

The Dependent Center: The First Decade of the AIDS Epidemic in New York City

Epidemics are by their nature both biological and political events. Just as a new microparasitic threat may destabilize the biological status quo, the rapid increase in disease may pose challenges to the political system. Much depends on the intensity of the epidemic threat, the severity of its exactions, the breadth of its assault, its impact on cultural and social institutions and values, and the social standing of those who are affected. Inevitably, the responses provoked by an epidemic challenge will reflect prevailing social arrangements. Those very responses will in turn shape a society's experience of the biological threat.

Insights about the impact of epidemic disease on society—the lessons of Charles Rosenberg's *Cholera Years* that appeared in 1962 and William McNeill's *Plagues and People*, published fourteen years later—took on an unanticipated immediacy in 1981, when the AIDS epidemic was first publicly recognized.

EPIDEMIOLOGY AND THE SOCIAL DIMENSIONS OF THE EPIDEMIC

What began with reports in mid-1981 of unusual and lethal diseases among gay men on both the East and West coasts has developed into an epidemic with profound impact in the United States. Also in 1981, reports of disease began to appear in Africa and Haiti, presaging the worldwide pandemic of AIDS. The United States would emerge as the center of the epidemic that was taking shape in the economically developed world, as East Africa would in the Third World. New York City was destined to become the epicenter of the American epidemic.

It was in June 1981 that the Centers for Disease Control (CDC) reported that between October 1980 and May 1981 five young men had been diagnosed with *pneumocystis carinii* pneumonia (PCP). All were gay.¹ One month later the CDC reported that in the prior thirty months, 26 cases of an unusual malignancy, Kaposi's sarcoma (KS), had been diagnosed in New York City and California. They, too, were among gay men.² On the first anniversary of the

39. Paul, *History*, 340–345.
40. *New York Times*, August 9, 1949.
41. *Time*, August 22, 1949.
42. *New York Times*, August 26, 1949.
43. *New York Times*, August 7, 1949.
44. *New York Times*, August 7, 1949.
45. *Newsweek*, September 5, 1949.
46. Turnley Walker, *Rise Up and Walk* (New York: E. P. Dutton, 1950), 7.
47. See, for example, Walker, *Rise Up and Walk*; Milton Lomask, *The Man in the Iron Lung: The Frederick B. Smithe, Jr., Story* (Garden City, N.Y.: Doubleday, 1956); and Anne Walters and Jim Marugg, *Beyond Endurance* (New York: Harper and Brothers, 1954).
48. Klein, *Trial by Fury*, 46.
49. Berg, *Polio and Its Problems*, 63–77, 108–110.
50. National Foundation for Infantile Paralysis, *1954 Speakers Handbook* (New York: Public Relations Department, National Foundation, [1954]), 3–5.
51. Smith, *Patenting the Sun*, 146–149.
52. *Ibid.*, 103–106, 137–139, 147–148.
53. Klein, *Trial by Fury*, 140–141; Paul, *History*, 445–448, 455–459.
54. Paul, *History*, 422–428.
55. *Ibid.*, 423–424, 443–444; see also Klein, *Trial by Fury*.
56. See Naomi Rogers, "Thomas Francis, Jr.: From the Bench to the Field," in Joel Howell, ed., *Medical Lives and Scientific Medicine at Michigan, 1861–1969* (Ann Arbor: University of Michigan Press, 1993), 161–187.
57. Smith, *Patenting the Sun*, 364–367.
58. *Ibid.*
59. Carter, *Breakthrough*, 109–111; see also Klein, *Trial by Fury*.
60. Klein, *Trial by Fury*, 135–136, 140–141.
61. Carter, *Breakthrough*, 81–82, 111–117.
62. Paul, *History*, 455–459.
63. Klein, *Trial by Fury*, 142–147; see also Paul, *History*.
64. Klein, *Trial by Fury*, 146.
65. *Ibid.*, 147.
66. Alistair MacLean, *The Satan Bug* (Greenwich, Conn.: Fawcett, 1962), 42.
67. Paul, *History*, 465–467.
68. Smith, *Patenting the Sun*, 72–73.

CDC's first report, the federal agency announced that 355 cases of disease had been reported. Eighty percent involved gay or bisexual men. Among the heterosexuals, the most striking characteristic was a history of intravenous drug use. Ultimately PCP, KS, and a host of other disorders were linked to the assault on the immune systems that each of those who had fallen ill had experienced, and the epidemic was given the name by which it would be known, AIDS (Acquired Immune Deficiency Syndrome).

Only after the Human Immunodeficiency Virus (HIV), the etiological agent responsible for AIDS, was identified, in 1984, and when a diagnostic test was developed to detect its presence, in 1985, was it possible to speak of the dimensions and history of the epidemic with any accuracy. The first manifestations of disease recorded by the CDC had been but the end stages of hidden infections that had occurred years earlier.

In New York City, retrospective analyses of medical records detected the first cases of AIDS in children in 1977. Their mothers, therefore, must have been infected prior to that time.³ A study of one cohort of drug users in Manhattan found that as of 1978, 9 percent were already infected with HIV. By 1980, a year before the first official reports of AIDS, 38 percent were infected.⁴ At the end of the epidemic's first decade, widely accepted estimates suggested that as many as 200,000 New Yorkers were infected with the AIDS virus.⁵ As of June, 1992, 41,598 cases had been reported (949 of which were among children); 28,871 people were dead. Gay and bisexual men bore the brunt of the epidemic in the first years. By 1992, however, what had once been called the "gay plague" was increasingly a disease of poor drug users and their sexual partners. Sixty-four percent of those who had been diagnosed were black and Hispanic.⁶ Although no dimension of the city's social, cultural, or political life remained unaffected by the epidemic, the communities within which those most at risk for HIV lived were most profoundly touched. The West Village and other locales where gay men lived in great concentrations, Harlem, the South Bronx, and parts of Brooklyn where intravenous drug use was so prevalent were severely touched. Among gay men entire friendship networks became sick and succumbed. Among blacks and Hispanics entire families—mothers, fathers, and their children—fell ill and died. Grandmothers were often left to care for those children who were orphaned, while other children were relegated to New York City's inadequate foster care system.

One study estimated that between 9 and 21 percent of all males between twenty-five and forty-four years of age were infected with HIV in the South Bronx.⁷ A survey of infection among women in New York State who had given birth in 1988 underscored the differential impact of the epidemic. The prevalence of HIV infection outside New York City was .16 percent (1 in 643). In Queens the rate was .68 percent, in Brooklyn 1.25 percent, in Manhattan 1.69 percent, and in the Bronx the figure was 1.89 percent (1 in 53). Two percent of black women who had given birth and 1.66 percent of the Hispanic

women who had done so were infected with the AIDS virus.⁸ As a consequence of this pattern of infection, 90 percent of pediatric AIDS cases in New York were black or Hispanic.⁹

Although initial uncertainty about the mechanisms through which AIDS could be transmitted provoked considerable anxiety about the risks of casual transmission, epidemiological and scientific study rapidly defined the limited routes of transmission. Against public anxiety, public health officials sought to provide the antidote of reassurance. HIV was spread by sexual intercourse; by sharing drug-injection equipment contaminated with infected blood; from mother to fetus; by infected blood transfusions; and in rare cases by blood contact between patients and health care workers. There were no other risks of contagion. Recent immigrants from Haiti were initially designated a special risk group because of an apparently elevated prevalence of AIDS among such men and women in New York, as well as because of the striking dimensions of the epidemic in Haiti itself. Closer analysis of the epidemiological data, in addition to political concerns over stigmatization, led New York City's health authorities to end the public designation of Haitians as a separate risk category. In the end, sexual orientation, the social demography of intravenous drug use, and the lines of social cleavage that affect the likelihood of sexual contact across class and ethnic lines would serve to define the epidemic's course in the city.

As a sudden threat, one for which there was no effective medical response, AIDS posed a challenge to the communities most affected, to the public health system that would be called upon to contain the epidemic's spread, and to the political system that would have to mobilize both the necessary material resources to fund such an effort and the leadership necessary to preserve public calm in the face of anxiety. There were, however, limits to what the city could do. Decisions about resources for care and prevention that would affect the capacity of the municipal authorities to respond to AIDS were often made in Albany and Washington, D.C. At the center of the epidemic, New York was, nevertheless, in an utterly dependent position.

FIRST RESPONSES: 1981 - 1985

Awareness of the threatening new afflictions besetting gay men preceded any definitive understanding of what it was that had caused the life-threatening disease. Why were gay men at risk? Had a pathogen that was sexually transmitted entered the gay community? Was there something unique to the pattern of sexual behavior among urban gay men that subverted the body's disease-fighting capacity?

The tentative manner in which the gay community first addressed the issue of the potential sexual transmission of AIDS in 1981 and 1982 reflected both profound disagreements and deep anxieties about how the open discussion of

gay sexual culture and practices might create an ideological climate within which the hard-won advances of greater sexual tolerance in America could be swept away in the name of public health. Writing about these two dimensions of the debate in the *Native*, New York's gay newspaper, Dr. Lawrence Mass said, "Outside the gay community the current epidemic is already inspiring the kind of medical-moral speculation that swept England a century ago. Within the gay community, a parallel crisis of ideology is threatening to explode. With much confusion on all sides, advocates of sexual 'fulfillment' are being opposed to critics of 'promiscuity.'"¹⁰

Nevertheless, as gay men spoke and wrote about AIDS there began to emerge a consensus about what needed to be done. By mid-1982 the voice of sexual moderation began to assume the characteristics of an orthodox demand by health, the health of each gay man as well as the health of the gay community. Physicians, many of them gay, began to urge their patients to exercise caution, to choose fewer partners, those in good health. "It is not sex itself as the moralists would have it, but the number of different sexual encounters that may increase risk."¹¹

But the brutal truth of the consensus on the risks of sexual encounters with many anonymous partners—which had come to define the cultural norm of some parts of the gay community—did in fact provoke expressions of opposition, some that reflected the desperation of those who believed their newfound freedoms were under attack. The calls for restraint were sometimes seen as nothing more than thinly disguised demands for a return to sexual conventionality. Once again, it was argued, physicians were seeking to establish their dominance over homosexuality, now with the collaboration of those who carried their message in the gay press.¹²

Writing in response to the cautionary advice that appeared in the *Native*, one correspondent asserted that the risks involved in hailing a taxi were a greater threat than sexual relations with a stranger. Faced with constraints that would follow from the warnings about promiscuity—"they are actually asking us to avoid all casual sex"—he preferred to take his chances. "I refuse to blight my life in order—supposedly—to preserve it."¹³

Such resistance drew the response of Larry Kramer, the playwright and AIDS activist, in "1,112 and Counting," a dramatic call to arms published in the *Native* in 1983. Like his earlier appeals to the gay community, this article thundered its message of alarm. "Our continued existence as gay men upon the face of this earth is at stake. Unless we fight for our lives, we shall die. In all the history of homosexuality, we have never been so close to death and extinction before. Many of us are dying and are dead already." A demand for more money for research into AIDS and a denunciation of government officials who failed to respond because it was the lives of gay men that were at stake, this jeremiad also pointed a finger of accusation at gay men who refused to change their sexual lives. "I am sick of guys who moan that giving up

careless sex until this blows over is worse than death. How can they value life so little and cocks and asses so much? Come with me, guys, while I visit a few of our friends in intensive care. . . . Notice the looks in their eyes, guys. They'd give up sex forever if you could promise them life."¹⁴

Unlike the situation that existed in San Francisco, where a politically well organized gay community was able to press local officials to launch campaigns designed to alert gay men to the threat of AIDS, New York's public health officials moved much more slowly.¹⁵ In the face of such an institutional vacuum, the Gay Men's Health Crisis (GMHC) was formed in 1982. As a voluntary association devoted to education and service, it would ultimately serve as a model of communal self-help efforts in both the United States and Europe. With its origins in the white middle-class gay community, it was inevitable that the GMHC's largely volunteer staff would, especially in the first years of the epidemic, primarily serve such men.

There was little to compare with such efforts in the black and Hispanic communities. Limited resources, the perception of AIDS as a disease of white gay men, homophobia, and profound antagonism to the drug users with whom so much of the terror of ghetto life was linked all conspired to produce virtual silence on the issue of AIDS.¹⁶ Writing as late as 1987, Sam Friedman could note, "There has been little organized Black or Hispanic response. The major Black and Hispanic institutions have done little or nothing, and there has been no grass roots flowering of AIDS-related organizations."¹⁷ That was to change in the last years of the 1980s, but by then years of HIV transmission had already sown the seeds of a grave public health crisis.

The New York City Department of Health responded with extraordinary caution to the emerging challenge in the early 1980s. Having emerged from the fiscal crisis of the 1970s with a weakened professional staff and a loss of its former prestige, it was, nevertheless, afforded the opportunity to assume a leadership role under the direction of Commissioner David Sencer, former director of the Centers for Disease Control. Although the Department of Health had responsibility neither for the provision of health care to the poor—that was the task of the Health and Hospitals Corporation—nor for the provision of drug abuse services—that was a responsibility of the state's Department of Substance Abuse Services—the department could have assumed a critical role in mobilizing public support for a campaign against AIDS and for providing social and clinical services to those who were ill. It did not. Characteristically, in calling a meeting of all interested parties in the city to discuss AIDS, the department declared that it sought "not to direct but to provide a neutral meeting ground."¹⁸

Sencer, who had presided over the swine flu vaccine fiasco while at the CDC, an effort to mobilize the nation for mass vaccination against an epidemic that never materialized, was wary of launching another dramatic effort.¹⁹ He was not convinced, at least initially, that AIDS would pose a grave threat.

Finally, as public anxiety began to mount, he believed that the assumption of a relatively low profile would contribute to the creation of a climate within which rash acts of discrimination against those with AIDS, and within which calls for repressive measures in the name of public health would be less likely to occur.

In assuming such a posture, he fashioned policies that often coincided with those being pressed by the gay community, which was increasingly concerned about how the threat of AIDS might contribute to the subversion of the hard-won rights of sexual privacy. Indeed, Sencer's recognition that overcoming the deep fear and suspicion that gay men had of agencies of the state was critical to any public health effort to control AIDS was a central element in shaping his initiatives. If the goal of AIDS-prevention policy was to foster the modification of behaviors linked to the spread of disease, then no effort that would create a breach between those at risk for infection and the authorities would advance the public health. In assuming such a stance, much of the traditional repertoire of the response to epidemic threats had to be subject to reconsideration. To those who viewed Sencer's perspective—shared to some degree by many public health officials in cities and states confronted with the threat of AIDS early in the history of the epidemic—the exercise of caution was a reflection of wisdom.²⁶ To others it represented an act of extraordinary timidity in the face of a lethal threat.

SHAPING POLICY IN THE FACE OF CONFLICT: 1985–1986

No controversy more sharply underscored the dilemma of how best to shape the public health policy response to AIDS in the early days of the epidemic than that which centered on gay bath houses. It was inevitable that such a controversy would emerge, since the bath houses were at once the expression of an exuberant gay sexuality, freed from the threat of state intrusion, and commercial settings within which gay men engaged in precisely those forms of anonymous sexual behavior linked to the spread of AIDS. Would the constitutional doctrines of privacy that had emerged in the late 1960s and 1970s protect such settings from public scrutiny, or would the demands of public health be so interpreted as to provide a warrant for their closure?

These issues first took the form of a bitter public controversy in San Francisco in mid-1983.²⁷ For almost fifteen months public health officials, gay leaders, and civil liberties advocates were locked in conflict that riveted the attention of the nation. Only after he had obtained the support of some gay leaders did Mervyn Silverman, the city's director of public health, move to shut the baths as a public health menace. When brought before the courts, that decision was ultimately amended so that the baths could remain open but under standards that would limit the extent to which sexual behavior could occur.

This was the backdrop against which a similar battle was fought in New York City. Commissioner David Sencer had made his opposition to closure clear from the outset. "I can see no reason why we would close the bath houses. I don't think that changing the habitat is necessarily going to change the behavior. . . . To try to legislate changes in lifestyle has never been effective. Public education through the route of organized groups who are at risk is the most important thing."²⁸ His San Francisco counterpart, who had also initially opposed closure, ultimately moved against the baths, but Sencer never changed his mind.

Despite the opposition of the city Health Department and the virtually unanimous opposition of the leadership of New York's gay community, as well as that of the New York Civil Liberties Union, pressure for closure continued to mount. Most critically, conservative political voices demanding the bath houses be shut began to emerge. In the fall of 1985 the Republican candidate for mayor as well as the candidate of the Right-to-Life Party gave voice to such a policy.²⁹ It was the political origins of these demands, linked as they were to a broader opposition to the protection of gay rights, that amplified the anxiety of gay organizations about the ultimate significance of the case for closure. Ultimately, however, the liberal Democratic governor of New York State, Mario Cuomo, also called for closure.³⁰ Finally, in October 1985, the health commissioner of New York State announced his decision that the public health required the bath houses to be shut.³¹ And so, despite the last-minute opposition of David Sencer, New York City was compelled to close institutions that permitted behaviors that everyone acknowledged were linked to the spread of the epidemic, but whose protection had taken on the symbolic significance of protecting civil liberties in the time of AIDS.

As he had displayed great caution—his opponents would term it a kind of paralysis—on the bath house issue, David Sencer also sought to prevent the embrace of other measures that might abrogate the rights of those at risk for AIDS and alienate their most vocal advocates. In mid-1985 a serological test was finally available to detect the presence of antibody to the AIDS virus.³² First developed to screen the blood supply in order to prevent the further spread of infection to those dependent upon transfusions or antihemophilia clotting agents, it was clear virtually from the outset that such a test would also play a role in seeking to prevent the sexual transmission of HIV. Although there was some early uncertainty about the significance of a positive test finding, and considerable controversy about the adequacy of the test, these doubts were quickly resolved. When it became clear that the test was as accurate as most diagnostic tests and that a positive finding represented the presence of active HIV infection, public health officials across the country increasingly began to urge those at risk to be tested as an adjunct to counseling about behavioral change.³³ Most important, the CDC began to call for widespread voluntary confidential testing.³⁴ For those who feared that confidentiality

would be insufficiently protected, the CDC undertook the funding of a nationwide network of anonymous testing sites.

To gay leaders in New York as well as across the country, the test represented a great threat. Vigorous encouragement of testing would ineluctably lead to mandatory testing.²⁹ Those who were infected would be subject to stigmatization and deprived of the rights to work, go to school, and to obtain insurance. Some even feared that the infected would be subject to quarantines. These fears merged the historical suspicions of the gay community in a nation where half the states still criminalized homosexual behavior and the experience of AIDS-related discrimination.

In the fall of 1985, Republican Diane McGrath, who had called for the closure of the bath houses during her electoral challenge to Mayor Edward Koch, also called for mandatory testing of all teachers, food handlers, health care workers, bakers, beauticians, and prostitutes and the banning of those found to be infected from their trades.³⁰ Two local school boards in the borough of Queens had launched a boycott demanding that no child with AIDS be permitted to enter the classroom.³¹ Hospitalized patients reported that orderlies as well as professionals were refusing to provide them with appropriate care.³² Despite epidemiologically rooted reassurances from public health officials, public anxiety, especially in the first years of the epidemic, continued to fuel acts of discrimination that would repeatedly be denounced by health officials as unscientific, irrational, and counterproductive.

The pattern of discrimination provided the backdrop to what was to emerge as a rallying cry by gay organizations, "Don't take the test."³³ Although some gay physicians broke ranks and urged their patients who would not change behavior simply on the basis of counseling and education to be tested, for the most part gay organizations continued to express great suspicion of the HIV antibody test until the late 1980s, when the prospects for early therapeutic intervention altered the political calculus.

Sensitive to the fears of the gay community and reflecting resistance to the adoption of policies that might heighten public anxiety about the AIDS epidemic, the New York City Health Department adopted a posture unique in the nation. It alone refused to establish testing sites where individuals could seek anonymous screening. Counselors employed by the city to respond to phone calls from those anxious about AIDS tended to discourage those interested in testing from seeking such services from physicians. When, at the end of 1986, the Centers for Disease Control urged women at risk for HIV infection to be tested as a way of identifying those who could transmit AIDS to their offspring, the Health Department's Bureau of Maternity Services and Family Planning sought to issue guidelines that would have discouraged testing.³⁴ Mirroring the perspective of the Health Department, the Health and Hospitals Corporation, which managed the city's municipal hospitals (serving the poor

and medically uninsured), sought to discourage clinicians from even offering HIV tests to patients who were free of AIDS symptoms.

It was only with regard to HIV infection among New York City's intravenous drug users that David Sencer sought to press for bold and innovative measures. Unlike those public health measures which he resisted because of concern over alienating the gay community and "pushing the epidemic underground," these were designed to lift the burden of criminalization that shaped the lives of drug users.

From the earliest days of the epidemic it was clear that those who injected drugs were at increased risk for AIDS because the needles they often shared were frequently contaminated. As early as 1984, drug sellers had begun to hawk sterile needles and syringes, or counterfeits of such equipment, at a premium, thus reflecting an awareness among users about the dangers associated with drug injection. "Get the good needles, don't get the bad AIDS."³⁵ Like others, Sencer began to consider the necessity of adopting policies that would permit those driven to use drugs to do so in a way that did not necessarily involve a risk of HIV transmission.

In the summer of 1985 Sencer wrote to New York's mayor urging that the laws restricting access to sterile injection equipment be radically changed.³⁶ "By forcing addicts to use others' needles and syringes we are condemning large numbers of addicts to death from AIDS. A live addict may be amenable to treatment of his drug abuse. But an addict infected with [the AIDS virus] continues the spread of AIDS, not only to other addicts but to their sex partners and, tragically, to children born of such parents." Although cautiously supported by the *New York Times* and the mayor, the proposal provoked an outraged response from law enforcement officials, who viewed it as a capitulation to drug abuse, a threat to the effort to contain such behavior.³⁷ Ultimately, the mayor yielded to such opposition. "How can I support something that the police and law enforcement leaders are totally against?"³⁸

NEW LEADERSHIP, HEIGHTENED CONFLICT, AND THE POLITICS OF EPIDEMIC CONTROL: 1986-1990

The response of the city's health department to AIDS underwent a fundamental change in mid-1986 when Stephen Joseph was appointed commissioner. Joseph was by temperament more drawn to the public fray than Sencer. Thus, he sought to use his office to mobilize public concern about AIDS. Assuming office at a time when increased federal and state funds enhanced the city's capacity to confront AIDS, Joseph presided over a rapid increase in his department's budget: from \$143 million in 1985 to \$241 million in 1989. The funds devoted to AIDS increased from less than 1 percent of that budget to more than 7 percent; the number of staff devoted to AIDS work from 17 to over

350.³⁹ During Joseph's tenure the department undertook an aggressive campaign to urge individuals to seek testing for HIV infection and launched a number of blunt public information campaigns directed at heterosexuals, drug users, and gay and bisexual men.

Committed to using his office as a "bully pulpit," Joseph was nevertheless hampered by the limited functions of his department. Whatever his vision of the mission of public health in the face of the AIDS epidemic, the unique division of public health functions among the city's bureaucratic structures frustrated his efforts. In an epidemic that was increasingly rooted in drug abuse, he was without the resources or authority to expand drug abuse treatment, which since the mid-1970s had been a state prerogative. Confronted with an ever growing crisis in the provision of care to the city's poor who were afflicted with AIDS, he had virtually no capacity to expand clinical services, a responsibility that rested largely with the Health and Hospitals Corporation and ultimately with the state's Health Department. In a city where many with AIDS were dependent upon the welfare system, he had no capacity to expand the services that were the responsibility of the Human Resources Administration. In short, what was for the Department of Health the preeminent challenge was for others one of a number of social crises requiring management.

From the perspective of gay activists and others for whom AIDS was the issue confronting the city, the result was an abysmal failure.⁴⁰ The mayor was often accused of refusing to assert his leadership. So was the governor. Finally, AIDS activists recognized that it was the federal government that was responsible for much of the local failure, since it was the administration of Ronald Reagan that had presided over the epidemic's first years by resisting the introduction of adequate funding of research into treatment, support for preventive activities, and needed clinical and social services. The volunteerism that had flourished in the face of AIDS was clearly inadequate to the task of facing the city's epidemic burden. The work of the Gay Men's Health Crisis, which by the late 1980s had entailed the efforts of more than 8,000 volunteers, and other community-based groups, often created and funded by New York State to serve the city's black and Hispanic communities, were inadequate to the tasks imposed by the needs of those who were ill with HIV-related diseases.⁴¹

This was the context within which an explosion of rage greeted Commissioner Joseph's mid-1988 announcement that earlier estimates of the number of infected New Yorkers had been vastly overstated. Rather than 400,000 infected individuals, he asserted, the figure was closer to 200,000.⁴² To those who believed that the recalculations were politically motivated there was but one explanation: in the absence of adequate services, simply declare a need for fewer services by reducing the number of infected persons. The new estimates

were based on careful epidemiological modeling. But despite the belief by local and federal officials that the new statistical projections represented a more accurate picture of the extent of HIV infection in the city, the atmosphere of profound distrust that characterized the public debate of AIDS made reasoned discussion all but impossible.⁴³

Most striking was the response of ACT-UP, the AIDS Coalition to Unleash Power. Disaffected by the more conventional styles of protest of mainline gay political and AIDS service organizations, ACT-UP, which adopted the pink triangle as its symbol, "Silence = Death" as its motto, relied upon the forms of direct action reminiscent of the 1960s. Joseph became the target of ACT-UP's wrath. His office was occupied by protesters, his speeches were greeted with cries of derision. Across the city, posters appeared emblazoned with a bloody hand. Because of his failures, Joseph was portrayed as being responsible for the deaths of thousands.

If the gay community was alienated from Joseph because of his "epidemiological politics," the city's minority community was outraged by his insistence that David Sencer's proposal for needle exchange be subjected to an experimental trial. Resisted for more than a year by the state's health officials, the proposal for such an experiment ultimately received the necessary approval on the condition that it be small and serve only as a bridge to treatment for addicts awaiting admission to conventional therapeutic programs.⁴⁴ Scheduled to begin in the fall of 1988, the needle plan, in which addicts would be required to exchange used drug injection equipment for sterile paraphernalia, produced a bitter reaction from the city's black and Hispanic leadership. Benjamin Ward, the black police commissioner denounced it as the equivalent of the infamous Tuskegee syphilis experiment.⁴⁵ In a letter published in the *American News*, New York's leading black newspaper, and signed by Harlem's congressional representative, Charles Rangel, Queens representative Floyd Flake, Sterling Johnson (the special assistant district attorney for drug prosecutions), Wyatt Walker (the pastor of Harlem's Covenant Baptist Church), and Wilbert Tatum (publisher of the *American News*), the plan was denounced as "a very serious mistake" that would represent the first step toward legalizing drugs. The Black and Hispanic Caucus of the City Council also denounced the proposal, declaring it "beyond all human reason and common sense." One black councilman termed the proposal genocidal and declared, "When the first needle is given out by Dr. Joseph, he ought to be indicted and arrested for murder and drug distribution."⁴⁶ Finally, community groups opposed the planned use of neighborhood health clinics as distribution points since centers would inevitably be too close to public schools.

Despite the expressions of distrust and vilification, the Commissioner, backed by the mayor, opened the first clinic in November 1988. Because of the community-based opposition, all needle exchange was centralized at the

Health Department's offices in the shadow of the Criminal Court Building. And so began a much-hobbled initiative that resembled David Sencer's initial proposal in only the remotest way.

The bitterness about the course of AIDS prevention policy during Stephen Joseph's tenure found its final expression in the summer of 1989. Convinced that the strategy of AIDS prevention in the epidemic's first years had failed to call effectively upon the tradition of public health epidemic control, and motivated by the prospects opened up by the rapid development of therapeutics in 1989, which suggested that early clinical intervention could slow the development of lethal disease in those infected with HIV, Stephen Joseph sought to chart a new direction. Using the venue of the Fifth International AIDS Conference in Montreal, he declared that it was time to begin "a shift toward a disease control approach to HIV infection along the lines of classic tuberculosis practice."⁴⁷ 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."

To gay leaders and advocates of civil liberties, Joseph's embrace of traditional public health practice, involving a more aggressive reliance on screening, the reporting of the names of infected persons to the Department of Health, contact tracing, and the selective use of the power to quarantine when infected persons continued to behave in ways that placed sexual or needle-sharing partners at risk, represented a profound assault on what they had come to believe was the appropriate strategy for confronting the AIDS epidemic—a strategy that recognized the centrality of the protection of the right of privacy. Marshaling evidence from studies across the nation that suggested that compulsory reporting of HIV infection would discourage individuals from coming forward for testing, they argued that the proposed new course would have the unintended consequence of driving individuals away from testing, precisely at a moment when clinical advances suggested that they seek testing. To groups such as GMHC, which had just undertaken a radical rethinking of their antagonism to testing, the commissioner's call seemed a special insult.

Joseph's proposal—in truth a reflection of the reconsideration of mandatory reporting by many public health officials—opened a debate that was only temporarily settled by the defeat of New York Mayor Edward Koch in his bid for reelection in the fall of 1989. When newly elected Mayor David Dinkins, who as the city's first black mayor had relied upon the support of New York's gay voters, announced the appointment of Woodrow Myers, Indiana's black commissioner of health, as Joseph's replacement, the issue resurfaced. Myers had supported named-reporting in Indiana.⁴⁸ Now the controversy took on distinctly racial overtones. White gay leaders and their liberal political allies opposed Myers's appointment when his past policies became known. To black leaders this opposition represented an insult to the black mayor and an assault on his right to shape a new administration. The controversy, which left many

embittered and some saddened, was brought to a close only when Dinkins announced that, despite the opposition of some gay leaders and especially that of ACT-UP, Myers would be the City's health commissioner, although there would be no reporting of the names of those with HIV infection.⁴⁹

The truce was once again shattered when Commissioner Myers, fulfilling a promise made by Dinkins during his campaign, ended the city's small needle exchange program.⁵⁰ Liberals and gay leaders, who had enthusiastically endorsed this aspect of Stephen Joseph's AIDS policy, were thus presented with a profound disappointment at the hands of the mayoral candidate they had supported. Disappointment turned to dismay when in the late spring of 1990 Commissioner Myers sought to cancel a small municipal contract with ADAPT, a community-based organization committed to educating drug users about AIDS prevention, because part of its effort involved the distribution of bleach for the sterilization of injection equipment.⁵¹ An approach to working with drug users that had rarely provoked opposition anywhere in the United States except from the most socially conservative, bleach education and distribution had attained an important symbolic status for those who sought to fashion policies designed to inhibit the spread of HIV infection.

In challenging such programs, Myers had made it clear that he had priorities beyond those of preventing HIV transmission—some began to wonder whether AIDS would be a priority of his at all. "There's a higher goal than the reduction of transmission of HIV and that goal is the elimination of the use of illegal narcotics by injection, period. . . . I just happen to believe very strongly that people who are using drugs ought to stop using drugs." As a consequence, he opposed efforts to "teach them how to use drugs safely."⁵² Myers's position reflected the views of the city's black and Hispanic leadership. His decision reflected the changing balance of power in local AIDS politics. Myers's action was supported by the Black Leadership Commission on AIDS, which saw the distribution of bleach as a "Trojan horse for the African American Community" and as failing to address the root causes of drug use and the scarcity of drug rehabilitation programs.⁵³ Myers's effort to cancel the city's contract with ADAPT provoked a sharp reaction from white AIDS activists in ACT-UP as well as from liberal political leaders, some of whom referred to it as "genocidal."⁵⁴ What this controversy underscored was the deepening fissure between the gay and white liberal constituencies that had helped to shape the broad outlines of AIDS policies in the epidemic's first decade and the ascendant leadership of the black community that sought to define a strategy appropriate to an epidemic that was increasingly taking on the dimensions of a dire problem for the city's impoverished black and Hispanic communities.

The conflict between the city's gay community and the health department abated with the sudden resignation of Myers, who had proved to be a poor manager. His replacement, Margaret Hamburg, found a department in disarray, many of its most talented officers had been forced to resign or had left

their positions in despair. Most important, Hamburg was not committed to the ideological posture that had characterized her predecessor. With evidence mounting on the potential efficacy of needle exchange programs—most strikingly from New Haven, which had undertaken a trial effort under the leadership of a black mayor—she was instrumental in moving Mayor David Dinkins to a more open position on the matter.

A confluence of factors, including a reversal of the position of the Black Leadership Commission—the incapacitation of the state's health commissioner, who had been unsympathetic to needle exchange; a major funding initiative for community-based needle exchange programs by the American Foundation for AIDS Research (AmFAR); and the acquittal on grounds of "necessity" of several ACT-UP members who had been arrested for illegal distribution of sterile injection equipment, cleared the way for the beginning of legal needle exchange efforts in New York City. In 1992, three such programs were functioning at a variety of locales in the city. Funded by the State Health Department and AmFAR, these efforts failed to provoke the outrage that had greeted the efforts of Stephen Joseph four years earlier. Remarkably, the opposition of the black community had all but vanished.

CARING FOR THE SICK: THE PRICE OF NEGLECT

The initial response of the city's black and Hispanic leadership to proposals for needle exchange must be viewed in the context of rising anger and despair over the city's failure to provide an adequate rehabilitative response to the problem of heroin, cocaine, and crack abuse. There were in New York City two hundred thousand drug injectors and many thousands more who used crack and other drugs. This failure was in turn a reflection of the unwillingness of both the state and federal governments to provide the necessary funding for such services. But such inadequacy was but a small part of a much broader problem: the inadequacy of funds to provide for the medical services needed to meet the clinical needs of the rising number of patients with AIDS-related disorders. As the importance of early prophylactic treatment with AZT (for slowing the progression of viral infection) and pentamidine (for inhibiting the occurrence of pneumocystis pneumonia) became clear in mid-1989, the crisis in health care became all the more obvious. It was not only those with frank disease who would now need care, but the much larger group of individuals with asymptomatic HIV infection.

As early as the spring of 1988, the dimensions of the impending crisis were already clear. Investigators writing in the *Bulletin of the New York Academy of Medicine* thus noted that "to ignore the possibilities inherent in the empirical evidence available is to create a social calamity even greater than the one

already perceived. . . . The AIDS epidemic threatens not only individual lives but the city's health care, education and research environment as well. The time is short, the need is great and is likely to grow rapidly."³⁸ Within a year three separate reports by public- or voluntary-sector groups detailed how far New York was from being able to meet the demands of the epidemic.³⁶ All agreed that community-based organizations, typically within the gay community, had provided an extraordinary range of services to those with HIV infection and AIDS but could not meet the needs that public bodies and large private-sector agencies were responsible for meeting. Volunteerism was no substitute for the institutional response that was demanded. Three to five hundred new acute-care hospital beds would be needed each year for five years in order to meet the requirements of those who would become ill. In addition, hundreds of nursing home beds and special housing units would be needed for those requiring less-intensive medical care. The capital costs alone for meeting these demands would be over \$700 million. And if only half of those who could benefit from ambulatory care for HIV infection were to seek it, the city's already overburdened clinic system would have to absorb an additional eight hundred thousand visits a year. Commenting on the care and attention to detail revealed in each of the report projections, Kenneth Raske, president of the Greater New York Hospital Association, said, "This is the biggest amount of planning for an epidemic with the least amount of action to go along with it."³⁹

When the state of New York, upon which the city was so financially dependent for health care services, announced its five-year plan for AIDS in early 1989, Governor Mario Cuomo acknowledged that he was not able to provide the funds to meet the state's goals "realistically." Liberal political leaders denounced the governor's fiscal restraint. Richard Gottfried, chair of the state assembly's health committee, termed the governor's proposed budget "a blueprint for disaster."⁴⁰ ACT-UP turned to the streets. Approximately three thousand demonstrators chanting "ACT-UP/Fight Back/Fight AIDS" appeared at City Hall. Two hundred were arrested.³⁹

The looming crisis in health care in New York as well as in other cities across the United States set the stage for congressional action in 1990 that could scarcely have been imagined a short time earlier. It was the fruit of dogged efforts on the part of AIDS activists, their allies, and some political leaders from the cities and states that had borne the disproportionate share of AIDS cases. In the winter of 1990, Senator Edward Kennedy, the exemplar of Democratic party liberalism, and Senator Orrin Hatch, a Republican whose stance on abortion often cast him in the role of a conservative, jointly sponsored legislation—Comprehensive AIDS Resource Emergency Act of 1990—that would provide a major infusion of federal assistance to those localities most severely burdened by 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.⁵⁰

As remarkable as 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 in favor was 95-4. When similar legislation, with even greater resource commitments, was voted on by the House of Representatives, the vote was 408-14.⁵¹

But the hopes of early summer 1990 were dashed by the fall as the Congress, confronted with a severe budgetary crisis, slashed funds for what was now called the Ryan White Act.

The limits of this federal initiative will inevitably have a profound impact on the capacity of New York City to manage the ever-growing burden posed by the AIDS epidemic. As the city and state began to confront new fiscal crises in the latter part of 1990, it was clear that capacity would be subject to even greater strain. In the spring of 1990 there were already signs of what the future might bring. Several clinics created to treat people with HIV infection had waiting lists of up to three months. Two clinics had closed their waiting lists, and only 13,000 of the estimated 40,000 to 140,000 who could benefit from AZT, the only licensed antiviral agent, were receiving it.⁵²

For close observers of the chronic but escalating crisis in health care in New York City, it was not too soon to start thinking of worst-case scenarios.⁵³ They began to argue publicly that the impact of AIDS would affect the ability of the city's medical and social service infrastructure to provide care not only to those with HIV infection but to others as well. As a consequence, middle-class patients together with their physicians might increasingly flee the city in search of medical care in the suburbs. If they remained and were able to protect their own interests by insulating themselves from the critical shortage of hospital beds, those institutions forced to bear the burden of caring for the poor would be compelled to restrict even further access to in-patient care for "elective" procedures. While middle-class patients with HIV infection would continue to receive increasingly effective outpatient care from their overworked physicians, the poor would face growing delays and waiting lists as they sought the benefits of early therapeutic intervention. Many, discouraged, would simply not seek care at all.

Shortages would impose the need for rationing, and in the political economy of a city like New York, competition among the desperate would ensue. In what Bruce Vladeck, then president of the United Hospital Fund, and now the assistant secretary of the federal Health Care Finance Agency, termed the "calculus of misery," it would become increasingly necessary to choose between AIDS cases and the frail elderly for admission to nursing homes; be-

tween 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; between HIV-infected pregnant women and women not yet infected for admission to drug abuse treatment programs.

New York, the epicenter of the American epidemic, yet dependent upon resources from the state and federal governments, would thus witness not only a grave medical challenge but increasingly aggravated social conditions as it prepared to face the second decade of AIDS.

ENVOI: THE RETURN OF TUBERCULOSIS

In 1992 the attention of public health officials as well as the media was seized by a new HIV-related challenge, the resurgence of tuberculosis, a disease that had long been thought tightly under control. Socially rooted in the rise of homelessness, untreated drug addiction, and a swelling prison population, the rise in new cases of tuberculosis was centrally linked as well to the AIDS epidemic. Those with HIV infection are, because of compromised immune systems, at vastly greater risk of developing TB once infected with *Mycobacterium tuberculosis* than those who are not dually infected. As a consequence, the epidemics were epidemiologically joined.

But it was the singular unpreparedness—despite the fact that TB cases had been rising since the early 1980s—on the part of the public health system that made the rising incidence of TB so perilous. Underfunded and understaffed, the city's TB control apparatus was utterly incapable of monitoring the treatment of those with disease. As a result, drug-resistant strains became ever more common. By April 1991, 20 percent of those diagnosed with tuberculosis in New York were resistant to treatment by Rifampin and Isoniazid, the two antibiotics most relied upon for TB treatment. While most drug-resistant cases occurred in individuals who had failed to complete an initial course of therapy, there were indications that resistant organisms were being transmitted to those who had never had tuberculosis. The overall case fatality rate for drug-resistant tuberculosis was 40-60 percent—precisely the case fatality of untreated drug-susceptible TB. In those cases where resistant strains were transmitted to individuals with HIV infection, the outcome was almost universally fatal.

Thus poverty, the AIDS epidemic, and the fiscal crisis in New York that so limited the responsiveness of the public health system threatened, in 1992, to turn a formerly treatable disease into a virulent new threat to all New Yorkers, but most especially to those infected with HIV.

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The City Responds



Interior of mobile Salk polio vaccination clinic operated by the New York City Department of Health, as an adult took advantage of the free Salk polio shot made available to him. New York, August 4, 1959. Collection of March of Dimes Birth Defects Foundation.