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## ESSAY

# HUMAN RIGHTS AND AIDS: THE FUTURE OF THE PANDEMIC

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The central challenge facing HIV prevention efforts today is understanding and learning how to respond, both directly and concretely, to the societal determinants of vulnerability to HIV. Awareness of this need to address directly the societal dimensions of HIV/AIDS has experienced a gradual evolution. As with biomedical research, progress in understanding human behavior in the context of HIV prevention has involved a continuous, often frustrating though occasionally exhilarating, process of discovery.

How society defines a problem determines the manner by which we confront it. Today, we can identify three periods in this history of conceptualization of behavior. During each period, available knowledge and experience produced somewhat different HIV prevention strategies. This Commentary outlines the evolution of HIV prevention strategies as well as the various social fac-

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tors identified as relevant to HIV/AIDS prevention. In addition, this Commentary focuses on the inherent inadequacies of past and current prevention strategies, and offers an approach to HIV/AIDS prevention that focuses upon, and incorporates, the modern movement of human rights.

## I. THE HISTORY AND CURRENT APPROACH TO HIV/AIDS PREVENTION STRATEGIES

### A. *The Three Periods of HIV Prevention Efforts*

The first period began with the discovery of AIDS in 1981,<sup>1</sup> and continued up to, and including, 1984. During this period, a series of epidemiological studies identified routes of spread and behaviors associated with increased risk of infection. Public health acted primarily to alert people about the danger of the new disease and sought to translate epidemiological facts into comprehensible messages for the public. Public information campaigns of unprecedented vigor and boldness sought to inform and often, explicitly, frighten people into at least knowing that AIDS existed. Recall, for example, the central message of the informational program in the United Kingdom: "AIDS: Don't Die of Ignorance." Recall also the awkward and confusing use of the term "bodily fluids" as epidemiology met the mass media.

Uncertainty and urgency combined throughout the first period. In addition to little attention given to a guiding concept of behavior and behavioral change, messages were often disconnected and ad hoc. Though the alert was sounded, little behavioral change ensued.

During the second period, from approximately 1985 to 1988, public health focused on individual risk reduction. The emphasis shifted from alerting individuals about AIDS to the more complex tasks of informing, educating, and providing specific health and social services to help stimulate, support and sustain individual behavior change. Programs were designed with a view, either explicitly or implicitly, of HIV-related behavior as fundamentally individualistic and rational. Therefore, whether based on the Health Belief Model,<sup>2</sup> the Theory of Reasoned Action,<sup>3</sup> or Personal

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1. CENTERS FOR DISEASE CONTROL, *Pneumocystis Pneumonia - Los Angeles*, 30 MORBIDITY & MORTALITY WKLY. REP. No. 21, at 250-52 (June 5, 1981).

2. For a discussion of the Health Belief Model, see Irwin M. Rosenstock, *Historical Origins of the Health Belief Model*, 2 HEALTH EDUC. MONOGRAPHS 329 (1974); see also, Irwin M. Rosenstock, *The Health Belief Model and Prevention Health Behavior*, 2 HEALTH EDUC. MONOGRAPHS 354 (1974).

3. For a discussion of the Theory of Reasoned Action, see Martin Fishbein & Susan E. Middlestadt, *Using the Theory of Reasoned Action as a Framework for Understanding and Changing AIDS-Related Behaviors*, in PRIMARY PREVENTION OF AIDS: PSYCHOLOGICAL APPROACHES 93-110 (Vickie M. Mays

Self-Efficacy,<sup>4</sup> preventive interventions focused on information and education, on counseling and other psycho-social support, and on teaching skills for sexual negotiation and condom use. In accordance with this understanding and approach to behavior, providing information, education and health services to individuals at risk became the central mission of national AIDS programs, which the World Health Organization fostered as part of its Global AIDS Strategy. This relatively traditional public health approach was the foundation of the unprecedented global mobilization of the mid-to-late 1980s.

The World Health Organization added a radically new element to this traditional formulation, namely information/education plus linked health and social services. Based on field experience, the Organization declared that coercion and discrimination towards HIV-infected people and people with AIDS undermined and reduced the effectiveness of HIV prevention programs. For example, wherever rumors spread that HIV testing facilities were providing lists of HIV-infected people to governments, participation in HIV-testing declined precipitously. Conversely, where HIV testing facilities instituted anonymous testing, thus explicitly guaranteeing, rather than merely promising confidentiality, participation in HIV-testing and counseling activities by those at greatest risk of HIV increased. Thus, the World Health Organization developed a "public health rationale" for preventing discrimination towards those infected with HIV.

The public health rationale was a pragmatic step and did not reflect any ideological or philosophical commitment to human rights per se, but arose rather from an appreciation for the instrumental value of respecting the rights and dignity of already HIV-infected and ill people. In this sense, discrimination was seen as a tragic and counterproductive side-effect or result of the pandemic. In any event, for the first time in history, preventing discrimination towards those affected by an epidemic became an integral part of a global strategy to prevent and control an epidemic of infectious disease.

Finally, in the third period, beginning in the context of a steadily expanding and intensifying global epidemic in 1988, increasing efforts emerged to add and integrate a societal dimension with the previous individually-centered, risk reduction approach. The concept of vulnerability, or focusing on constraints and barriers to individual control over health, has been central to this effort. The vulnerability analysis considered the larger, societal contextual factors such as political, social, cultural and economic consid-

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et al. eds., 1989).

4. For a discussion of the Personal Self-Efficacy theory, see Albert Bandura, *Self-Efficacy: Toward a Unifying Theory of Behavioral Change*, 84 PSYCHOL. REV. 191 (1977).

erations. These factors, of course, clearly influence individual behavior and decision-making. While this period witnessed a salutatory shift from a nearly exclusive focus on individual risk reduction towards an increasing concern with societal issues, public health has had great difficulty going beyond the stage of simply listing a broad range of contextual factors and influences.

### *B. The Future of the Pandemic: A Fourth Period*

The difficulty in moving forward in understanding why, how, and in what ways a societal dimension can and must be added to HIV prevention, reflects the combined and interconnected influences of the traditional public health paradigm and its core science: epidemiology.<sup>5</sup> Epidemiology is a powerful tool, though it has important underlying assumptions and limits. Applying classical epidemiological methods to HIV/AIDS ensures, even pre-determines, that "risk" will be defined in terms of individual determinants and individual behavior. Epidemiology has thus far failed to develop models and methods suited to discovering the societal dimensions which strongly influence and constrain individual behavior.

It was natural for public health to turn to epidemiology to describe the scope and distribution of infection and for discovery of routes of transmission. However, the direct translation of epidemiological data on risk behavior to public health, defined exclusively in individual terms, results inevitably in activities focusing on individuals in order to influence their risk-taking behavior. This is accomplished through information, education and services. Thus, we have the traditional public health approach: to consider diseases as dynamic events occurring within an essentially static social context. The reliance on classical epidemiology virtually ensures that this vision of disease and society will predominate.

The work of designing and implementing relatively traditional public health programs in order to assist individual risk-reduction has been an enormous task. When focusing upon the positive, there is evidence from a range of settings worldwide that when implemented with care, sensitivity, and community involvement, the combination of information, education, and health services can substantially slow HIV spread. Indeed, such programs among injection drug users, sex workers, gay men, and heterosexual women and men, have been as successful, if not more successful, than any other public health efforts relying on behavior change. Focusing on the positive, however, does not represent the complete picture. Unfortunately, neither the scope, comprehensiveness, nor effectiveness of traditional HIV prevention programs

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5. Epidemiology is the branch of medicine that focuses upon detecting the sources and underlying causes of epidemics in a society.

have been optimal. Many people today still do not have access to these programs. Moreover, many programs do not provide the necessary services, nor provide them in a useful and appropriate manner.

Worldwide experience demonstrates that while the HIV risk-reduction approach is necessary and useful, it is not sufficient to control the pandemic. Though it has worked well for a few people, it has been somewhat helpful for many, and yet not very helpful for most. The focus on individual risk reduction was simply too narrow, for it was unable to deal concretely with the live, social realities of women, men and children around the world. For several years now, it has been clear to everyone working on AIDS that simply continuing to do what has thus far been done, albeit necessary, useful and important, cannot bring the pandemic under control.

Faced with this painful situation of knowing that what we have been doing is necessary but clearly not sufficient, public health efforts in AIDS have reached a crossroads. One path leads us to those who have tacitly agreed to accept the inherently limited approach and its consequences. We can see the subtle tendency to accept current limits appear in many ways. For example, in the United States, the fact that forty to eighty thousand people will become newly infected with HIV each year is deemed acceptable. As incidence figures plateau or even decline, there is increasing talk of "endemic" AIDS, thus taking advantage of the calming effect of leaving the word "epidemic" behind. Moreover, the slow slide into complacency takes an academic direction. For example, some debate endlessly whether this or that wording on a brochure or in a television spot will be best. In the end, we thereby focus on something we can deal with, rather than facing the threatening reality of an expanding, intensifying, still dynamic and volatile epidemic.

Others, however, are taking a different path at the crossroads. Resisting the traditional public health tendency to learn to accept certain levels of preventable disease, disability and premature death as the "normal background," they reject the idea that we can do no more. They refuse to accept the unacceptable. They are exploring ways forward, and asking "what would need to be done to uproot the pandemic?"

This is precisely where we stand today. Can we find ways to deal concretely with the broader, societal factors that constrain, and influence to an enormous extent, individual behavior? Vulnerability to HIV reflects the extent to which people are, or are not, capable of making and effectuating free and informed decisions about their health. Therefore, a person who is able to make and effectuate free and informed decisions is least vulnerable. Conversely, the person who is ill-informed, and with quite limited

ability to make and/or carry out decisions freely arrived at, is most vulnerable. How, or more precisely, *through which conceptual prism*, can we best identify and act positively upon the factors, beyond the individual, which constrain, limit, and interfere with the making and carrying out of free and informed choices about behavior? What are the societal preconditions for reducing vulnerability to HIV? The following analysis offers an overview and answers some of these difficult questions.

## II. THE INHERENT DIFFICULTIES OF HIV/AIDS PREVENTION PROGRAMS

### A. *Traditional Relevant Factors*

Thus far, in many places a variety of social factors have been identified as relevant to HIV/AIDS prevention. These can be grouped roughly into three categories: (1) political and governmental; (2) socio-cultural; and (3) economic. Political factors include the inattention or lack of concern about HIV/AIDS, as well as governmental interference with the free flow of complete information about HIV/AIDS. Socio-cultural factors involve social norms regarding gender roles and taboos about sexuality. Economic issues include poverty, income disparity, and the lack of resources for prevention programs.

Once identified, these contextual factors become potential objects of focused public health work and activism by non-governmental organizations. Thus, specific governmental actions have been challenged, specific social norms have been highlighted and opposed, and many have pointed to economic constraints on successful HIV prevention work. Nevertheless, the efforts thus far to deal directly with these societal factors influencing HIV prevention have several important, limiting characteristics.

First, the prevention efforts are usually focused exclusively on the HIV/AIDS issue. These efforts may involve challenges to proposed regulation requiring mandatory HIV testing, discrimination against gay men in the context of HIV and insurance, or the lack of resources to sustain successful HIV prevention programs. Second, this work lacks a coherent conceptual framework to describe and analyze the nature of the societal factors. The economist, political scientist, anthropologist, and social scientist all have their disciplinary perspectives. As a consequence, there is no consistent and accessible vocabulary to speak of and compare societal factors in situations arising in very different social, cultural and political contexts.

What commonalities can be identified regarding the vulnerability of commercial sex workers in India, injection drug users in the United States, street children in Brazil, and adolescents in sub-Saharan Africa? Without a coherent conceptual understand-

ing and vocabulary, only the differences and local particularities can be seen. The current approach to the societal determinants of HIV vulnerability is essentially tactical, rather than strategic. There is no common understanding, let alone consensus, about the ways in which the societal factors should change to better promote and protect health.

Consequently, the societal-level work carried out thus far, while courageous and creative, remains inherently limited in its scope, applicability and impact. It has become clear that a deeper understanding of the societal nature of the pandemic and the societal pre-conditions for HIV vulnerability is now required. To this end, insight can be derived from two lines of evidence: the evolution of the pandemic and the inherent limitations in the existing HIV prevention approach.

### *B. The Evolution of the Pandemic*

A meta-analysis of the evolving HIV epidemics in countries around the world has revealed a feature of the pandemic which was previously unknown, unknowable and hidden. The history of AIDS has shown that HIV can enter a community or country in many different ways. In each country, where HIV enters clearly defines the early history of the epidemic.

In the United States and France, white gay men were first noted to be affected. In Brazil, by contrast, the first cases occurred among members of the "jet set" in Rio de Janeiro and Sao Paulo. In Ethiopia, AIDS was initially noted among the social elite. With the passage of time, and as the epidemic matures, it evolves and moves along a clear and consistent pathway, which although different in its details within each society, nevertheless has a single, vital, common feature. In each society, those people who, before HIV/AIDS arrived, were marginalized, stigmatized and discriminated against, became over time those at highest risk of HIV infection.

Regardless of where and among whom the epidemic may start, the brunt of it gradually and inexorably turns towards those who bear this societal burden. Thus in the United States, the epidemic has turned increasingly towards "minority" populations in inner cities, injection drug users and women. In Brazil, the HIV epidemic now rages through heterosexual transmission in the favelas around Rio and Sao Paulo. In Ethiopia, HIV is concentrated among the poor and dispossessed. The French have a simple term which says it all: HIV is now becoming a problem mainly for *les exclus*, the "excluded ones," living at the margin of society.

### *C. Inherent Limitations on Existing Prevention Efforts*

The second source of insight about the societal dimensions of HIV prevention arises through a detailed analysis of limits and

failures in existing prevention programs. To illustrate, married and monogamous women who receive the normal benefits of HIV prevention programs, including distribution of information, education, access to testing and counseling, and condom availability, may nevertheless be at risk of HIV infection. Indeed, in some countries, being married and monogamous is considered a "risk factor" for HIV infection. To understand this apparent paradox one must appreciate the real-life situations facing women.

Consider, for example, the recommendations given to both women and men to reduce the number of sexual partners, as part of risk-reduction approaches. Yet, as many have pointed out, this recommendation fails in the real world for several reasons. First, the risk to many women is related to the sexual behavior of their partner. Second, having multiple partners may be necessary for survival. Finally, women may often lack control over their sexual relationships. In marriage, the pervasive threat of physical violence or divorce, without legal recourse or legal rights to property, may totally disempower a woman. This can happen despite being educated about AIDS, even if condoms are available, and even if the woman knows her husband is HIV-infected. Clearly, therefore, the central issue is the inferior role and subordinate status of women. The disadvantages created by such a society cannot be addressed through individually-focused information/education or HIV-specific health services.

This is one example among many. Consider gay and lesbian people, commercial sex workers, adolescents whose competence is rarely acknowledged and whose voice is rarely heard in any meaningful way, intravenous drug users, or people living in absolute or relative poverty within each society. This relationship between society, how people are treated within a society, and risk for HIV infection and inadequate HIV/AIDS care, is something that has been "known" for a long time. It has been difficult to speak about, however, for at least three reasons.

First, as mentioned previously, a common conceptual approach and vocabulary was lacking for analysis and action. In the absence of an adequate conceptual framework, only the particular and unique features of each group and place could be seen. Second, members of vulnerable communities and AIDS workers feared that others would misuse these observations about society and AIDS to reinforce the false, yet persistent notion that AIDS is only a problem for the marginalized and thus is no longer a threat to the "general public." Third, many AIDS workers and organizations were reluctant to broaden the debate surrounding AIDS out of concern that limited resources would become too thinly spread.

### III. A NEW APPROACH: FOCUSING UPON HUMAN RIGHTS

To move forward, there must be a mixture of the pragmatic and the theoretical, and a blend of insight and practical experience. Once we have determined that for HIV/AIDS, as for all other health problems, the major determinants are societal, it ought to be clear that since society is an essential part of the problem, a societal-level analysis and action will be required. In other words, the new public health considers that both disease and society are so inter-connected that both must be considered dynamic. An attempt to deal with one, the disease, without the other, the society, would be inherently inadequate.

Fortunately, entirely outside the domain of public health or biomedical science, a series of concepts and a framework for identifying the societal preconditions for health has been developed. The modern movement of human rights, born in the aftermath of the Holocaust in Europe and born of the deep aspiration to prevent a recurrence of government sponsored violence towards individuals, provides AIDS prevention with a coherent conceptual framework for identifying and analyzing the societal root causes of vulnerability to HIV. It also provides both a common vocabulary for describing the commonalities which underlie the specific situations of vulnerable people around the world, and a clarity about the necessary direction of health-promoting societal change.

Modern human rights involves the world's first efforts, necessarily incomplete and partial, to define the societal preconditions for human well-being. For this reason, promotion of human rights is one of the four principal purposes of the United Nations, founded in 1945. The Universal Declaration of Human Rights,<sup>6</sup> adopted by the UN General Assembly in 1948, provides a list of societal conditions considered essential for well-being, peace and health.

The Universal Declaration can be thought of as the trunk of the human rights tree, with the UN Charter as its roots. The two major branches, the two major International Covenants on Civil and Political Rights, and on Economic, Social and Cultural Rights, emerge from and expand upon the trunk with further elaboration through many important treaties and declarations. Two such examples are the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW)<sup>7</sup> and the Convention on the

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6. Universal Declaration of Human Rights, G.A. Res. 71, U.N. GAOR, 3d Sess., art. 17, ¶ 2, U.N. Doc A/810 (1948).

7. Convention on the Elimination of all Forms of Discrimination Against Women, *opened for signature* Mar. 1, 1980, 19 I.L.M. 33 (entered into force Sept. 3, 1981).

### Rights of the Child (CRC).<sup>8</sup>

These documents describe what governments and societies should not do to people -- namely torture them or imprison them arbitrarily or under inhuman conditions. In addition, the documents describe what governments and societies should ensure for all people in the society, namely shelter, food, medical care and basic education. When and where human rights and dignity are respected, there will still be rich and poor, Mozarts and people who cannot carry a tune, but all will be ensured of a basic minimum in which their individual potential can be freely and fully developed.

We propose that, as respect for human rights and dignity is a *sine qua non* for promoting and protecting human well-being, that the human rights framework offers public health a more coherent, comprehensive, and practical framework for analysis and action on the societal root causes of vulnerability to HIV/AIDS than any framework inherited from traditional public health or biomedical science. We propose that promoting and protecting human rights is therefore inextricably linked with our ability to promote and protect health. Clearly, human rights work will obviously not bring to a halt all preventable illnesses or premature deaths. However, the realization of rights and increasing respect for human dignity will reduce or even eliminate the societal contribution, which we know is the major contribution to this burden of disease, disability and death.

What would it mean to incorporate a human rights dimension into HIV/AIDS prevention? It would mean that in addition to everything we already do, we would identify the specific rights whose violation contributes to HIV vulnerability in our particular community or country. It might involve the right to information, or to the equal status of women and men in marriage or its dissolution, the right to medical care, or even to the basic proposition of non-discrimination. Then, we must work with those individuals and groups, whether official, non-governmental, or private, who are already working to promote respect for human rights and dignity within the society.

We concerned about AIDS can add our voice, credibility and knowledge to the work of others to promote rights through education, seeking legal changes, catalyzing awareness, and by monitoring, identifying and drawing attention to human rights problems. It also suggests that helping to educate people about human rights may ultimately be as important, or even more important, for their health than any specific AIDS educational program. However, there is no need to choose one or the other. Both are needed. Human rights work for public health is not a substitute for traditional

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8. Convention on the Rights of the Child, G.A. Res. 44/25, U.N. GAOR, 44th Sess., Supp. No. 49, at 166, U.N. Doc A/44/736 (1989).

public health activities, though it is essential and necessary if we are to refuse the unacceptable about the HIV/AIDS pandemic.

Adding a human rights dimension to HIV prevention work will have major advantages, though it will also create some difficulties. Some major advantages will include acting at the deeper level of societal causes, so as to help *uproot* the pandemic. It will also be linking health issues with the mobilizing power of human rights and expanding the ability of people to see the connection between a "rights issue" and their health. In addition, it will enhance the capacity for cross-disciplinary work which occurs when people can identify a larger commonality of interest. Finally, the result will be revitalizing global thinking within the collective response to HIV/AIDS.

Some potential difficulties, however, will be the inevitable accusation that public health is "meddling" in societal issues which "go far beyond" its scope or competence. In addition, public health workers may be unfamiliar with rights concepts and language. Public health workers may desire to "own" the problem of HIV/AIDS, thereby keeping the discourse at a medical and public health level, thus assuring the pre-eminent role of health workers. Finally, critics may argue that issues of human rights inherently and inevitably put the person concerned with rights potentially "at odds" with governmental and other sources of power in the society.

Thus, as our capacity for understanding the pandemic deepens, so do the challenges of response become ever more difficult. It is clearly easier for public health agencies and organizations to alert the public about HIV/AIDS than to ensure comprehensive services to support individual risk-reduction. Similarly, while quite difficult, it is easier to attack a single AIDS-related political issue than to develop and undertake a human rights based analysis and response to the pandemic.

The history of the response to HIV has demonstrated that we can bring the best of traditional public health together with new societal insights and understanding. This brings us to the threshold of *empowerment*, which is a critical concept not only for others, but also for ourselves. This empowerment rests on two pillars. One is knowledge: an understanding of the importance of societal determinants of health, of the ways in which human rights helps us to analyze and respond to societal deficiencies which underlie vulnerability to preventable disease, disability and premature death. The second pillar is equally critical: the belief, the faith and the confidence that the world can change. This belief, while it may be inspired by historical examples, or fostered by peers and participation in community organization and social movements, is ultimately quite personal. It is not clear exactly how people who have considered themselves powerless may begin to believe in the *possibility of change*, but this step is at the heart of personal and

ultimately, societal transformation. That next step, that possibility for change towards a more human world, will require a "leap of confidence" based on analysis, reflection and hard work. Only we can empower ourselves.

#### CONCLUSION

Once we acknowledge that the goal of public health, beyond HIV/AIDS, is to "ensure the conditions in which people can be healthy,"<sup>9</sup> and recognize the enormous burden of evidence which tells us that societal factors are the dominant determinants of health status, we realize that, ultimately, to work for public health is to work for societal transformation. Linking human rights with health offers us a coherent vision of how to add the critical societal dimension to our public health work which, all too often, has stopped at the threshold of real societal issues.

For this reason, since 1990, all graduates of the Harvard School of Public Health receive two scrolls at Commencement. The first is the degree they have earned. The second is a copy of the Universal Declaration of Human Rights, their common birthright. The Dean reminds graduates that the Universal Declaration of Human Rights is as vital to their future in public health as the Hippocratic Oath, or similar document would be to a medical doctor. In this way, we symbolize the inherent, rich, complex, difficult and ultimately indispensable linkage between society and health, for which we in public health have a special role and responsibility.

I believe it is for this reason that after fifteen years of struggle against a global pandemic, despite the burden of death and illness, those working on HIV/AIDS can carry forward a message of hope and confidence. Not only a confidence in our ability to continue learning and understanding, but a confidence in our belief about the value of human rights and human dignity. This gives us hope and confidence in each other, in ourselves, and ultimately, in our world and its future.

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9. INSTITUTE OF MEDICINE, *FUTURE OF PUBLIC HEALTH* (1988).