AIDS: the politics of prevention and neglect

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With 1991, the second decade of the American acquired immunodeficiency syndrome (AIDS) epidemic has begun. As of this writing, more than 175,000 people have been diagnosed with AIDS; over 100,000 are dead. It is a moment of great promise but also of great risk. The remarkable advances in the biomedical realm and the formulation of public policies designed to limit the spread of human immunodeficiency virus (HIV) infection and protect the rights of those who are infected or at risk of infection stand as singular accomplishments. Their success is all the more striking because it has come as a consequence of intense political conflict, spurred by the demands of those who have borne the burden of disease and their allies. But these achievements also set the stage for new controversies in public health. The central political and ethical question of privacy that provided the core theme of political debate in the epidemic’s first phase has now been joined, although not displaced, by that of equity.

Recent clinical developments are critical to an understanding of the evolving political debates about AIDS and public health. While it is still too soon to speak of AIDS itself as a chronic disease, HIV infection will increasingly require the long-term clinical management associated with such conditions. As a consequence, identifying those who are infected has become even more crucial. No longer is the question before public health officials solely a matter of preventing infection. Increasingly, providing the million or more infected Americans with appropriate clinical supervision has become a higher priority. Within this changed context, screening, reporting, and partner notification—issues that figured so prominently in the early controversies over AIDS prevention—have provoked fresh debates about the appropriate role of the state. The traditional approaches of public health officials to epidemic disease, so
vigorously challenged in the early and mid-1980s, have found new support from those who had recently considered these approaches inadequate or ethically unacceptable.

**HIV Antibody Testing And Early Intervention**

No issue has consumed more attention in the disputes over public policy and AIDS than the use of the antibody test to identify those infected with HIV. Out of these debates emerged a broad consensus, often codified in state statutes, that testing should be conducted only with the informed voluntary and specific consent of individuals. Despite that standard and the carefully defined, though always contested, exceptions to its scope, many clinicians and hospitals undertook surreptitious testing of patients, justifying their practices by the belief that the protection of health care workers and sound diagnostic work required such screening.\(^1\)

In mid-1989, clinical trials revealed the efficacy of early therapeutic intervention in slowing the course of illness in asymptomatic but infected persons and in preventing the occurrence of *Pneumocystis carinii* pneumonia. At this point, the political debate about testing underwent a fundamental change. Groups such as Project Inform in San Francisco and the Gay Men’s Health Crisis in New York City began to encourage those they had formerly warned against testing to determine whether or not they were infected.\(^2\) Physicians pressed more vigorously for the “return of AIDS to the medical mainstream” so that testing might be routinely done under conditions of presumed consent.\(^3\) Public health officials (most notably in New York and New Jersey, which had borne so much of the burden of AIDS) launched aggressive testing campaigns.

Although physicians and public health officials have typically avoided the language of compulsion, stressing instead routine testing, the threat of coercion continues to loom before gay activists, their liberal political allies, and proponents of civil liberties. So too has the risk of increased stigma and discrimination within the context of medical institutions.

As early therapeutic intervention continues to show promise, the alliances forged in the first phase of the epidemic have begun to unravel. Nowhere is this clearer than in the emergence of a powerful movement, supported by obstetricians and pediatricians, for the routine screening of pregnant women who could transmit HIV to their offspring and the mandatory screening of infants at high risk for infection. In the case of the former, the public health practice of testing for syphilis and hepatitis B serves as a model. In the latter instance, the wide-scale and broadly accepted tradition of screening for congenital conditions such as phenylketonuria (PKU) provides the standard. The promise— with little
The erosion of the alliance that had resisted the application of traditional public health practices to AIDS can be seen also in the shifting trends on the issue of reporting the names of those infected with HIV to confidential public health department registries. Gay groups and their allies had fiercely resisted such reporting requirements because of concerns about privacy and confidentiality. Public health officials in areas with large numbers of AIDS cases also opposed reporting because it might leave people less willing to seek voluntary HIV testing and counseling. As a consequence, reporting requirements had become policy in only a few states. By the late 1980s, fissures had begun to appear in the alliance opposing named reporting in those states where the prevalence of HIV infection was high and where gay communities were well organized.

In June 1989, Stephen Joseph, then commissioner of health in New York City, told the Fifth International Conference on AIDS in Montreal that the prospect of early clinical intervention necessitated “a shift toward a disease control approach to HIV infection along the lines of classic tuberculosis practices.” Central to such an approach would be the “reporting of seropositives” to assure effective clinical follow-up and “more aggressive contact tracing.” Joseph’s proposals opened a debate that was only temporarily settled by the defeat of New York’s Mayor Edward Koch in his 1989 bid for reelection. When newly elected Mayor David Dinkins selected Woodrow Myers, formerly commissioner of health in Indiana, to replace Joseph, his appointment was almost aborted, in part because he had supported named reporting. The festering debate was ended only by a political decision on the part of the mayor, who had drawn heavily on support within the gay community, to stand by his appointment while promising that there would be no named reporting.

In New Jersey, which shares with New York City a relatively high level of HIV infection, the commissioner of health also supported named reporting, but the politics surrounding the issue were very different. There, both houses of the state legislature endorsed without dissent a confidentiality statute that included named reporting of cases of HIV infection. New Jersey simply exemplified a national trend. For, although
at the end of 1989 only nine states required named reporting without any provision for anonymity, states increasingly were adopting policies that required reporting in at least some circumstances. And always the arguments were the same. New therapeutic possibilities provided the warrant for reestablishing a standard of traditional public health practice.

Ironically, pressure to extend the provision of Medicaid coverage for early treatment and to expand government-funded clinics to treat those with HIV infection will inevitably result in the creation of records on growing numbers of infected individuals, regardless of whether states adopt mandatory reporting requirements. The move toward early clinical intervention then is incompatible with the preservation of anonymity. As a result, creating and enforcing regimes to protect the rights of infected persons from acts of discrimination will become even more important than in the epidemic’s first years. In this context, not only state-level protections for individuals with HIV infection will be crucial. More important will be the implementation and enforcement of the Americans with Disabilities Act, legislation that explicitly includes those with HIV infection among the protected class covered by the enactment.

The move toward named reporting was linked only in part to the argument that state health departments needed the names of individuals to assure adequate clinical follow-up. Public health officials also asserted that effective contact tracing, now more critical than ever because of the need for early clinical intervention, could be undertaken only if those with HIV infection, but who were not yet diagnosed as having AIDS, could be interviewed. Despite its central and well-established role in venereal disease control, the notification of sexual and needle-sharing partners in the context of AIDS had been a source of ongoing conflict between gay groups and civil liberties organizations on the one hand, and public health officials who had proposed such a strategy in the early years of the epidemic on the other. This notification was always predicated on the willingness of those with sexually transmitted diseases to provide public health workers with the names of their partners in exchange for a promise of anonymity. A standard disease control measure, it had been viewed by AIDS activists as a threat to confidentiality and as a potentially coercive intervention. Indeed, opponents of contact tracing typically denounced it as “mandatory.”

With time and a better understanding of how contact tracing functioned in the context of sexually transmitted diseases (STDs), some of the most vocal opponents of tracing yielded their principled opposition at least in private meetings and discussions and instead centered their concerns on the cost of so labor-intensive an intervention. Nevertheless, support for voluntary contact tracing was ultimately to come from the
Institute of Medicine and the National Academy of Sciences, the Presidential Commission on the HIV Epidemic, the American Bar Association, and the American Medical Association (AMA).\textsuperscript{8} Indeed, it was the AMA’s support for tracing, justified by then executive vice-president James Sammons as having “the potential in the heterosexual society to substantially reduce the proliferation and spread of AIDS,” that provided the grounds for the group’s support for mandatory HIV reporting.\textsuperscript{9}

The U.S. Centers for Disease Control (CDC) has been most active in pressing for the adoption of contact tracing programs at the state level, where all such programs are organized and funded.\textsuperscript{10} Critically involved in the training of STD workers and in the funding of local venereal disease programs, CDC had from the outset urged the adoption of this standard public health approach to AIDS and HIV infection. In February 1988, the federal agency took on a more aggressive posture, making the adoption of partner notification by the states a condition for the receipt of funds from its HIV Prevention Program.\textsuperscript{11} Despite such pressure, the response on the part of the states has been variable. States most heavily burdened by AIDS have continued to favor programs that encourage infected individuals to notify their own partners. Of the states that stressed the role of professional public health workers—the “provider referral” model—most have tended to have relatively modest AIDS case counts.\textsuperscript{12} Thus, local epidemiological factors as well as political forces have continued to influence the course of public health policy.

In part, both the early and the lingering resistance to partner notification can be explained by the confusion of the standard public health approach to STD control with policies and practices that are rooted in a very different tradition, entailing a “duty to warn” or protect those who might be threatened by individuals with communicable conditions. When such warnings have been deemed appropriate and legal, they have occurred without the consent of the index case and typically have involved the revelation of the identity of the threatening party.

The early and strict confidentiality rules surrounding HIV screening and medical records in many states all but precluded physicians from warning individuals placed at risk by their sexual and needle-sharing partners. In recent years, the recognition that such limitations placed physicians in a position that sometimes violated professional ethical norms, the realization that some patients could pose a grave threat to unsuspecting partners, and the increasing importance of early therapeutic intervention have led to modifications of early confidentiality restrictions. Such modifications were often opposed on principled grounds by those who believed that physician/patient communications should never be violated and by those who argued that such breaches of confidentiality
would have the counterproductive consequence of reducing patient candor, thus limiting the capacity of clinicians to effectively counsel and persuade individuals who might harm their partners. Yet they have been given strong support in a number of state legislatures and by the AMA and the Association of State and Territorial Health Officials. As of 1990, no state had imposed upon physicians a duty to warn unsuspecting partners. But about a dozen had adopted legislation granting physicians a “privilege to warn or inform,” thus freeing physicians from liability for either warning or not warning those at risk.

The question of how to respond to individuals whose behavior represented a threat to unknowing partners inevitably provoked continued discussion of the public health tradition of imposing restrictions on liberty in the name of communal welfare. Although all efforts to bring AIDS within the scope of state quarantine statutes have been fiercely opposed, more than twenty states did so between 1987 and 1990. States typically used the occasion to modernize their disease control laws to reflect contemporary constitutional standards that detail procedural guarantees, and to require that restrictions on freedom represent the “least restrictive alternative” available to achieve a “compelling state interest.”

With the exception of the few notable cases that have received press attention, there is no well-documented review of the extent to which newly revised quarantine statutes have been applied to the AIDS epidemic. There are, however, data to suggest that the power vested in public health officials by such laws has been used more often to warn than to incarcerate those whose behavior has posed a risk of HIV transmission. But, in any case, the numbers have been small. It is clear, therefore, that the enactment of revised quarantine laws has been responsive to political pressures and the belief in the efficacy of symbolic bulwarks.

The enactment of statutes criminalizing behavior linked to the spread of AIDS has paralleled political receptivity to laws extending the authority of public health officials to control individuals whose behavior posed a risk of HIV transmission. Such use of the criminal law, broadly endorsed by the Presidential Commission on the HIV Epidemic in 1988, called upon a tradition of state enactments that made the knowing transmission of venereal disease a crime. Though they almost never were enforced, these older laws served as a rationale for new legislative initiatives. Between 1987 and 1989, twenty states enacted such statutes, most of which defined the proscribed acts as felonies, despite the fact that older statutes typically treated knowing transmission as a misdemeanor. Recent congressional action to increase federal support for local AIDS initiatives has conditioned the receipt of funds on the existence of state authority to prosecute individuals who knowingly expose unsuspecting
persons to HIV. As important, aggressive prosecutors have relied on laws defining assaultive behavior and attempted murder to bring indictments, even in the absence of AIDS-specific legislation.

Any effort to determine to what extent prosecutions of HIV-related acts have occurred must confront the difficulty of monitoring the activity of local courts when there is neither a guilty verdict nor an appeal to a higher state tribunal. One survey, relying on newspaper accounts as well as official court reports, estimated that 50–100 prosecutions had been initiated involving acts as diverse as spitting, biting, blood splattering, blood donation, and sexual intercourse with an unsuspecting partner. Though small in number, these cases have drawn great attention. In many cases, prosecution has been unsuccessful. Nevertheless, punishment for some of those found guilty has been unusually harsh.

### Prevention And Behavior Change

Whatever the allure of such measures and of the rediscovery of traditional public health approaches in the effort to combat the spread of HIV infection, it has remained clear that the future course of the AIDS epidemic will be determined by the creation of a social and institutional milieu within which radical voluntary changes in behavior can occur and be sustained. Educational campaigns and counseling programs, most effectively undertaken by groups linked to the populations at risk, have remained the centerpiece of that preventive effort. Such efforts are, however, still limited by moralistic trends in American society, especially by those reflecting abhorrence of homosexuality.

The most striking failure in the preventive realm, however, is rooted in the unwillingness to commit the resources necessary to treat drug abuse. The dimensions of that failure were underscored in the 1988 preliminary report of the Presidential Commission on the HIV Epidemic. In its first report to President George Bush issued in December 1989, the National Commission on Acquired Immune Deficiency Syndrome underscored the continuing failure. As did its predecessor, the National Commission on AIDS—chaired by June Osbom, a well-known critic of federal AIDS policy, and vice-chaired by David Rogers, a persistent voice for increased federal support to the cities most severely affected by the epidemic—called for the availability of treatment “on request” for all drug users.

Concern about budgetary deficits, ten years of ideological opposition to welfare state–like programs by conservative national administrations, and the absence of a strong political constituency capable of effectively clamoring for the needs of the underclass have resulted in a politics of
neglect. It is in this context that opposition or suspicion on the part of black and Hispanic community leaders to the halfway measures of needle exchange and education about the use of bleach to cleanse drug injection equipment must be understood. In the absence of a strong commitment to treatment, such measures appear to write off the needs of the poor. Thus, there has emerged an alliance of the moralistic right and those who speak in the name of the dispossessed. The first black commissioner of health in New York City, acting at the behest of the city’s first black mayor, terminated a small and politically hobbled needle exchange program soon after assuming office. More stunning, he sought to cancel a small municipal contract that funded a community-based group to provide drug users with bleach and education about how to sterilize injection equipment.

The failure to fund drug abuse services was but a portion of a much deeper problem: the failure of the federal government to plan for and assist those localities that were compelled to bear the burden of providing care for large numbers of patients with AIDS. The dimensions of that failure would become even starker with the 1989 announcements on the potential benefits of early therapeutic intervention for people infected with HIV.

The Challenge Of An Equitable Response To AIDS

Here then was a paradox not new to the American health care system. Extraordinary advances in medicine must inevitably confront the social reality of the most inequitable system of medical care among advanced democratic societies. Could such a health care system meet the challenge of providing between 500,000 and 1,000,000 persons, many of whom are impoverished, with the outpatient clinical services and the expensive drugs they would require? Would it be possible for an unjust health care system to fashion a just response to those infected with HIV? Before these questions, the earlier important debates about discrimination by private medical insurers paled.

Emergency federal programs to assist the states in paying the cost of zidovudine, or AZT, for those without insurance, Medicaid reimbursement policies, and a host of patchwork programs in the states provided some relief but were clearly inadequate. In its December 1989 report to the president, the National Commission on AIDS warned that medical breakthroughs would “mean little unless the health care system can incorporate them and make then accessible to people in need.” The existence of a medically disenfranchised class meant that, for many, access to care was almost solely through the “emergency room door of one of
the few hospitals in the community that treats people with HIV infection and AIDS." This is hardly the foundation for the kind of care HIV infection will require in the 1990s.

The situation that prevailed in New York City, the epicenter of the American AIDS epidemic, was extreme because of the existence of a number of concurrent sociomedical and economic crises, including drug abuse, homelessness, and dire fiscal conditions. Nevertheless, it revealed how a failure to plan effectively and commit sufficient resources, itself a consequence of federal default, could have catastrophic results, not only for those with HIV-related disorders and the poor—so dependent on publicly provided medical services—but for the system of health care more generally.

It was not too soon to start thinking of worst-case scenarios. Shortages would impose the need for rationing, and in the political economy of a city such as New York, competition among the desperate would ensue. In what Bruce Vladek has termed the "calculus of misery," it would become increasingly necessary to choose between AIDS cases and the frail elderly for admission to nursing homes; between single adults with AIDS and homeless families with young children for access to newly renovated apartments; between homeless persons dying of AIDS and children for access to transitional shelter; and between HIV-infected pregnant women and women not yet infected for admission to drug abuse treatment programs.

The looming crisis in health care for those with HIV disease set the stage for congressional action in 1990 that could scarcely have been imagined a short time earlier. This action was the fruit of dogged efforts by AIDS activists, their allies, and some political leaders from the cities and states that had borne the disproportionate share of AIDS cases. Early in 1990, Sen. Edward Kennedy (D-MA), the exemplar of Democratic party liberalism, and Sen. Orrin Hatch (R-UT), a Republican whose stance on abortion and other social issues casts him in the role of a conservative, jointly sponsored legislation—the Ryan White Comprehensive AIDS Resources Emergency Act of 1990—that would provide a major infusion of federal assistance to those localities most severely burdened by AIDS. As the government had responded to natural disasters, the Ryan White bill asked it to respond to the medical disaster of AIDS: "The Human Immunodeficiency Virus constitutes a crisis as devastating as an earthquake, flood or drought. Indeed, the death toll of the unfolding AIDS tragedy is already a hundredfold greater than any natural disaster to strike our nation in this century."28

As remarkable as was the joint sponsorship of this legislation, which promised to provide $2.9 billion over five years in a complex political
formula to the cities and states most severely struck by AIDS, was the overwhelming support the legislation received in the Senate, where the vote was 95 to 4.\textsuperscript{29} When similar legislation with even greater resource commitments was voted on by the House of Representatives, the vote was 408 to 14.\textsuperscript{30}

However late in coming, this legislation represented on both symbolic and practical levels an important act of national solidarity. But the hopes of early summer were dashed by fall as Congress, confronted with a severe budgetary crisis, slashed funds for the Ryan White Act. What allocations will be made in successive years cannot be foretold. It is certain, however, that such an emergency act cannot be a substitute for the fundamental change in the organization and financing of health care in the United States that will be required for the chronic management of the medical and social needs of all HIV-infected persons at a moment when so many other medical needs of the nation’s poor remain unmet.

Conventionally, the public health emphasis on prevention and the clinical commitment to caring for the sick have been viewed as conceptually distinct; they compete in the day-to-day struggle over limited resources. With the rapid development of therapies for HIV disease, it has become clear that prevention and care are joined in a critical way. Public health officials have used the occasion of new therapeutic prospects as a justification for rethinking preventive policies adopted in the epidemic’s first years. But the prospect of new therapies is not enough. They must be available to those who need them if lives are to be prolonged and if the public health goal of preventing the further spread of HIV infection is to be achieved. The possibility of engaging those with HIV infection in ongoing clinical care provides a crucial opportunity to sustain behavioral change where it has occurred and to encourage and support such change where it has not. A failure to provide care and counseling, especially to the poor among whom intravenous drug use plays so critical a role in HIV transmission, will entail both a sentence of needlessly shortened life and a lost opportunity to intervene in the epidemic’s epidemiological course.

NOTES

15. Based on a review of all AIDS-related legislation in the files of the Intergovernmental Health Policy Project, Washington, D.C.