

SOUNDING BOARD

PUBLIC HEALTH POLICY AND THE AIDS EPIDEMIC

An End to HIV Exceptionalism?

IN the early and mid-1980s, when democratic nations were forced to confront the public health challenge posed by the epidemic of the acquired immunodeficiency syndrome (AIDS), it was necessary to face a set of fundamental questions: Did the history of responses to lethal infectious diseases provide lessons about how best to contain the spread of human immunodeficiency virus (HIV) infection? Should the policies developed to control sexually transmitted diseases or other communicable conditions be applied to AIDS? If AIDS were not to be so treated, what would justify such differential policies?

To understand the importance of these questions, it is necessary to recall that conventional approaches to public health threats were typically codified in the latter part of the 19th or the early part of the 20th century. Even when public health laws were revised in subsequent decades, they tended to reflect the imprint of their genesis. They provided a warrant for mandating compulsory examination and screening, breaching the confidentiality of the clinical relationship by reporting to public health registries the names of those with diagnoses of "dangerous diseases," imposing treatment, and in the most extreme cases, confining persons through the power of quarantine.

As the century progressed, the most coercive elements of this tradition were rarely brought to bear, because of changing patterns of morbidity and mortality and the development of effective clinical alternatives. Nevertheless, it was the specter of these elements that most concerned proponents of civil liberties and advocates of gay rights as they considered the potential direction of public health policy in the presence of AIDS.¹ Would there be widespread compulsory testing? Would the names of the infected be recorded in central registries? Would such registries be used to restrict those with HIV infection? Would the power of quarantine be used, if not against all infected persons, then at least against those whose behavior could result in the further transmission of infection?

Although there were public health traditionalists in the United States and abroad who pressed to have AIDS and HIV infection brought under the broad statutory provisions established to control the spread of sexually transmitted and other communicable diseases, they were in the distinct minority. Typically, it was those identified with conservative political parties or movements who endorsed such efforts — e.g., the Christian Social Union of Bavaria — although not all conservatives pursued such a course.² Liberals and those identified with the democratic left tended to op-

pose such efforts. There were striking exceptions, such as the Swedish Social Democrats,³ but in the end it was those who called for "HIV exceptionalism" who came to dominate public discourse.

In the first decade of the AIDS epidemic, an alliance of gay leaders, civil libertarians, physicians, and public health officials began to shape a policy for dealing with AIDS that reflected the exceptionalist perspective. As the second decade of the epidemic begins, it is clear that the potency of this alliance has begun to wane. The evidence of this change with regard to HIV testing, reporting, partner notification, and even quarantine is most visible in the United States, but it may begin to appear in other democratic nations as well. What follows is drawn from the American experience, but it most certainly has parallels in other countries.

TESTING AND SCREENING

The HIV-antibody test, first made widely available in 1985, was the subject of great controversy from the outset. Out of the confrontations emerged a broad consensus that, except in a few well-defined circumstances, people should be tested only with their informed voluntary and specific consent. When the clinical importance of identifying those with asymptomatic HIV infection became clear in mid-1989, the political context of the debate over testing underwent a fundamental change. Gay organizations began to urge homosexual and bisexual men to have their antibody status determined under confidential or anonymous conditions. Physicians pressed for AIDS to be returned to the medical mainstream and for the HIV-antibody test to be treated like other blood tests — that is, given with the presumed consent of the patient.

Thus, four clinical societies in New York State, including the New York Medical Society, unsuccessfully sued the commissioner of health in 1989 to compel him to define AIDS and HIV infection as sexually transmitted and communicable diseases.⁴ Among the goals of the suit was the liberalization of the stringent consent requirements for HIV testing. In December 1990 the House of Delegates of the American Medical Association called for HIV⁵ infection to be classified as a sexually transmitted disease. Although the delegates chose not to act on a resolution that would have permitted testing without consent, their decision on classification had clear implications for a more routine approach to HIV screening, one in which the standard of specific informed consent would no longer prevail.⁵

The movement toward routine or mandatory testing has been especially marked in the case of pregnant women and newborns. Pregnant women are already tested in this way for syphilis and hepatitis B. The screening of newborns for phenylketonuria and other congenital conditions is standard. Although as of this writing a deeply divided AIDS task force of the

American Academy of Pediatrics had not recommended mandatory HIV screening of newborns, that decision was a function of the lack of specificity of the test and the lack of a definitive clinical regimen for seropositive newborns. The publication in the *Morbidity and Mortality Weekly Report* on March 15, 1991,⁶ of recommendations for the prophylaxis of *Pneumocystis carinii* pneumonia in newborns will undoubtedly affect future discussion of the importance of identifying infants born to mothers with HIV infection.

REPORTING OF NAMES

Clinical AIDS has been a reportable condition in every state since 1983. But since the inception of HIV testing, there has been a sharp debate about whether the names of all infected persons should be reported to confidential registries of public health departments. Gay groups and their allies have opposed HIV reporting because of concern about privacy and confidentiality. Many public health officials opposed such a move because of the potential effect on the willingness of people to seek HIV testing and counseling voluntarily. By 1991 only a few states, typically those with relatively few AIDS cases, had required such reporting.⁷

Divisions have begun to appear in the alliance against the reporting of names in states where the prevalence of HIV infection is high and where gay communities are well organized. In New York State, as noted above, four medical societies have demanded that HIV infection be made a reportable condition.⁴ In 1989, Stephen Joseph, then commissioner of health in New York City, stated that the prospects of early clinical intervention warranted "a shift toward a disease-control approach to HIV infection along the lines of classic tuberculosis practices," including the "reporting of seropositives."⁸ Although political factors thwarted the commissioner, it is clear that his call represented part of a national trend.

At the end of November 1990, the Centers for Disease Control declared its support for reporting. In a carefully crafted editorial note in the *Morbidity and Mortality Weekly Report*, the agency stated that

by using measures to maintain confidentiality, the implementation of a standardized system for HIV reporting to state health departments can enhance the ability of local, state, and national agencies to project the levels of required resources . . . [and aid] in the establishment of a framework for providing partner notification and treatment services. . . .⁹

Within a week, the House of Delegates of the American Medical Association endorsed the reporting of names as well.

NOTIFICATION OF PARTNERS

Most important in the move toward the reporting of names has been the belief on the part of public health officials that effective programs of partner notification require reporting the names of persons with HIV in-

fection as well as the names of those with a diagnosis of AIDS. Despite its long-established, though recently contested, role in the control of other venereal diseases, notification of the sexual and needle-sharing partners of patients with HIV infection or AIDS has been the exception rather than the rule. Opponents of such notification or contact tracing have denounced it as a coercive measure, even though it has always depended on cooperation with the index patient and protection of that patient's anonymity.

The early opposition to partner notification by gay and civil-liberties groups has begun to yield, as a better understanding of the practice has developed. Since 1988 the Centers for Disease Control has made the existence of partner-notification programs in states a condition for the granting of funds from its HIV-prevention program.¹⁰ Such programs have also been endorsed by the Institute of Medicine, the National Academy of Sciences,¹¹ the Presidential Commission on the HIV Epidemic,¹² the American Bar Association,¹³ and the American Medical Association.¹⁴

Many of the early strict-confidentiality statutes relating to HIV infection and AIDS appeared to prevent physicians from acting when confronted with infected patients who indicated that they would neither inform their partners nor alter their sexual practices. More recent acknowledgment of clinicians' ethical responsibilities under such circumstances has led to modifications of the stringent prohibitions on breaches of confidentiality. Both the American Medical Association¹⁵ and the Association of State and Territorial Health Officials¹⁶ have endorsed legislative provisions that would permit disclosure to people placed at risk by the HIV infection of a partner.

As of 1990, only two states had imposed on physicians a legal duty to warn spouses that they were at risk for HIV infection. Approximately a dozen states had passed legislation granting physicians a "privilege to warn or inform" sexual and needle-sharing partners, thus freeing clinicians from liability whether or not they issued such warnings.¹⁷ In a remarkable acknowledgment of the extreme sensitivity of the issues involved, some of the legislation stipulated that the warnings could not involve revealing the identity of the source of the threat to the person being warned.¹⁸

QUARANTINE AND CRIMINALIZATION

On epidemiologic, pragmatic, and ethical grounds, there has been virtually no support for extending the power to quarantine to apply to all HIV-infected persons. There has, however, been periodic discussion of whether the tradition of restricting liberty in the name of the public health should be invoked when a person's behavior poses a risk of HIV transmission.¹ Although bitter opposition has greeted all attempts to bring such behavior within the scope of existing quarantine statutes, more than a dozen states did so from 1987 through 1990. When such measures have

been enacted, they have generally provided an occasion to revise state disease-control laws to reflect contemporary constitutional standards of due process (Intergovernmental Health Policy Project: unpublished data). There have been a few well-reported instances of efforts to impose control over recalcitrant persons for reasons of public health. Almost always, states have used the existence of the authority to quarantine to warn those who persist in unsafe sexual practices and to counsel them aggressively about the need for a change in behavior.

More common, though still relatively rare, has been the use of the criminal law under such circumstances. From 1987 through 1989, 20 states enacted statutes permitting the prosecution of persons whose behavior posed a risk of HIV transmission (Intergovernmental Health Policy Project: unpublished data), a move broadly endorsed by the Presidential Commission on the HIV Epidemic.¹⁹ The 1990 Ryan White Comprehensive AIDS Resources Emergency (CARE) Act requires that all states receiving funds have the statutory capacity to prosecute those who engage in behavior linked to the transmission of HIV infection to unknowing partners. Perhaps more crucial, aggressive local prosecutors have relied on the general criminal law to bring indictments against some people for HIV-related behavior, even in the absence of statutes specifically defining such behavior as criminal.

In the vast majority of instances, such prosecutions have resulted either in acquittal or in a decision to drop the case. When there have been guilty verdicts, the penalties have at times been unusually harsh.²⁰

THE ROOTS OF THE CHALLENGE TO HIV EXCEPTIONALISM

What accounts for the pattern of changes described above? When the communal welfare is threatened, public health policy always requires more than the application of a repertoire of standard professional practices. Inevitably, public health officials must contend with a range of extraprofessional considerations, including the prevailing political climate and the unique social forces brought into play by a particular public health challenge. In the first years of the AIDS epidemic, U.S. officials had no alternative but to negotiate the course of AIDS policy with representatives of a well-organized gay community and their allies in the medical and political establishments. In this process, many of the traditional practices of public health that might have been brought to bear were dismissed as inappropriate. As the first decade of the epidemic came to an end, public health officials began to reassert their professional dominance over the policy-making process and in so doing began to rediscover the relevance of their own professional traditions to the control of AIDS.

This process has been fostered by changing perceptions of the dimensions of the threat posed by AIDS.

Early fears that HIV infection might spread broadly in the population have proved unfounded. The epidemic has been largely confined to the groups first identified as being at increased risk. As the focus of public health concern has shifted from homosexual men, among whom the incidence of HIV infection has remained low for the past several years, to poor black and Hispanic drug users and their sexual partners, the influence of those who have spoken on behalf of the gay community has begun to wane. Not only do black and Hispanic drug users lack the capacity to influence policy in the way that homosexual men have done, but also those who speak on their behalf often lack the singular commitment to privacy and consent that so characterized the posture of gay organizations. Furthermore, policy directed toward the poor is often characterized by authoritarian tendencies. It is precisely such authoritarianism that evokes the traditions of public health. Finally, in the United States as in virtually every Western democracy, the estimates of the level of infection put forth several years ago have proved to be too high.²¹ As AIDS has become less threatening, the claims of those who argued that the exceptional threat would require exceptional policies have begun to lose their force.

The most important factor in accounting for the changing contours of public health policy, however, has been the notable advances in therapeutic prospects. The possibility of managing HIV-related opportunistic infections better and the hopes of slowing the course of HIV progression itself have increased the importance of early identification of those with HIV infection. That, it turns, has produced a willingness to consider traditional public health approaches to screening, reporting, and partner notification.

CONCLUSIONS

As of the end of 1990, 11 states had classified AIDS and HIV infection as sexually transmitted or venereal diseases. Twenty-two states had classified them as communicable diseases, infectious diseases, or both. Strikingly absent from this group are New York, California, and New Jersey, the three states that have borne the heaviest burdens during the epidemic (Intergovernmental Health Policy Project: unpublished data). Whether they and other states will follow will depend on epidemiologic and clinical developments. But more important will be the balance of political forces.

The pattern that has begun to emerge so clearly in the United States may not be replicated in every respect in other democratic nations where HIV exceptionalism has held sway in the first years of the epidemic. Much will depend on the tradition of public health practice with regard to sexually transmitted and communicable diseases and on the relative strength and viability of the alliances forged in the phase of the epidemic marked by therapeutic impo-

tence. But what is clear is that the effort to sustain a set of policies treating HIV infection as fundamentally different from all other public health threats will be increasingly difficult. Inevitably, HIV exceptionalism will be viewed as a relic of the epidemic's first years.

Finally, the broad political context within which decisions will be made about the availability of resources for prevention, research, and the provision of care will be affected by the changing perspective on AIDS. The availability of such resources has always been the outcome of a competitive process, however implicit. In the beginning, the desperate effort to wrest needed resources from an unresponsive political system in the context of a health care system that failed to provide universal protection against the cost of illness compelled AIDS activists and their allies to argue that AIDS was different and required funding commitments of a special kind. However late these funds were in coming, and however grudgingly they were provided, it was inevitable that in a resource-constrained climate there would be challenges to the allocations that were made. Thus, in 1990 the Office of Technology Assessment was compelled to address the question of whether the resources made available for AIDS research had distorted the funding allocated for other medical conditions.²² Winkenwerder et al. argued in 1989 that further increases in federal expenditures for AIDS would be disproportionate to the burden of disease in the population.²³ Such concern has begun to find expression in the popular media as well.²⁴ The erosion of the exceptionalist perspective on HIV infection will inevitably foster the further expression of such doubt, precisely when greater resources are required to treat those with HIV disease.

That the difference between the public health response to the HIV epidemic and the response to other conditions has been eroding does not necessarily mean that public health traditionalists will inevitably win out over those who have argued for a new public health practice. In Denmark, for example, the experience with AIDS has led to a reconsideration of the traditional approach to venereal disease.²⁵ Indeed, there are many reasons, both pragmatic and ethical, that some of the practices that have emerged over the past decade in response to AIDS should inform the practice of public health more generally. There are good reasons, for example, to argue that the principle of requiring informed consent for HIV testing ought to apply to all clinical tests to which competent adults may be subject. Furthermore, the lessons learned — about mobilizing an effective campaign of public health education, about the central importance of involving in the process of fashioning such efforts those who speak on behalf of those most at risk, and about the very limited and potentially counterproductive consequences of recourse to coercion in seeking to effect a radical modification of private behavior — could be applied profitably to the patterns of morbid-

ity and mortality that represent so much of the contemporary threat to the public health.

Were the end of HIV exceptionalism to mean a reflexive return to the practices of the past, it would represent the loss of a great opportunity to revitalize the tradition of public health so that it might best be adapted to face the inevitable challenges posed not only by the continuing threat of AIDS but also by threats to the communal health that will inevitably present themselves in the future.

Columbia University
New York, NY 10032

RONALD BAYER, PH.D.

Supported by the American Foundation for AIDS Research, the Conanima Foundation, and the Josiah Macy Jr. Foundation.

REFERENCES

1. Bayer R. Private acts, social consequences: AIDS and the politics of public health. New Brunswick, N.J.: Rutgers University Press, 1991.
2. Frankenberger G. In the beginning all the world there was America: AIDS policy in West Germany. In: Bayer R, Kirp D, eds. Passions, politics and policy: AIDS in eleven democratic nations. New Brunswick, N.J.: Rutgers University Press (in press).
3. Henriksson B, Ytterberg H. Swedish AIDS policy: a question of contradictions. In: Bayer R, Kirp D, eds. Passion, politics and policy: AIDS in eleven democratic nations. New Brunswick, N.J.: Rutgers University Press (in press).
4. New York State Society of Surgeons et al. v. Axelrod, 1989.
5. Jones L. HIV infection labeled as STD; board to clarify testing policy. American Medical News. December 14, 1990;3: 28.
6. Working Group on PCP Prophylaxis in Children. Guidelines for prophylaxis against *Pneumocystis carinii* pneumonia for children infected with human immunodeficiency virus. MMWR 1991; 40(RR-2):1-13.
7. Intergovernmental Health Policy Project. HIV reporting in the states. Intergovernmental AIDS Reports. November-December 1989:1-3.
8. Joseph SC. Remarks at the Fifth International Conference on AIDS, Montreal, June 4-9, 1989.
9. Update: public health surveillance for HIV infection — United States, 1989 and 1990. MMWR 1990; 39:861.
10. Fed Regist 1988; 53:3554.
11. Altering the course of the epidemic. In: Institute of Medicine, National Academy of Sciences. Confronting AIDS: update 1988. Washington, D.C.: National Academy Press, 1988:82.
12. Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic: submitted to the President of the United States. Washington, D.C.: Presidential Commission on the Human Immunodeficiency Virus Epidemic, 1988:76.
13. American Bar Association, House of Delegates. Report from the House of Delegates, August 1989: annual meeting. Chicago: American Bar Association, 1989:23-5.
14. Abraham L. AIDS contact tracing, prison test stir debate. American Medical News. July 8-15, 1988:4.
15. American Medical Association Board of Trustees. Report X: AMA HIV policy update. In: AMA Proceedings of the House of Delegates, December 3-6, 1989, 43rd interim meeting. Chicago: American Medical Association, 1989:76-95.
16. Association of State and Territorial Health Officials, National Association of County Health Officials, Conference of Local Health Officers. Guide to public health practice: HIV partner notification strategies. Washington, D.C.: Public Health Foundation, 1988.
17. Intergovernmental Health Policy Project. 1989 legislative overview. Intergovernmental AIDS Reports. January 1990:3.
18. New York State Public Health Law, Article 27-F.
19. Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic: submitted to the President of the United States. Washington, D.C.: Presidential Commission on the Human Immunodeficiency Virus Epidemic, 1988:130-1.
20. Gostin LO. The AIDS litigation project: a national review of court and human rights commission decisions, part 1: the social impact of AIDS. JAMA 1990; 263:1961-70.
21. Estimates of HIV prevalence and projected AIDS cases: summary of a workshop, October 31-November 1, 1989. MMWR 1990; 39:110-9.
22. Office of Technology Assessment. How has federal research on AIDS/HIV disease contributed to other fields? Washington, D.C.: Government Printing Office, 1990.
23. Winkenwerder W, Kessler AR, Stolec RM. Federal spending for illness caused by the human immunodeficiency virus. N Engl J Med 1989; 320:1598-603.
24. Krauthammer C. AIDS getting more than its share? Time. June 25, 1990:80.
25. Albaek E. AIDS: the evolution of a non-controversial issue in Denmark. In: Bayer R, Kirp D, eds. Passions, politics and policy: AIDS in eleven democratic nations. New Brunswick, N.J.: Rutgers University Press (in press).