

## RESPONDING TO HIV/AIDS: A Historical Perspective

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**T**he global response to HIV/AIDS clearly illustrates the maxim that how a problem is defined determines what we believe can be done about it, and from there what is actually done to address it. The history of the response to HIV/AIDS has developed in four phases, from a danger to be alerted about, to a problem of individual behavior, to a societally contextualized behavioral issue, and finally, to a human rights-linked challenge. Each stage in this evolution reflects a learning process, a building on experience. And in a sense, the HIV/AIDS response recapitulates the history of public health, and how it has faced, and needs to address, the challenges of human behavior.

Recognition of AIDS in mid-1981 resulted in a need to inform the public about a new disease threat, at a time when the modes of spread were not entirely known, diagnosis was based on the end-stage disease, and no therapy was available. A sense of urgency defined the problem, and the public information materials developed in this period often emphasized "danger" at the expense of clear information about prevention measures.

The first global AIDS strategy, articulated by the World Health Organization in 1986-87, defined HIV/AIDS in terms of individual risk behaviors. This approach resulted directly

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from two traditions within public health: an application of traditional epidemiological methodology which predetermined that risk factors would be identified at an individual level (e.g. sex acts, number of partners, use of condoms), and the pervasive, unspoken acceptance within public health of the individual-centered health belief model and its derivatives as the dominant approach to health-related behavior change.

Specification of risk behaviors as the central concern led to risk-reduction programs designed to change individual behaviors. Drawing from the history of public health practice, these programs generally focused on two elements: information, education, and communication; and provision of (usually) clinic-based services. Thus, information about the need for condom use was linked to making condoms available, of good quality and at reasonable cost. Similarly, admonitions to be tested were connected to the creation of sites for quality testing with counseling and protection of confidentiality.

The WHO Global AIDS Strategy sought to help countries set up national AIDS programs, to ensure that information and services to help change individual behavior would be widely available. An additional element of great importance, although new to traditional public health, involved preventing discrimination towards HIV-infected people and people with AIDS.

The global mobilization of 1986-89 was based on this approach: with individual behavior change as the goal, countries set up plans and programs to provide information, education, and related health and social services, and to ensure non-discrimination.

As the individual-behavior based approach to prevention proceeded, questions inevitably arose about the societal context in which individuals were "behaving." These questions were prompted by the recognition that HIV epidemics were disproportionately affecting people in developing countries and marginalized populations in industrialized countries. And as awareness of the economic, political, social, and cultural dimensions of HIV/AIDS and related behaviors increased, HIV/AIDS was perceived as resulting from, and therefore re-defined, as a combination of individual behavior and societal or contextual forces.

Analysis of the societal context advanced painstakingly along disciplinary lines (economic, political, sociocultural), and in doing so began to enrich global understanding of risk behaviors. Whereas the concepts easily found their way into the HIV/AIDS discourse, the ability to translate these insights into action lagged behind. For example, when poverty was identified as a central contextual issue, public health had difficulty going beyond pointing to poverty as a problem: concrete actions against poverty as an integral part of public health strategy did not result. And, when specific actions directed at contextual issues did occur, such as pressuring a political figure to speak openly about HIV/AIDS, the impact on prevention was generally short-term and minimal.

This dissonance between analysis and action mirrored the central dilemma of modern public health: how to address directly the societal determinants of health?

Insight about not only how to analyze but also how to address the societal basis of vulnerability to HIV/AIDS emerged from two major lines of reasoning and experience. First, as national and community HIV epidemics matured, a societal-level risk factor was identified. Those who—before the arrival of HIV/AIDS—were societally marginalized, stigmatized, or discriminated against, were found gradually and increasingly to bear the brunt of the HIV/AIDS epidemic. For example, in the United States, the majority of new HIV infections are occurring among racial and ethnic minority populations, and within them, primarily among women, adolescents, injecting drug users, and poor inner-city residents. Second, analysis of the inability of women to apply HIV/AIDS information and to access services led to awareness that women's ability to make and effectuate free and informed choices about their sexual behavior was strongly linked to their roles and status in society. Together, these real-world lessons suggested that a form of analysis which identified the societal-level basis of vulnerability to HIV/AIDS was required.

At first implicitly, then explicitly, public health drew on the human rights framework to analyze societally-based vulnerability and to guide efforts at societal transformation. For through its focus on societal-level determinants of human well-being, human rights has provided public health with

a more useful framework, vocabulary and guidance for analysis, and direct response to the societal determinants of health than any other framework inherited from the past biomedical or public health traditions.

Having defined societal conditions in this manner, public health can act by working directly to promote and protect human rights, through many forms of advocacy, data collection and analysis, policy development, and community organization. Viewing the contribution of societal factors to vulnerability to HIV/AIDS through a rights perspective disaggregates the societal issues into discrete elements—such as promoting the right to information, or equal rights in marriage—which are amenable to concrete actions at local and national levels. The goal of combined HIV risk reduction and vulnerability reduction strategies is not to *replace* more traditional public health efforts with a purely human rights approach, but rather to *add* a human rights dimension, and thereby to create a modern public health.

Thus, the most recent phase in the evolving understanding of HIV/AIDS is to see human behavior as a blend of individual characteristics and a societal context best defined by the concepts and the language of human rights. And while, in the mid-1980s, discrimination and other human rights violations directed towards HIV-infected people and people with AIDS were identified as tragic and counter-productive effects of the pandemic, human rights violations are now recognized to be primordial *root causes* of vulnerability to the epidemic. In turn, this has helped catalyze the modern health and human rights movement, which leads far beyond AIDS, for it considers that promoting and protecting health and promoting and protecting human rights are inextricably connected.

How and to what extent the health and human rights approach will be applied in community, national, and global strategies, policies, and programs in responding to HIV/AIDS remains to be seen. Human rights inevitably challenge the status quo—political, economic, social and cultural—and so does AIDS.