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Ronald Bayer

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## COMMENTARIES

### RETHINKING ASPECTS OF AIDS POLICY\*

*Ronald Bayer\*\**

The first cases of AIDS were recognized at the very moment that Ronald Reagan came to Washington. The struggle against AIDS in the United States thus took shape against the backdrop of a conservative political administration. It was that accident of history as much as the nature of the virus that formed the strategies put forward by AIDS activists and public health officials in the most profoundly affected regions of the United States. These strategies were designed to hold at bay those who would have employed repressive measures and to mobilize public support when those in Washington did all that was possible to ignore the threat of HIV, which is the virus that causes AIDS. This Commentary focuses on three elements of that strategy. Because, at that time, HIV/AIDS had most profoundly affected racial, ethnic, and sexual minorities who viewed themselves, and were viewed by others, as beyond the cultural mainstream, it became part of the central thesis of educational efforts for the mass modification of behavior that they should be culturally sensitive. Because the biology of HIV clearly suggested that the epidemiology of AIDS—as an affliction primarily of gay and bisexual men and intravenous drug users—was an accident of history, it was crucial to compel America to recognize the universal threat of the epidemic's spread. Such an approach was especially critical at a moment when neglect, rooted in disregard, if not hatred, of those most at risk dominated official thinking. Finally, with the ever-present threat of the intrusion of a repressive ideology into the framing of public health policy and practice, it became imperative to assert that good public health was apolitical, above the fray. This was especially so when conservative political advocates at-

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\*\* Ph.D. 1976, University of Chicago; Professor, Columbia University School of Public Health.

tacked the unique set of policies shaped at the local level in response to the AIDS epidemic.

But strategies and their rationales may have become ossified. If the efforts to contain the spread of HIV are to be effective, it is essential to confront the rigidities of thought that have emerged over the years.

That is a task especially appropriate to undertake in an essay written in honor of Margaret Somerville. No one who has worked with her or who has listened to her can miss her special capacity to pierce the cant that too often passes as analysis in public discourse, to pose questions that may create discomfort, to propose solutions that may unsettle the status quo. With her very special grace and quality of mind, she has made a singular contribution to the discussion of a broad set of ethical, legal, and policy issues posed by medicine, including AIDS. With that in mind this Commentary takes up three questions posed by AIDS policy, questions that must be addressed if efforts at AIDS prevention are to be effective. The first of these questions touches on matters that are relatively circumscribed; the last raises issues of a global dimension.

- Is it true that effective AIDS education must and should be culturally sensitive?
- Is it true that we are all equally at risk for HIV infection, and that prevention policies should be broadly based, rather than targeted?
- Is it true that sound public health policy should be founded on a radical disjunction between science and politics?

#### I. HIV PREVENTION AND CULTURAL SENSITIVITY<sup>1</sup>

It has become a matter of conventional wisdom that AIDS prevention programs should be culturally sensitive. Repeated in almost talismanic fashion, the call for cultural sensitivity is heard from podiums, in testimony before governmental bodies, and in the journals. But is it true?

Two arguments are typically made on behalf of the centrality of cultural sensitivity. The first is instrumental and pragmatic; the second is ethical and political. The pragmatic-instrumental claim is that HIV prevention efforts which are not culturally sensitive will be ineffective. Therefore, such efforts will fail to promote, support, and sustain the behavioral modifications that are the *sine qua non* of AIDS prevention.

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1. This discussion is drawn from a more detailed analysis located in Ronald Bayer, *AIDS Prevention and Cultural Sensitivity: Are They Compatible?*, 84 AM. J. PUB. HEALTH 895 (1994).

They will fail to do so because they will not reach their intended audience, will not be understood by those who are reached, will not be accepted by those who understand. Indeed, such efforts may provoke outright opposition.<sup>2</sup>

A second claim on behalf of the cultural sensitivity, less often explicitly made, but nevertheless of central importance, is moral and political. The basic principle of ethics: that individuals be treated with respect and that their dignity not be violated, is by extension applied to cultures. Cultural sensitivity is thus required of us by the ethics of pluralism.<sup>3</sup> A failure to respect the cultural integrity of others is almost always characterized as the consequence of the imposition of the values of the dominant and the powerful on the subordinate and marginal. As such, the insistence on cultural sensitivity is premised on an egalitarian ethos, the ethos that should inspire public policy in a multi-cultural democratic society. Employing the concept of neo-colonialism to oppose those who act without regard to cultural sensitivity, the African-American law professor Harlon Dalton notes in his widely read *AIDS in Blackface*,<sup>4</sup> “[w]hen we want help, white America is nowhere to be found. When, however, you decide that we need help, you are there in a flash, solution in hand. You then seek to impose that solution on us, without seeking our views, hearing our experiences, or taking account of our needs and desires.”<sup>5</sup>

What then is meant by cultural sensitivity? It is important to distinguish three very different ways in which the conception is used: the instrumental, the manipulative, the principled. The first two are rooted in the pragmatic arguments for cultural sensitivity. The last is rooted in moral and political claims.

The instrumental conception of cultural sensitivity underscores the importance of conveying AIDS prevention messages in a form that makes the content understandable, a form that uses the linguistic and stylistic features of those to whom it is addressed.<sup>6</sup> Failure to understand the complex ways in which language and culture filter prevention messages is a recipe for failure in AIDS prevention. The importance of understanding the ways in which language is used stems not only from the fact that

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2. Collins O. Airhihenbuwa et al., *HIV/AIDS Education and Prevention Among African-Americans: A Focus On Culture*, 4 AIDS EDUC. PREVENTION 267 (1992).

3. Charles Taylor, *The Politics of Recognition*, in MULTICULTURALISM AND “THE POLITICS OF RECOGNITION” 25 (Amy Gutmann ed., 1992).

4. Harlon L. Dalton, *AIDS in Blackface*, DAEDALUS, Summer 1989, at 205.

5. *Id.* at 218 (emphasis in original).

6. See Meryl Sufian et al., *Impact of AIDS on Puerto Rican Intravenous Drug Users*, 12 HISPANIC J. BEHAVORAL SCI. 122 (1990).

within different cultures different words may be used to describe the same behaviors or things, but that the same words may have different meanings.

According to the instrumental conception of cultural sensitivity what is demanded is that the universalistic and uniform messages of AIDS prevention be packaged in a way that is appropriate for the diverse target audiences. This conception of cultural sensitivity raises few problems from the perspective of public health. Indeed, it has been the decade long efforts on the part of those who have opposed to the use of vernacular or "street language" that have exemplified the hobbling of AIDS prevention messages. In the United States, the imposition of restraints upon the Centers for Disease Control by Congress and the White House and the subsequent imposition of restraints upon local and community AIDS prevention programs have represented a profound corruption of the public health mission in the face of AIDS. It is a corruption defined by the cultural norms of those opposed to homosexuality and non-monogamous heterosexual relations.

The second conception of cultural sensitivity is manipulative. It underscores the importance of understanding the cultural context of sexual, drug using, and procreative behavior in order to facilitate the transformations of those behavioral norms that foster the transmission of HIV infection.

In the literature on both women and ethnic minorities this conception of cultural sensitivity finds repeated expression.<sup>7</sup> Not only is the manipulative conception of cultural sensitivity compatible with the goals of public health, but it also seeks to advance them with a solid grounding in cultural studies and analysis. In so doing it reflects the insights of "social marketing,"<sup>8</sup> which has sought to harness the understanding derived from commercial advertising for the ends of "social betterment." In pursuit of

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7. See, e.g., Vickie M. Mays et al., *The Language of Black Gay Men's Sexual Behavior: Implications for AIDS Risk Reduction*, 29 J. SEX RESEARCH 425 (1992); Gina M. Wingood & Ralph J. DiClemente, *Cultural, Gender, and Psychosocial Influences on HIV-Related Behavior of African-American Female Adolescents: Implications for the Development of Tailored Prevention Programs*, ETHNICITY & DISEASE, Fall 1992, at 381; Janet W. McGrath et al., *Anthropology and AIDS: The Cultural Context of Sexual Risk Behavior Among Urban Baganda Women in Kampala, Uganda*, 36 SOC. SCI. MED. 429 (1993); Larry D. Icard et al., *Preventing AIDS Among Black Gay Men and Heterosexual Male Intravenous Drug Users*, 38 SOC. WORK 440 (1992); Merrill Singer, *Confronting the AIDS Epidemic Among IV Drug Users: Does Ethnic Culture Matter?*, AIDS EDUC. & PREVENTION, Fall 1991, at 258.

8. RICHARD K. MANOFF, SOCIAL MARKETING (1985).

public health goals, social marketing must identify, in order to overcome, so-called cultural "resistance points" so that "awareness" may be converted into "practice." Ever-popular with public health experts, it is this conception of cultural sensitivity that has drawn the ire of libertarians like Patricia Illingworth.<sup>9</sup>

The third conception of cultural sensitivity represents a radical departure from the two thus far discussed. While they seek to overcome the cultural barriers to public health intervention, the third, which is the principled conception of cultural sensitivity would, serve to prohibit those interventions that violate cultural norms. Respect for the cultural integrity of those to whom public health experts direct their efforts and the moral claims of pluralism provide the foundations for this conception. It is in this strong sense of cultural sensitivity that a profound clash between the goals of public health and the demand that public health interventions respect the cultural integrity of groups finally becomes clear. Indeed, the clash is inherent in the broadly understood ends of HIV prevention, which require fundamental changes in sexual and drug using behavior, and the norms that inform and structure such behavior.

Three brief examples will serve to underscore the fissure between the norms of public health and the demand for cultural sensitivity in the principled sense of the term.

In recent years, some public health officials and almost all AIDS activists called for the provision of condoms and condom education to high school students among whom sexual activity poses a risk of HIV transmission. Endorsed by those who adhere to liberal, secular values, these efforts to undertake such condom programs faced fierce resistance not only from political conservatives, but most importantly from many working class and lower middle class parents. Bolstered by the Roman Catholic church and fundamentalist Protestants, local community groups viewed condom programs as an assault on parental prerogatives and the values of their own communities. These groups have sought to defend against secularism their moral/religious views of appropriate sexual behavior among their children. As a member of the New York City School Board representing the lower middle class district of Staten Island asserted, "There is no way in this city, in these United States that someone is going to tell my son he can have a condom when I say he can't."<sup>10</sup>

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9. See generally Patricia Illingworth, *Review Essay*, 4 *BIOETHICS* 340 (1990) (reviewing RONALD BAYER, *PRIVATE ACTS, SOCIAL CONSEQUENCES* (1989)).

10. *CONDOMS IN THE SCHOOLS* (Sarah E. Samuels & Mark D. Smith eds., Henry J. Kaiser Family Foundation 1993).

In the face of such opposition was the obligation of public health officials to seek to protect the boys and girls whose lives were placed at risk by their sexual behavior. Or were they obligated to respect the culture of the parents who so opposed them? That ACT-UP has been in the forefront of condom distribution efforts on school grounds, even when school or health department officials demonstrated reluctance, timidity, or non-commitment, demonstrates that the challenge to cultural sensitivity may come not only from the authorities, but from AIDS activists imbued with a sense of mission as well.

There was, of course, also the case when ACT-UP and other AIDS activists confronted the timid resistance on the part of officials fearful of conservative politicians and the outrage of the African-American community on the matter of providing sterile injection equipment to intravenous drug users. Since the early 1980s, public health officials recognized the critical role of needle sharing among intravenous drug users, and from the mid-1980s an increasing number of public health experts argued that the creation of sterile needle exchange programs could play an important role in inhibiting the spread of HIV infection.<sup>11</sup> That those associated with the Reagan and Bush administrations, a conservative political posture, and law enforcement would oppose such efforts can come as no surprise.<sup>12</sup> More troubling, even startling, was the fierce opposition of the leadership of the black community<sup>13</sup>—ministers, physicians, politicians—that saw needle exchange as one more experiment visited upon powerless African Americans, resonating with the infamous Tuskegee Syphilis Experiment, or as threatening whatever fragile efforts existed to prevent drug abuse. The black community denounced such efforts as genocidal.

Should public health officials have acceded to the concerns of the African-American community, respecting its culturally informed weighting of the risks and benefits of needle exchange, or should they have pressed vigorously to challenge the cultural resistance to such efforts and the political forces that gave it expression? When public health officials failed to overcome the black community's opposition should they have acknowledged defeat and sought conciliation, or should they have proceeded to impose needle exchange through the exercise of their political

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11. See generally RONALD BAYER, *PRIVATE ACTS, SOCIAL CONSEQUENCES: AIDS AND THE POLITICS OF PUBLIC HEALTH* (1989).

12. See generally David L. Kirp & Ronald Bayer, *The Politics*, in *DIMENSIONS OF HIV PREVENTION: NEEDLE EXCHANGE* 77 (Jeff Stryker & Mark Smith eds., 1993).

13. Stephen B. Thomas & Sandra Crouse, *Understanding the Attitudes of Black Americans*, in *DIMENSIONS OF HIV PREVENTION: NEEDLE EXCHANGE*, *supra* note 12, at 99.

power and authority, hoping that the unified opposition to needle exchange would either splinter or wither?

A third example: those committed to inhibiting the heterosexual transmission of HIV infection have come to recognize the necessity of a fundamental change in the culturally embedded relations of power between men and women. Indeed the literature on HIV prevention increasingly asserts that the "empowerment" of women is essential if heterosexual transmission is to be limited. Such empowerment is necessary if women are to gain control over the conditions under which they engage in sexual intercourse. In short, AIDS prevention is viewed as requiring a rupture in the cultural norms that define the status of women as subordinates, that define the very nature of their relationships to their sexual partners.

In this instance as in the others discussed above, it is clear that acceding to the demands of cultural sensitivity, in the principled sense of the term, is not only a prerequisite of effective public health practice, but would also be inimical to the goals of HIV prevention.

Certainly it is necessary to recognize cultural differences and differences in linguistic styles as HIV prevention efforts are fashioned. Crucial, too, is an understanding of the cultural barriers to HIV prevention. In the face of such barriers it is, of course, desirable to reach for understanding, to persuade, even to cajole. Diktat and Ukase are to be avoided when possible. This is so in the case of the cultural norms of dominant social groups because of their capacity to politically thwart the efforts of those committed to AIDS prevention. This is so in the case of social and ethnic minorities, as well as those whose beliefs place them beyond the mainstream, because impositions from above can mortify and humiliate.

But in the end no strategy of effective AIDS prevention can be limited by the demand that the cultural barriers to behavioral change be respected. There is here an irony: the demand for cultural sensitivity in the instrumental and manipulative senses—the two weakest senses—raises few problems from the perspective of public health. The demand for cultural sensitivity in the principled and strongest sense, the sense that compels us to think carefully about the political and moral warrant for public health intervention, is, ultimately, incompatible with the goals of AIDS prevention. Candor and intellectual integrity demand that homilies on cultural sensitivity be replaced by a forthright acknowledgment that we cannot at once see the goal of public health in terms of radical normative change while adhering to a principle that can only serve to protect the status quo.

## II. HIV PREVENTION AND THE TARGETING DEBATE

Are we all equally at risk of HIV infection? If not, what are the implications for policy? On February 4, 1993, the National Research Council released a report entitled *Social Impact of AIDS in the United States*.<sup>14</sup> To the surprise of its authors, the report, which they viewed as uncontroversial, became the subject of an important debate. That debate had two interrelated dimensions: the first focused on the characterization of the AIDS epidemic's impact on the United States epidemiologically and socially; the second focused on the need to reconceptualize AIDS prevention policy in the light of the concentration of AIDS in a relatively small number of locales. The former dimension was an explicit aspect of the report; the second dimension emerged after the report's publication and was not a feature of the report's conclusions.

*Social Impact* noted that, despite the tragic cost in human life, the AIDS epidemic had not had a major impact on the institutions of American life. It explained this striking fact by stating that the "limited responsiveness of institutions [to the AIDS epidemic] can in part be explained because the absolute numbers of the epidemic, relative to the U.S. population, are not overwhelming, and because U.S. social institutions are strong, complex, and resilient."<sup>15</sup> More important, however, was the "concentration of the epidemic in socially marginalized groups."<sup>16</sup> Although AIDS spared no region of the country, "many geographical areas and strata of the population are virtually untouched by the epidemic and probably never will be; certain confined areas and populations have been devastated and are likely to continue to be."<sup>17</sup> The report concluded with a dire prediction: "HIV/AIDS will 'disappear' not because, like smallpox, it has been eliminated, but because those who continue to be affected by it are socially invisible, beyond the sight and attention of the majority population."<sup>18</sup>

Despite the care with which this analysis was prepared, it provoked an outraged response. Based mostly on a misreading—or more commonly—a nonreading of the report—many AIDS advocates denounced *Social Impact* as a way of minimizing the suffering of gay men, intravenous drug users, and people of color in the nation's ghettos. In San Francisco, one

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14. THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES (Albert R. Johnson & Jeff Stryker eds., 1993).

15. *Id.* at 7.

16. *Id.*

17. *Id.*

18. *Id.* at 9.

commentator summed up his understanding of the report with the headline "National Research Council to Gays and Minorities: Drop Dead." Why would the National Research Council's characterization of the epidemiological trends and its prediction provoke such a response? It is clear that there was a great fear that, if Americans came to believe that AIDS no longer threatened every hamlet and every citizen, the fragile political basis for the support of AIDS prevention and research would be shattered. Only through universalizing the threat of AIDS could the needs of those who were truly vulnerable be met. Underscored here, in a stark way, was the complex question of the appropriate relationship between epidemiology and public policy, between science and politics. It is that theme that informed the second dimension of the controversy surrounding the report itself. In brief, the controversy centered on the question of whether an undifferentiated strategy for dealing with the AIDS epidemic—one that in some ways suggested universal vulnerability—entailed a misallocation of resources and effort. As John Gagnon noted:

[T]he Government's resources are aimed scattershot at the epidemic. This policy results from a misunderstanding of where the epidemic has been and where it is going. In California, where 80 percent of people living with AIDS are gay men, only 10 percent of prevention dollars are spent on gay men . . . . We need to recognize that the AIDS epidemic is actually a number of micro-epidemics. Prevention and treatment both require an approach tailored to the particular needs of those afflicted.<sup>19</sup>

What followed was a need to develop an intensive effort focused on those communities where the HIV epidemic had taken root. Among those pitted against each other in the controversy were two leading members of the National AIDS Commission, Dr. Don Des Jarlais, the expert on drug abuse, and Dr. June Osborn, the Commission's well-known Chair. The former favored targeting that the latter bitterly opposed. Indeed in an editorial published by the *Journal of the American Medical Association*, June Osborn and her co-Chair Dr. David Rogers charged that the NRC's report as well as the proponents of targeting were "subtly encourag[ing] . . . the virus' spread through all segments of our society."<sup>20</sup> They lamented it as a "cruel influence" and "truly painful setback" for responsible public policy.<sup>21</sup>

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19. John Gagnon, *Losing Ground Against AIDS*, N.Y. TIMES, Jan. 6, 1994, at A21.

20. David E. Rogers & June E. Osborn, *AIDS Policy: Two Divisive Issues*, 270 JAMA 494, 494 (1993).

21. *Id.*

The debate in the United States mirrors controversies that have surfaced in Holland<sup>22</sup> and Australia. In each case the conflict has engaged epidemiologists, AIDS activists, and sometimes politicians as well. Clearly, the debate about targeting rests upon conflicting epidemiological views of the current state of the HIV epidemic and the most likely course of the epidemic in the future. Is the current pattern of new infections highly centralized in geographically identifiable centers, or is a pattern of diffusion occurring which makes the epidemic more general? Even if agreement could be reached on the current state of the epidemic, it is inevitable that there will be important degrees of uncertainty about the future.

Crucial ethical and policy issues are posed by the targeting debate. Does current AIDS prevention policy suffer because of a "scatter shot approach," one that is not epidemiologically grounded? Are those most at risk for HIV infection poorly served by current approaches? Would a shift toward a more targeted approach place those at risk outside current centers of HIV infection? Would a more targeted approach to prevention foster stigmatization? And, most important, would targeting weaken the delicate political alliance that currently supports HIV prevention and research?

The issues are, of course, critical not only for policy in North America, but in our relationship to the Third World, where the brunt of AIDS is being and will be felt. There was a time when one could speak about a world united against AIDS. We were united in our common dread, united in our common therapeutic impotence, united in our common uncertainty of the epidemiological course that HIV would take. Given that shared condition, we could also hope to forge a common political commitment. Much has changed and that change stems, in part, from the fact that because of therapeutic achievements, the experience of AIDS in the Third World and in the wealthy North are now very different. But, more important, while the epidemiological trajectory of HIV infection in Asia and Africa remains tragically steep, a plateau appears to have been reached in North America and Western Europe. When James Chin first pointed this out some years ago, his remarks were greeted with dismay by some, in part, because it suggested a diminution of the threat to the advanced in-

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22. Jan K. van Wijngaarden, *The Netherlands: AIDS in a Consensual Society*, in *AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS, AND POLICIES* 252 (David L. Kirp & Ronald Bayer eds., 1992).

dustrial countries; in part because it suggested a loosening of the bond between those nations and the Third World.

How committed would the rich nations be to AIDS research, and to AIDS prevention, as the disease became a disease of the "other." Would whatever fragile political basis of support for international solidarity be weakened, even shattered?

There is no reason to be optimistic here. Recall that one-third of the world's population is infected with mycobacterium tuberculosis (TB), that worldwide there are eight million TB cases a year, and 2.9 million deaths.<sup>23</sup> How many of us gave much thought to TB, a disease primarily affecting Africa and Asia until the resurgence in North America began in the mid-1980s?

My point here is that a recognition of the focal nature of the AIDS epidemic may, in fact, shatter the fragile political bond that supports AIDS-related work, and yet without a recognition of the focal nature of AIDS, we may witness a failure to target scarce resources appropriately. The ethical and policy conundrum is made even more complex by the fact that a failure to acknowledge the focal nature of the epidemic would involve a public health equivalent of scientific fraud; fraud which time will make apparent, thus provoking a profound political response on the part of those who will feel that they had been manipulated.

### III. HIV EXCEPTIONALISM AND THE POLITICS OF PUBLIC HEALTH<sup>24</sup>

With good reason, those concerned about an effective public health response to AIDS have also been concerned about political intrusions reflective of moralistic antihomosexual biases. As a consequence, there has been a tendency to characterize public health in apolitical terms. But is it true that good public health practice should be above politics?

A common set of questions confronted all democratic societies as they were faced with the HIV epidemic in the early 1980s. How would the out-of-the-ordinary threat of a lethal infectious disease be met? How would historical policies on the treatment of sexually transmitted diseases and communicable disorders be applied? Would HIV be incorporated into the standard policy perspective or would AIDS be treated differ-

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23. Barry R. Bloom & Christopher J.L. Murray, *Tuberculosis: Commentary on a Reemergent Killer*, 257 *SCIENCE* 1055, 1056 (1992).

24. This discussion is in part drawn from my more extended discussion in Ronald Bayer, *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?*, 324 *NEW ENG. J. MED.* 1500 (1991).

ently? If it were to be treated differently, what would justify such treatment?

To understand the significance of these questions, one must recall that conventional approaches to public health threats were typically codified early in this century or in the latter part of the Nineteenth Century; that they generally entailed provisions for mandatory screening; that they often entailed statutory provisions for the abrogation of patient confidentiality; that they established conditions under which those who posed a risk to the public health could be confined—the power of isolation or quarantine.

In the face of the AIDS epidemic, this tradition of public health—rarely enforced in recent decades because of changing patterns of morbidity and mortality, the emergence of effective clinical alternatives, and changed conceptions of the rights of individuals—was viewed as posing a threat to those who were committed to protecting civil liberties and privacy. Many feared that the social anxiety provoked by the AIDS epidemic would provide the circumstances for the reestablishment of a regime of control in the name of public health. What is most remarkable about the course of the public policy debates in advanced democratic societies was how such fears were confronted; how the question of whether AIDS should be treated like other communicable and sexually transmitted diseases was answered.<sup>25</sup>

In each country there have been public health traditionalists typically, though not always, associated with the right wing of the political spectrum who have argued that the laws on sexually transmitted and infectious diseases should apply to AIDS because it is both sexually transmitted and infectious. In Germany, this perspective was most forcefully pressed by the conservative Christian Social Union in Bavaria.<sup>26</sup> In Sweden, however, it was the perspective of the Social Democrats.<sup>27</sup> (But even these traditionalists are to be distinguished from those who, in the name of public health, favored a policy of absolute control—a posture adopted by the politically paranoid LaRouche movement in the United States and Jean Marie Le Pen's xenophobic National Front in France).<sup>28</sup>

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25. van Wijngaarden, *supra* note 22.

26. Guenter Frankenberg, *Germany: The Uneasy Triumph of Pragmatism*, in *AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS, AND POLICIES*, *supra* note 22, at 99.

27. Benny Henriksson & Hasse Ytterberg, *Sweden: The Power of the Moral(istic) Left*, in *AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS, AND POLICIES*, *supra* note 22, at 317.

28. Monika Steffen, *France: Social Solidarity and Scientific Expertise*, in *AIDS IN THE*

Opposing the public health traditionalists were gay leaders, civil libertarians, clinicians, and many public health officials who argued that AIDS was so different that it required policies unlike those conventionally applied to public health threats. Because AIDS was incurable and required difficult modifications in the most intimate behaviors, a new approach to prevention was required—one that avoided all of the trappings of coercion and control historically associated with public health.

A voluntarist consensus emerged to inform public policy decisions. The strategy for AIDS prevention was to reflect the proposition that the defense of public health was not dependent upon the abrogation of civil liberties and privacy, but, rather, was dependent upon the protection of such liberal values. A failure to recognize the importance of such values would have the counterproductive consequence of “driving the epidemic underground.” “HIV exceptionalism” became the benchmark of enlightened public health policy in democratic nations.

That the very concept of HIV exceptionalism provoked an outraged response from those committed to intellectual orthodoxy in the United States is a striking illustration about how conventional thought can cripple the capacity for critical inquiry. Descriptive rather than prescriptive, the concept of exceptionalism was designed to illuminate a fault line in policy, not to urge a course of action. And yet this is what one critic had to say:

The argument has [been put forth] that so-called AIDS exceptionalism [has] triumphed over so-called standard public health and that much evil flowed from that unfortunate divergence? That outraged me! As a prime perpetrator of what was being called “AIDS exceptionalism” let me make several comments. First, there is no such school of public health thought. There is a school of thought—to which I and most other public health people in the world subscribe—that says that we should use our best science in the interest of public health, and that in the light of new knowledge (new virology, new epidemiology, new behavioral science insights, new health education approaches) we should use our very best strategies to curtail a deadly epidemic at the earliest moment. To use quarantine or frightening mandatory approaches to try to affect private, personal behavior over the ten-year silent interval of HIV infection would be as archaic as trying to march regiments of redcoated troops in

nineteenth century formation up Pork Chop Hill in Vietnam!<sup>29</sup>

Why this response? In large measure it stems from the fact that to acknowledge that AIDS had been treated differently and that AIDS policy, in a remarkable way, represents the success of efforts on the part of the gay community and its political allies, would open the way to the charge that the public health had been sacrificed to special interests. To acknowledge, furthermore, that exceptionalist policies were the product of the mobilization of political influence and hard work would entail, some feared, an admission to the charges made by the most conservative political forces.

Public health policy is always the outcome of factors beyond the narrow application of professional practice. In the early days of the AIDS epidemic this was clearly the case. As the epidemic has matured and as attention has begun to shift toward intravenous drug users and their sexual partners, the initial influence of those whose broad political and social concerns drove them to press for an exceptionalist perspective has begun to wane. Public health officials have begun to assert the relevance of their own professional traditions. Hence, the practices that represent the repertoire of traditional responses to epidemic disease have begun to regain legitimacy.

Second, in almost every western country recent epidemiological studies have suggested that estimates of the level of HIV infection made in the mid-1980s were overstated. Furthermore, the failure of the epidemic to spread rapidly beyond those groups first identified as being at increased risk, gay and bisexual men, intravenous drug users and their sexual partners and children—the failure, in short, of a general heterosexual epidemic—the great fear of 1986—to materialize—has made the epidemic appear less awesome. As AIDS has become less threatening, more “normal,” the claims of those who had argued that it was so different that it required exceptional policies have begun to lose their force.

But most important was the impact of the radically changing perspective on HIV disease that followed on the advances in therapeutic prospects. The sense of impotence of physicians began to yield, and a sober optimism began to replace the fatalism of the early years. The prospects for better management of HIV-related opportunistic infections and, until recently, hopes of slowing the course of HIV progression itself through

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29. June E. Osborn, Unpublished Lecture, delivered at the Harvard University School of Public Health (confirmation on file with the J. CONTEMP. HEALTH LAW & POL'Y). See also Michael T. Isbell, *AIDS and Public Health: The Enduring Relevance of a Communitarian Approach to Disease Prevention*, 8 AIDS & PUB. POL. 157 (1993).

early clinical prophylaxis led physicians to argue increasingly for the "mainstreaming" of AIDS and for the critical importance of early identification. The necessity of early identification—with obvious implications for policies on HIV screening and contact tracing—had a profound ideological impact on how AIDS was viewed.

It is, of course, impossible to predict the precise form that AIDS policy will take in economically advanced democratic nations in the next few years. But what is clear is that the effort to treat HIV as fundamentally different from all other public health threats may well be viewed as a relic from the epidemic's first years, when so little was understood and so little could be done for those who bore the burden of infection. Either AIDS will be treated in the way other sexually transmitted diseases have historically been treated, or those broader policies will change to reflect the important lessons learned from dealing with AIDS. But the era of AIDS exceptionalism that so marked the epidemic's first decade is coming to an end.

To those who view the changes now occurring as terribly mistaken, it is common to argue that politics has usurped the position of public health. From that perspective, the balances struck in the epidemic's first decade were the consequence of rational apolitical choices. Although it would be impossible for the proponents of this viewpoint to claim that there were no political pressures exerted in the AIDS epidemic's first years, they do assert that it was a politics designed to hold at bay those who would have fostered irrational public health policies. In short, they claim that theirs was a politic in the service of an apolitical scientific public health.

Deeply divided as they are, the antagonists share a common perspective on the nature of public health. Each claims that good public health is scientific, that it exists above politics. As each side seeks to appropriate the mantle of a supra political public health, each seeks to tar the other with the brush of politics.

Both are wrong. In the struggle to shape an effective public health strategy in the face of AIDS—one that perforce had to confront the tension between the individual and the collective—it was inevitable that political choices had to be made. It is inevitable that such choices will have to be made again in the future. In this view, the task before us is not to banish political considerations from public health. Rather, it is to assure that the political choices we make will be compassionate, protective of the interests of the weak or powerless, effective, compatible with the broad traditions of liberalism, and wise. But the most profound political

challenge to be faced in the next years will center not on the topics of such deep concern primarily to those who live in the United States and other liberal, wealthy nations; it will, rather, concern our relationship to the Third World.

How will we deal with the massive suffering, disease, and death caused by HIV infection in Africa, Asia, and Latin America? Will the advances in therapeutics be reserved for those who live in wealthy nations? Will the resources necessary to provide the social foundations for effective HIV prevention programs be made available? The test of our politics and ethics will be found in answers to these questions. Whatever we do now, the die is already cast for many millions of people. The AIDS epidemic will exact an enormous toll in the Third World. What is at stake is the possibility of shaping the future course of the epidemic, of modulating the suffering that inevitably will occur as a result of the infections that already exist. An epidemiological catastrophe is unavoidable. What can be limited are the dimensions of the catastrophe. There are not many reasons to be optimistic about the extent to which the resources will be forthcoming. But, however, one confronts this awesome situation, it is clear that political concerns in the broadest sense will frame the response.

#### IV. CONCLUSION

This Commentary, dedicated to Margaret Somerville, begins with the assumption that intellectuals and researchers have a moral obligation to break free of blinkered views that inhibit their own capacity to see clearly, to raise questions forcefully, and to propose solutions candidly. In dealing with three issues: the challenge of cultural sensitivity; the targeting of AIDS prevention efforts; and the role of politics in the shaping of AIDS policy, I have sought to underscore the implications of that assumption. This Commentary closes by linking those professional obligations to the much broader issue of the responsibility of intellectuals and researchers to the world of politics. What are those responsibilities? They are to hold up a mirror that can reflect an uncompromised picture of the toll of the HIV epidemic and to frame inquiries in a way that preserves the possibilities of policy innovation, all in the hope that the forces that would weaken the fragile social resolve to confront the challenges posed by the AIDS epidemic can be bested. That is a tall order, but if they strive for anything less, intellectuals and researchers will have lost the capacity to make the kind of modest, but critical, contributions demanded from those who seek to grasp the protean nature of AIDS in the world.