," *Health and Human Rights Journal* 17/2 (2015).

27. 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).

28. See, for example, World Health Organization, "Right to Health: Standing against Rights Abuses" (March 17, 2022), <https://www.who.int/news-room/facts-in-pictures/detail/right-to-health>.

29. World Health Organization, *Guidance on Community Mental Health Services: Promoting Person-Centred and Rights-Based Approaches* (Geneva: World Health Organization, 2021); see also World Health Organization, "QualityRights Materials for Training, Guidance and Transformation," <https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools>.

30. P. Braveman, "Social Conditions, Health Equity, and Human Rights," *Health and Human Rights Journal* 12/2 (2010).

31. G. Gray, "The Center for Justice and Accountability," *Health and Human Rights Journal* 4/1 (1999); M. Akashah and S. P. Marks, "Accountability for the Health Consequences of Human Rights Violations: Methodological Issues in Determining Compensation," *Health and Human Rights Journal* 9/2 (2006); S. Mayhew, M. Douthwaite, and M. Hammer, "Balancing Protection and Pragmatism: A Framework for NGO Accountability in Rights-Based Approaches,"

Health and Human Rights Journal 9/2 (2006); A. E. Yamin, "Beyond Compassion: The Central Role of Accountability in Applying a Human Rights Framework to Health," *Health and Human Rights Journal* 10/2 (2008); V. Maru, "Allies Unknown: Social Accountability and Legal Empowerment," *Health and Human Rights Journal* 12/1 (2010).

32. Mofokeng (see note 12).

33. Mann (1994, see note 3).