Commentary

AIDS and Human Rights: Where Do We Go from Here?

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The continuing challenges of HIV/AIDS have brought public health to the threshold of a new era, based on the inextricable connection between health and human rights. For human rights provides public health with an explicit response to its central dilemma: how to address directly the societal forces which determine, more than anything else, vulnerability to preventable disease, disability, and premature death. Put bluntly, public health has known about the societal dimension of health, but has failed to learn what to do about it. Now, through the insights provided by the health and human rights connection, public health is learning how to respond, by adding explicit efforts to promote and protect human rights to the list of traditional, useful public health approaches to promoting health and preventing disease. As public health considers how best to proceed along this path from insight to concrete action, two major and immediate challenges arise.

First, *the forms and mechanisms of human rights action may seem uncomfortable, foreign, or even inappropriate to many public health workers.* How can this perceptual gap be closed; how can public health professionals promote and protect human rights? Actually, decades of experience by nongovernmental organizations (NGOs) working in the

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human rights field provide a rather clear picture of the range of possibilities, which include:

- investigation, fact-finding, and documentation of human rights violations;
- presenting complaints about human rights violations to responsible political authorities;
- seeking to hold national authorities to their obligations under treaties and to their other international legal obligations;
- involving prominent figures (e.g., from sports, the arts) to raise awareness of human rights violations;
- creating publicity about human rights violations through the media;
- providing legal representation to victims of human rights violations;
- providing aid and relief directly to victims of human rights violations; and
- educating various groups/populations about human rights.

Once a public health professional has figured out which rights are most immediately relevant to the particular public health problem—in this case, for example, vulnerability to HIV/AIDS in a specific population and setting—the next step is to identify a list of pragmatic activities designed to promote and protect those rights. To do so requires a slight expansion of thinking. The goal is to bridge public health experience, expertise, and perspective with human rights forms of action.

For example, in a certain setting, the vulnerability of women to HIV may be associated with constraints or violations of several rights, such as the right to association, the right to information, or the right to equality in marriage and its dissolution. If, for example, the right to association is identified as important (e.g., in this particular place, women's NGOs concerned with AIDS are not allowed to exist), public health workers could contribute to promoting and protecting this particular right in several ways:

- by describing violation of the right to association as a danger to public health, given what is known broadly about the importance of nongovernmental organizations for health;
- by using the example of AIDS-specific NGOs to illustrate the importance of respecting the right to association;
- by connecting the restriction against women's AIDS-related NGOs to the larger issues of community involvement in health.

This is advocacy work, most usefully undertaken in collaboration with others. It means adding a public health voice to the efforts of those already seeking to improve respect for human rights in the particular community or nation. Advocacy skills and tools are entirely within the purview of public health.

Second, *neither health-related institutions nor human rights organizations may provide sufficient or sustained moral and logistic support for health/human rights-based action.* The primary work of human rights can be understood as a challenge to the status quo, to the way things are currently organized. This status quo is not an abstraction: many public health professionals work for and within governments—whose actions and inactions are the principal objects of human rights concern and challenge. This status quo includes cultural norms, religious practices, and economic systems, in which public health professionals may fully and willingly participate. The status quo also involves the societal role and status of health professionals themselves.

Precisely because they are embedded in the status quo, it would be unrealistic to expect official organizations, whether at national or international levels, to provide strong and sustained support for concrete human rights-based action (as opposed to rhetoric). This problem is not restricted to HIV/AIDS, nor to the health-related United Nations organizations; the entire UN system is riven by the conflicting pressures of respect for national sovereignty (often the defender of the status quo) and promotion of universal human rights norms. Support for human rights-based action to promote health (to reduce vulnerability to HIV/AIDS) at the level

of declarations and speeches is welcome, and useful in some ways, but the limits of official organizational support for the call for societal transformation inherent in human rights promotion must be recognized.

From the viewpoint of human rights organizations, health-related issues such as HIV/AIDS constitute a special challenge. First, because it necessarily entails working closely with health professionals, with whom human rights has had a complex and often conflictual relationship. (Even under the best circumstances, time and effort are required to bridge gaps arising from the different disciplinary approaches, pre-conceptions, and languages of human rights and health). Second, because health invokes the full range of economic and social rights, as well as the often more familiar and comfortable territory of civil and political rights. Third, because health-related work (particularly in the context of prevention-oriented public health) focuses more on promoting rights and dignity than on protection. Thus, the current capacity of human rights organizations to provide effective and sustained support for health/human rights actions (beyond rhetoric) may also be limited, although clearly increasing.

To move ever forward into action towards HIV/AIDS based on the health and human rights connection, four steps are proposed.

First, *connections between human rights and HIV/AIDS and with other health issues must be established and reinforced*. One of the major conceptual contributions of the health and human rights approach is its ability to link an understanding of HIV/AIDS vulnerability to vulnerability to other major public health concerns, such as cancer, heart disease, violence, injuries, reproductive health, and other infectious diseases. Use of the health and human rights approach implies connectivity, and can help prevent further isolation of HIV/AIDS work.

Second, *the training and continuing education of public health professionals and human rights workers must be strengthened*. Despite recent progress, most public health workers remain uninformed about human rights, just as most human rights professionals remain uneducated about health. To advance, every channel for increasing knowledge and expanding awareness about human rights must be actively uti-

lized, so that understanding of human rights can reach a critical mass among health professionals. Future public health training programs must include explication of human rights and health/human rights concepts. Similarly, engagement of human rights workers with health issues and colleagues will increase mutual understanding, and will challenge the traditional limits and forms of thinking of human rights when faced with the concrete realities of disease, disability, and premature death.

Third, *forms of research capable of identifying and verifying linkages between human rights and health must be developed*. One approach, analogous to the single pathogen, single disease model, is to search for a specific disease outcome resulting from violations of human rights. While this may be useful, it may be more appropriate to use an AIDS-like analogy, anticipating that violations of rights increase vulnerability to a wide range or opportunistic, adverse health events, the details of which would then be shaped by environmental exposures, genetic or other factors. Clearly, innovative research methods and creative research strategies will be required to advance understanding of the health and human rights connection.

Finally, *to work on human rights requires a willingness to deal with values*. Public health professionals are trained to respect and appreciate quantitative methods, but are not often educated regarding a discourse on values. Indeed, public health, by rigorously applying biostatistical, epidemiological and laboratory methods, has sometimes seemed to aspire to an illusory "value-free" status. Human rights reflect deeply held, often unspoken values, translated into the practical language of what governments (States) should not do and what they should ensure to all. Therefore—to advance the health and human rights connection, to work to promote human rights as an inextricable part of seeking to promote health, and to conduct research on health and human rights—all require a willingness to work and live at the level (as a student once remarked) not only of "p" values but of values.

Work in these areas, keeping in mind the inherent difficulties outlined above, can expand and advance a health and human rights agenda for HIV/AIDS prevention, control, and care.

Is this enough? While the forms of action to be undertaken, and the collective experience thereby gained will undoubtedly constitute important progress, the world of HIV/AIDS cannot and must not be isolated from the larger currents of change in the worlds of public health and of human rights. For beyond the synergistic contribution of a human rights dimension, the health and human rights dialogue is stimulating a profound rethinking of the taxonomy of health.

Biomedicine and its language are extremely useful and superbly adapted for specific purposes. Yet biomedicine is quite constrained when seeking to address the concept of well-being, so central to a modern understanding of health (as physical, mental, and social well-being). What forms of human suffering escape biomedical detection and what mechanisms may link societal forces with these injuries to well-being?

Human rights violations, such as discrimination, may be considered primary pathogenic forces. Consider, for example, how much and what kinds of damage to physical, mental, and social well-being can be traced to racism? Or consider dignity. Violations of dignity have such significant, pervasive, and long-lasting effects that injuries to individual and collective dignity may represent a thus far unrecognized pathogenic force of destructive capacity towards well-being at least equal to the capacity of viruses or bacteria.

In a related manner, this re-thinking of the taxonomy of health calls for re-consideration of the conceptual framework of human rights. For the boundaries of well-being (the goal of human rights as well as health work) are not defined by the actions of governments. If the focus of concern is to identify, stop, and prevent violations of discrimination and dignity, as powerful sources of damage to well-being, the sphere of concern must broaden to include wherever, whenever, however, and by whoever they arise. This strongly challenges the inherited framework of human rights thought and action.

We are at the threshold of a rebirth—a set of new perspectives—so clearly possible because (to paraphrase Newton) we stand on the shoulders of the giants—in health and in human rights—who have preceded us. Now we have the responsibility to move forward by recognizing that true interdependence and real interconnectedness requires that we—

from health and from human rights—advance together: equal partners in the belief that the world can change.