Searching Eyes
Privacy, the State, and Disease Surveillance in America

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invocations of the honorable history of public health practice must be understood not simply in terms of the broad social climate surrounding homosexuality (fig. 21). Whatever the commitments of public health advocates of surveillance, political forces favoring repressive measures could not be ignored. Just as the director of the CDC and other public health leaders were signaling their interest in the option of HIV case reporting, a furious battle over AIDS policy was taking shape in California which was, with New York, an epicenter of the unfolding American epidemic. The battle was to touch not only on matters of privacy but on the full range of rights of those infected with HIV.

THE SPECTER OF REPRESSION

It was not only those seeking to protect the interests of people with HIV who took advantage of the democratization of public health policy formation. In October 1985 the attorney general of California was notified by officials of the National Democratic Policy Committee—the political arm of Lyndon LaRouche’s extremist movement—that they intended to submit a proposition on AIDS to the electorate in the November 1986 election. Under their leadership, the Prevent AIDS Now Initiative Committee (PANIC) began its remarkable effort to obtain the 400,000 signatures needed to qualify for a place on the ballot.

Critical of the refusal of public health officials to adopt harsh measures to control AIDS, LaRouche called for mass testing and quarantine. “In order to insure that the rapid spread of AIDS is halted, nothing less than universal screening and then, under full medical care, ‘isolating’ or ‘quarantining’ all individuals who are in the active carrier state” was required. In cities and states across the country, adherents of LaRouche’s movement pressured local school boards to remove schoolchildren with AIDS from the classroom and demanded the screening of all food handlers and teachers so that those who showed signs of antibody to HIV could be barred from work that, they asserted against all evidence, would place others at risk. The proposition ultimately drafted by PANIC bore none of these strident elements in its text. Instead, California voters were to be asked to support a series of ambiguously framed amendments to the state’s health and safety code. The proposition required that both AIDS and HIV be defined as infectious, contagious and communicable. Both were to be listed by the Department of Health Services among the reportable diseases and conditions covered by existing relevant state statutes. By the summer of 1986, PANIC had succeeded in obtaining 683,000 signatures for what would be officially termed Proposition 64.

Opposition to the referendum came from the medical establishment: the California Medical Association, the California Nurses Association, and the
California Hospital Association. A statement to voters stressed the irrationality of a proposal that assumed the existence of casual transmission of HIV in schools, the workplace, or restaurants. Only those who were expert in the scientific and clinical dimensions of AIDS were qualified to fashion public health policy, not those driven by politically motivated “partial truths and falsehoods.” Asked the medical community, “Would you let a stranger with no medical training or no medical background diagnose a disease or illness that you have? Would you let a political extremist dictate medical policy?” Their answer was straightforward: “OF COURSE NOT.”44 Underscored here were the complex ways in which scientific evidence and expertise would play a role in the politics of democratic privacy with its emphasis on lay participation.

On election day close to seven million voters cast ballots on Proposition 64. Seventy-one percent opposed it; 29 percent favored it.45 Though this was a stunning defeat for PANIC, it was a hard-won victory for those who had mobilized against the proposition. Still, just fewer than two million voters, almost one in three, had been persuaded to support an initiative linked to one of the most extreme political movements in America. The referendum demonstrated the existence of a popular base that could be mobilized for a repressive turn in public policy. The specter of California’s proposition would leave an indelible mark as AIDS activists encountered proposals for HIV case reporting in the next years.

NAME REPORTING AND THE REASSERTION OF CONVENTIONAL PUBLIC HEALTH CONTROL

While the victorious alliance of gay leaders, civil liberties advocates, and public health officials and medical practitioners was able to hold off the pressure for name-based case reporting in populous states with large epidemics, there were indications as the 1980s drew to a close that the political climate was shifting. This change was driven, in part, by more optimistic assumptions about the role of early clinical interventions. Public health officials increasingly saw the value of adopting conventional approaches to disease control and viewed the enumeration of AIDS cases as a poor measure of current patterns of HIV infection.46 Furthermore, clinicians evinced a growing interest in returning AIDS to the “medical mainstream.” In short, across a range of policy issues, the exceptionalism that characterized the response to AIDS in its first years was under challenge. In mid-1988, when only thirteen states had adopted name reporting for HIV, Ronald Reagan’s Presidential Commission on the Human Immunodeficiency Virus Epidemic recommended that all states adopt case notification for HIV.47 That decision was all the more distressing to opponents of reporting since so much of the commission’s final report contained proposals applauded by liberal critics of the Reagan administration’s failure to commit either sufficient resources or political leadership to the struggle against AIDS.

Ultimately more significant were the fissures that had begun to appear in the alliance opposing reporting in those states where the prevalence of HIV infection was high and where gay communities were well organized. In a June 1989 address that was met with cries of protest, Stephen Joseph, commissioner of health in New York City, told the attendees of the Fifth International Conference on AIDS 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.” A central feature of such an approach would be the “reporting of seropositives” to assure effective clinical follow-up and the initiation of “more aggressive contact tracing.”48 Joseph’s proposals opened a debate that was only temporarily settled by the defeat of New York’s mayor Edward Koch in his bid for reelection. Newly elected David Dinkins, New York’s first African American mayor, selected Woodrow Myers, formerly commissioner of health in Indiana and also an African American, to replace Joseph. Myers’s appointment was almost aborted, in part because he had supported named reporting.49 The fester 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 York.50

Change was occurring at the national level as well. In 1989 the House of Delegates of the AMA endorsed a resolution calling for HIV reporting, explicitly linking such notification to the need for contact tracing.51 Among the most avid proponents of the new position was the president elect of the Arkansas Medical Association. In addressing the delegates, he inveighed against the exceptional treatment of AIDS. The failure to adopt standard public health reporting measures had resulted, he said, in sixty-five thousand deaths. “How many more lives have to be lost before we take a stand that, every physician in this country knows, should have been taken several years ago?”52 Writing in the Journal of the Arkansas Medical Society, he was more direct in pointing the finger of blame. The AMA delegates had embraced name reporting, he argued, because “the silent majority was fed up with being intimidated and mesmerized by the vocal civil libertarian—homosexual advocate minority with its self-centeredness and calloused disregard for the health of others.”53 Without endorsing either the substance or tone of such denunciations, the Board of Trustees of the AMA, its highest policy-making body, recommended name reporting in December 1990.54 But the vitriolic language of some of the most avid proponents of reporting would not be lost on those who sought to forestall such measures in the states.

At the CDC, whose director had signaled its sympathy for HIV reporting, important efforts were made to bring some coherence to the pattern of
1980s and a senior official at the AIDS Action Council, had given voice to the primacy of privacy for gay men. At the consultation Schram explained why the gay and bisexual community would never support name reporting, especially when linked to partner notification. Levi took a fundamentally different position. It was no longer possible, he said, to speak of unanimity on the issue of reporting in the gay community. While acknowledging the persistence of American homophobia, he believed that "we are in a different place than we were when we first had the discussions 15 years ago." Both the "science and sociology" of the epidemic had undergone a fundamental change. How, he asked, could AIDS advocates press government to expand the range of social and medical services to people with HIV and at the same time oppose name reporting because of a lack of trust? Then, echoing a perspective that had characterized many African American AIDS spokespersons who were more concerned about access to life-saving care than privacy, he noted: after HIV testing patients ideally would be referred to primary care, possibly in a public clinic with services covered by Medicaid, "and they have your name, your address, your Social Security number, your entire medical history, your HIV status, your CD4 count, your viral load. . . So we trust the government to have everything there is to know about us when it comes to care." He believed that "we are in a different place than we were when we first had the discussions 15 years ago." Both the "science and sociology" of the epidemic had undergone a fundamental change. How, he asked, could AIDS advocates press government to expand the range of social and medical services to people with HIV and at the same time oppose name reporting because of a lack of trust? Then, echoing a perspective that had characterized many African American AIDS spokespersons who were more concerned about access to life-saving care than privacy, he noted: after HIV testing patients ideally would be referred to primary care, possibly in a public clinic with services covered by Medicaid, "and they have your name, your address, your Social Security number, your entire medical history, your HIV status, your CD4 count, your viral load. . . So we trust the government to have everything there is to know about us when it comes to care."105

If the changed clinical, social, and political context of AIDS had provided the conditions for sharp divisions to emerge among formerly allied AIDS activists on the issue of name reporting, that was not so clearly the case with one of the central rationales for such surveillance: partner notification. For years, advocates of name reporting had argued that it would permit health departments to contact the sexual and needle-sharing partners of those who were infected, replicating a practice central to sexually transmitted disease control programs.

At the consultation, Jeff Levi acknowledged that some forms of partner notification—those that were truly voluntary and protected the identity of the index patient—were acceptable. But other advocates did not. Cornelius Baker, of the National Association of People with AIDS, was willing to concede the issue of case reporting, "I think part of the fear that the community has always had, at least from my perspective, is that we open the door and the flood rushes in. That we start with name reporting, and then we're talking about partner notification, and then we're talking about contact tracing, and then we're talking about quarantine." The history of initiatives linking partner notification and case reporting—the LaRouche referendum years earlier and then congressional legislation proposed in 1996, 1997, and 1998 by conservative Oklahoma representative Tom Coburn—served to underscore the malevolent intentions of those who advanced such a "public health" agenda.107

It was on this terrain of shifting perspectives that the CSTE finally moved to call definitively for name reporting.108 The CSTE made clear that efforts on the part of AIDS advocates to press for the adoption of the unique identifiers, enthusiastically pioneered by Maryland, would face professional resistance. Unique identifiers were inadequate to assure the accurate epidemiological characterization of the epidemic and were deemed unacceptable because they posed difficulties for follow-up referrals to social and clinical services.

In September 1997 the CDC formally announced that it would call upon all states to adopt a system of HIV case surveillance.109 Support could be anticipated from the all-important medical community. The AMA had long supported HIV name reporting, and in 1997 the prestigious New England Journal of Medicine editorially took the same position.110 To demonstrate the broad-based support for change, John Ward, a senior surveillance official at the CDC, joined with Lawrence Gostin, a Georgetown University law professor with a history of advocacy for civil liberties, and Cornelius Baker, an African American AIDS activist, to coauthor an article published in the New England Journal of Medicine. "We are," they asserted, "at a defining moment in the epidemic. . . Unless we revise our surveillance system, health authorities will not have reliable information about the prevalence, incidence, and future directions of HIV infection. . . We propose that all states require HIV case reporting."111

But the aura of inevitability and consensus could not mask the persistence of bitter opposition to name reporting. The American Civil Liberties Union brought its considerable intellectual and political resources to the fray. "There may come a time when HIV is so unremarkable a part of our social landscape, and care for it is so routinely available to those who need it, that no one will reasonably fear being identified as a person with HIV. But we are nowhere close to that time yet. On the contrary, the best evidence we have suggests that those who most need HIV testing are afraid of name reporting because they fear discrimination. Moreover, we know those fears are not groundless."112

As the CDC began what would ultimately be a more-than-two-year process of developing a set of recommendations for states on HIV case reporting, it was faced with divisions among its senior personnel.113 Those involved directly in surveillance activities were firmly convinced that only a name-based system would be effective. By contrast, among those primarily engaged in prevention activities, where direct, ongoing contact with at-risk communities defined the work environment, there was much greater sympathy for fears about the dangers of stigmatization and discrimination. Even when such personnel did not themselves think the threats credible, they believed that respecting community fears was crucial for purposes of sustaining their all-important working relationships.

But such internal disagreements did not determine what the CDC would

CHAPTER 7

2. Ibid.
8. Ibid.
11. Ibid.
13. Ibid.
14. Ibid.
20. Ibid.
21. Ibid., 18.
25. Colorado Board of Health, Minutes, August 21, 1985, as cited in Bayer, Private Acts.
105. Ibid.
106. Ibid.
114. Ibid.

CHAPTER 8

3. See, for example, Walter R. Coles to John L. Rice, October 1, 1940, Box 141511, Smallpox Folder, New York City Department of Health Archives, New York.