

COMMENTARY

The Health and Human Rights Impact Assessment: The Preeminent Value of Equity

LAWRENCE O. GOSTIN AND ERIC A. FRIEDMAN

The year was 1994. Contracting HIV was a death sentence. Triple therapy was still two years away in the United States. Efforts to achieve antiretroviral treatment at scale in Sub-Saharan Africa would not begin for nearly another decade. In the United States, AIDS was still heavily associated with men who have sex with men, and later also users of injection drugs. People living with HIV faced stigma, discrimination, and even animus. In the mid-1980s, Ryan White, a young boy from Indiana living with AIDS, insisted, “Mom, I want to go to school.” But he was excluded.

It was also a very different era for health and human rights. It would be six years before the Committee on Economic, Social and Cultural Rights (ESCR Committee) would issue General Comment 14 on the right to health. At the time, there was a widespread belief that public health and human rights were in deep, sometimes irresolvable, conflict. On issues ranging from mandatory HIV testing to named reporting to partner notification, public health would trump human rights. The debate was rarely informed by whether public health interventions were actually effective.

In February 1987, I (LOG) met a young American public health professional named Jonathan Mann in Geneva. The World Health Organization’s Global Programme on AIDS comprised only Jon and a Swiss secretary. By the time Jon left Geneva, it had become the largest program in the World Health Organization’s history. Jon had become widely renowned for founding the health and human rights movement, grounded on the idea that human rights and public health were not in tension but were synergistic.

By 1994, Jon and I had become close friends and he joined me at the Harvard School of Public Health. Standing at a chalkboard in the basement of Longwood Avenue, we drafted the outlines of a health and human rights impact assessment to guide the creation and evaluation of public health policies.

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That was the genesis of our article in the inaugural issue of *Health and Human Rights*.² The impact assessment would be informed by evidence of a policy's effectiveness, its real-world consequences, the extent of its human rights burdens, the public health gain (if any), and whether the policy is narrowly tailored to achieve a compelling public health purpose. The impact assessment would serve as an analytical tool to ensure that data, ethics, and human dignity—rather than fears and stereotypes—inform public health policy. The impact assessment we developed had seven steps:

- Step I: Clarify the public health purpose.
- Step II: Evaluate likely policy effectiveness.
- Step III: Determine whether the public health policy is well targeted.
- Step IV: Examine the policy for possible human rights burdens.
- Step V: Determine whether the policy is the least restrictive alternative that can achieve the public health objective.
- Step VI: If a coercive public health measure is truly the most effective, least restrictive alternative, base it on the “significant risk” standard.
- Step VII: If a coercive measure is truly necessary to avert a significant risk, guarantee fair procedures for persons affected.

Our article followed the very first paper in the journal, simply entitled “Health and Human Rights.”³ That paper focused on the synergies between health and human rights—how respecting, protecting, and fulfilling human rights is essential for public health. It foreshadowed a value that animates the health and human rights movement, and what public health emergencies—from HIV/AIDS to COVID-19—have made inescapably clear: that equity must be at the heart of health and human rights. Justice demands it.

Here, we examine the centrality of health equity to human rights, and how and why equity has risen on the global health agenda—and has become firmly embedded in health and human rights impact assessments. How to now unleash the full potential of these assessments?

Equity and the nondiscrimination principle

The right to health would be all but meaningless without a powerful focus on equity. If governments had to ensure rights only for some but not for all, then the most marginalized and disadvantaged—the people who depend most on the right to health—would be left behind.

The full power of the International Covenant on Economic, Social and Cultural Rights' prohibition on discrimination requires recognizing the breadth of its delineated grounds for prohibited discrimination. This breadth became clear in 2009, when the ESCR Committee issued its authoritative General Comment 20. Crucially, the general comment clarifies that the nondiscrimination obligation bars not only facially discriminatory measures but also discrimination that is substantive and indirect (i.e., that disproportionately burdens a population), with positive obligations for states to adopt measures to redress discrimination that exists in practice. And it offers a comprehensive list of grounds for applying the treaty's nondiscrimination principle, going beyond those expressly named in the covenant, including disability, economic or social situation (e.g., poverty), and nationality, among others. Several treaties further detail discrimination against particular populations, prominently women, racial and ethnic groups, and people with disabilities. These treaties encompass nondiscrimination with respect to the right to health, as well as other rights closely linked to people's ability to achieve the highest attainable standard of health, such as the rights to housing, education, and employment.

The rise of equality on the global health agenda

Thirty years ago, the global health community was focused primarily on reducing the enormous burdens in low- and middle-income countries of readily—and largely inexpensively—preventable death and disease, such as maternal and child mortality. In the aggregate, the quarter century from

1990 to 2015 was indeed one of significant health improvements. The global maternal mortality rate fell by 44%.⁴ The child (under five) mortality rate fell by over half (53%), as did the proportion of the world's population experiencing hunger (falling about 54%).⁵ Yet as the total burden of disease continued to fall, the inequities grew ever more glaring. Global health was improving, but *global health with justice*, not so much.

In India, the mortality rate of women in the lowest wealth quintile is four times that of women in the top wealth quintile (most recent data as of 2017).⁶ Globally, children under five were twice as likely to die when in the poorest wealth quintile compared those in the richest wealth quintile in 1990—and still in 2015.⁷ Life expectancy disparities within countries, even within cities, can exceed 20 years.⁸ Billions of people remain without access to essential health services, medicines, water, or sanitation.

Globally, while the life expectancy gap has narrowed, a child born in a low-income country has a life expectancy 18 years shorter than a child born in a high-income country (2021 data).⁹ In 2017, the maternal mortality ratio was 40 times greater in high-income countries than in low-income countries.¹⁰ Little could make clearer the divergence between health improvements and equitable health improvements than the record-breaking speed at which scientists developed highly effective COVID-19 vaccines contrasted with the global disparities in vaccine access. Painfully obvious, too—helping further bring health equity into the public consciousness—was the extra toll of COVID-19 on traditionally marginalized populations, such as Indigenous peoples, who experienced infection and death rates far exceeding those of their countries' overall population.

One issue had, by the turn of the century, already begun to turn the world's eye to equity—the tremendous disparities in HIV treatment between wealthy countries and those in Sub-Saharan Africa, where HIV/AIDS posed practically an existential risk. The power of the AIDS movement, the level of inequality, and the particularly glaring nature of it—pills that made the difference between life and

death, available to the rich but not the poor—catalyzed major initiatives to make treatment available to people everywhere.

Beyond the issue of access to antiretroviral treatment, the emergence of the AIDS movement, as well as the growth of health rights advocacy organizations, has been transformative. The AIDS movement forced governments—their own and development partners⁷—to see people who were marginalized, such as LGBTQ+ people, users of injecting drugs, and sex workers. Other equity-focused social movements have also taken off around the world, such as movements on behalf of and led by women and girls, and people with disabilities.

Health-related civil society organizations have taken up the mantle of advocacy, not only service delivery. Equity is central to their agendas. These, in turn, have increasingly influenced the global health agenda.

Also advancing attention to health equity has been the evolution of global health assistance. The prevailing model of global health assistance had been one of charity—funding provided and essential vaccines and medicines donated as acts of generosity. But people in lower-income countries, especially in Sub-Saharan Africa, have always known that charity comes too little and too late. By the early 2000s, that model began to change (at least nominally) with the language of partnership. “Donors” became “development partners,” and “recipients” were “host countries.” Modern thinking rejects a charitable model of rights, seeing assistance as an obligation. These changes, though, failed to bring anything near equity to access to vaccines and other essentials during the COVID-19 pandemic. The idea of high manufacturing capacities in low- and middle-income countries has now taken hold, requiring intellectual property waivers, investment in national and regional capacities, and technology transfer.

We see the growing influence of health equity, from universal access to HIV treatment to the centrality of equality in the 2030 Agenda for Sustainable Development, which pledges that “no one will be left behind” and includes goals directly addressing equality.¹¹ COVID-19's inequities ensured

that equality would be a core theme of the Principles and Guidelines on Human Rights and Public Health Emergencies, which include equitable international distribution of scarce resources during public health emergencies.¹² The equity focus has even extended to extraterritorial obligations related to economic, social, and cultural rights, as the Maastricht Principles on Extraterritorial Obligations of States in the Area of Economic, Social and Cultural Rights include prioritizing the rights of marginalized and disadvantaged groups.¹³

And for all the shortcomings of COVAX, it was an unprecedented effort to ensure COVID-19 vaccines for people wherever they lived. It enabled many millions of people in low- and middle-income countries to receive COVID-19 vaccines earlier than they would have otherwise.

There is little more unjust than the happenstance of people's lives—factors beyond their control—shaping their opportunities to live long, healthy lives and to flourish.¹⁴ To disadvantage people in this way is like stealing from them both life itself and the ability to write the stories of their lives.

Realizing the promise of the impact assessment for rights and equity

Equity, as well as the participation of affected communities, has become central to the health and human rights impact assessments that have built on our article in the founding issue of *Health and Human Rights* and are now frequently used, even as many do not take an explicit rights approach. Most assessments evaluate the potential health effects of a policy, program, or action and recommend how to maximize positive and minimize negative health effects.

Some assessments are framed around human rights and also incorporate other elements of the right to health, including accountability mechanisms and comparisons of the health effects of the policy or project to the AAAQ (availability, accessibility, acceptability, and quality) framework. Impact assessments should also include right to health education and capacity-building for both

rights holders and duty bearers.¹⁵

The ESCR Committee and United Nations Special Rapporteurs on health and education have already encouraged the use of impact assessments.¹⁶ The Special Rapporteur on the right to food has said that authorities “should systematically perform *ex ante* impact assessments on the right to food when engaging in large-scale infrastructural projects, such as dams,” with community participation.¹⁷

It's past time to go a step further and recognize health and human rights impact assessments as an immediate right to health obligation. The International Covenant on Economic, Social and Cultural Rights' progressive realization stipulation was intended to recognize that countries face resource constraints. Yet there are many ways to advance health rights with relatively low resource demands; for the most vital health rights, particularly those with limited resource implications—like impact assessments—state duties should be immediate. General Comment 14 already recognizes that core aspects of the right to health, including nondiscrimination and the equitable distribution of health resources, are immediate. The ESCR Committee should extend these core obligations to include health and human rights impact assessments. This obligation should include the right of affected populations to receive government (or business) feedback on the assessments, which is critical for accountability. Feedback should include how and why a government (or business) did, or did not, follow the impact assessment's recommendations. And this feedback should justify how the ultimate policy or proposal is consistent with human rights obligations.

The United Nations General Assembly and Human Rights Council could also recognize health impact assessments as required under the right to health. The World Health Assembly could urge states to establish legal frameworks on regular government and business use of impact assessments.

All of these bodies should also provide guidance to governments and nongovernmental organizations on fulfilling their duties. Such guidance should encompass common core standards centered in equity. This would include inclusive

participation in conducting assessments together with matrices to measure equitable outcomes. The guidance could also offer a framework or threshold for determining when health and human rights impact assessments should be required (e.g., for laws, policies, programs, and projects that have the potential to substantially affect health rights).

Civil society organizations need not wait for further global, or regional, action on health and human rights impact assessments in order to press their governments to include robust impact assessments in their policy and legal frameworks. Our original impact assessment proposal called for a new paradigm for HIV/AIDS policies and laws. Success in institutionalizing even more forceful impact assessments, emphasizing equity, participation, and accountability, could be transformative.

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