The AIDS perplex

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The first decade of the AIDS epidemic is drawing to a close, with no clear understanding of the full scope of the disease's impact. The present situation—95,000 AIDS cases reported in the United States in mid-1989—is bad enough, but not nearly so troubling as what inevitably lies ahead in the next five years. The Centers for Disease Control (CDC) estimate that AIDS has already infected between 945,000 and 1.4 million Americans; by 1993, say the CDC, there will be 450,000 full-blown AIDS cases in the U.S. Even as the rate of infection among homosexual men declines, increased rates of viral transmission through intravenous drug use and heterosexual sex, disproportionately among blacks and Hispanics, will push these figures higher.

Worldwide, there will be more than a million reported cases by the early 1990s, the World Health Organization (WHO) reports. More than half will be from Africa, where inadequate epidemiology, social taboos, and political calculations rooted in (perhaps not entirely unjustified) suspicions of racist finger-pointing will keep the official numbers artificially low. The actual worldwide count, says WHO, could be more than twice as high.
Beyond this more or less knowable immediate future, things are more uncertain and potentially far more catastrophic. Mathematical forecasting models reach very different conclusions about the spread of AIDS a decade from now. Reputable optimists in the scientific community imagine a disease that is running its course, at least in the developed nations. Equally reputable pessimists such as Stephen Jay Gould speculate about a pandemic that could claim the lives of a quarter of the world's population. Those gross differences, and the entirely different visions they evoke in our imaginations, are inevitable when key factors—among them the projected rates of transmission through heterosexual sex and intravenous drug use, the likelihood that an effective vaccine can be developed, and the possible development of new HIV strains that will complicate efforts to defeat AIDS—cannot be predicted.

It is not just the AIDS numbers that are hard to grasp but also, more significantly, their meanings. From the beginning, there have been alarmists who have seen AIDS as an apocalypse. The tocsin has been sounded by different people for different reasons—by homosexual activists (most notably Larry Kramer in his play The Normal Heart), to inform their fellows of the perils of promiscuity; by social scientists and laboratory researchers, to attract political interest and money to study the disease; by sexologists Masters and Johnson, who in Risk: Heterosexual Behavior in the Age of AIDS, published last year, misuse epidemiological data to claim that "the AIDS virus is now running rampant in the heterosexual community"; and by extremist Lyndon LaRouche, to incite popular paranoia.

Understandably, there has also been a countertendency to domesticate AIDS by describing it in familiar terms. This urge to minimize is apparent in calls to treat AIDS simply as a matter of public health, disentangled from politics and passions. In the ceaseless debates over AIDS policy, each side has frequently accused the other of using science for political purposes. The argument over whether the names of all those who test positive for HIV must be reported to public-health officials, waged during 1988 in Congress and in California (where a proposition requiring such reporting was defeated by the voters in November 1988), has just this character. Proponents insist that AIDS be treated like any other sexually transmitted disease and accuse their antagonists of caving in to the militant homosexual crowd. They find a scattering of doctors who support their view. Opponents maintain that de-
manding notification is the politicizing act, producing only fear and driving underground those most at risk. They rest their argument on the seemingly neutral wisdom of former Surgeon General C. Everett Koop.

In *AIDS and Its Metaphors*, 1 Susan Sontag’s subject is public language, not public policy. But as George Orwell pointed out decades ago in “Politics and the English Language,” the two are intimately connected: we are, in good part, what we say. Sontag’s ambition is to strip the barnacles of meanings from AIDS, to treat it as just a disease. Sandra Panem, in *The AIDS Bureaucracy*, 2 has a very different subject: the management of the federal agencies that make AIDS policy. But her goal, like Sontag’s, is to put AIDS into a familiar category—disease, for Sontag; public-health emergencies, for Panem—and in so doing to deemphasize its uniqueness.

Both Sontag and Panem are undone by this common intention. The implications of AIDS are unlike those of cancer, Sontag’s signal example of a disease made more killing by the language of fault that has been attached to it. Nor, pace Panem, is AIDS like swine flu or tuberculosis.

AIDS is a plague, the kind of event that, as recently as fifteen years ago, many scientists believed would never again trouble us. It has sweeping and entirely contemporary consequences for relations between intimates, and between the government and the governed. AIDS tests both personal and public character—a point made with force and grace in Ronald Bayer’s *Private Acts, Social Consequences*. 3 Thinking through its implications without succumbing to paralysis requires us to resist both the familiar and the apocalyptic.

**AIDS metaphors and their meanings**

With AIDS, even more than with other diseases, imagery bears on policy; consider, for instance, the mammoth quilt memorializing the victims of AIDS that has stirred passions around the country. A decade ago, when she herself was seriously ill with cancer, Susan Sontag wrote *Illness as Metaphor*. That essay was, and re-

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mains, an influential statement of the consequences of using disease as a cultural metaphor. Such images, Sontag argued, invite people afflicted with the disease—cancer in the 1970s, tuberculosis earlier—to perceive themselves with shame, which encourages them in their denial and dissuades them from receiving treatment that could save their lives.

“The purpose of my [earlier] book was to calm the imagination,” Sontag declares in *AIDS and its Metaphors*, “by insisting on candor and not mystification in approaching cancer, by rejecting the contention that this disease had any intrinsic meaning.” Never mind that all thinking—including medical thinking—is metaphorical, that we cannot understand something except by likening it to another thing: there is something of value in the intention to stand against interpretation.

With AIDS, too, it is useful to calm the imagination; but AIDS and cancer are different in ways that undermine Sontag’s project. If cancer made newly vulnerable those it affected, AIDS seemingly singled out the already vulnerable—homosexuals and intravenous drug users—as its targets, condemning both the actors and the acts. Cancer patients have generally met with humane concern rather than revulsion, while victims of AIDS were already the targets of ancient hatreds.

It is unclear where, precisely, Sontag locates the mischief inherent in AIDS metaphors. In some passages of her essay she cites metaphorical language itself as the source of destructiveness, but that is to attack every attempt at description. Elsewhere she directs her animus against the military metaphor for disease: “It overmobilizes, it overdescribes, and it powerfully contributes to the excommunicating and stigmatizing of the ill” by demonizing the disease and its patients. Yet the symbols of belligerence can be powerful aids to those suffering from AIDS, actually encouraging them to seek help and to come to their own defense. This is true of all illnesses, but AIDS (for which, unlike cancer, there are no cures) seems to magnify the need to deploy military metaphors. That much is attested to by the volumes of prose, drenched in the language of combat, that have been written by those touched by the disease.⁴

It is the uses of metaphor, not metaphor itself, that potentially cause the most trouble. The language of warfare can be applied to define someone with AIDS as the alien, as in columnist Patrick Buchanan's assault on the "sodomist," upon whom nature takes "revenge" for having "declared war on nature." But even here the critique of metaphor needs qualification, for the same imagery can also help mobilize us against a disease (the War on Cancer) or a social evil (the War on Poverty), by invoking what William James called the moral equivalent of war. In those instances, as Sontag acknowledges, the military metaphor is a way of asking people to act in ways that the calculus of self-interest does not contemplate—to set aside the notion of pleasure without price, of harmless recreational sex and drug use, and to replace it with a commitment to civic-mindedness.

Metaphors are useful when they help us to comprehend the incomprehensible. To refer to AIDS as the "gay plague," as did a 1983 *Newsweek* cover story, was to misdescribe the disease. But the less charged reference to AIDS as a plague evokes memories of our greatest collective disasters. It invites us to resist the temptation to minimize the implications of the disease. It also invites us to imagine, as in Albert Camus's *The Plague*, the possibility of a communal response to something that touches us all. As with the language of warfare, the meaning of this metaphor depends on circumstance, but there is no escaping the need for metaphor.

**Mismanaged AIDS**

Sandra Panem's account of the management of AIDS in *The AIDS Bureaucracy* occupies the middle-brow terrain of policy discourse. There are no multifaceted metaphors here, but only a discussion of the structural weaknesses of the federal agencies (including the National Institutes of Health, the Centers for Disease Control, the Public Health Service, the Food and Drug Administration, and the Department of Health and Human Services) that have shared—more precisely, have juggled and sometimes evaded—responsibility for AIDS research, preventive education, and health care.

Those structural weaknesses—redundancy and overlap on the one hand, gaps on the other—explain governmental failures, Panem argues. Although the standard operating procedures of our public-health system were sufficient to handle routine demands,
they could not respond with adequate speed or coordination to an emergency like AIDS.

Panem proposes creating a system to deal with what she calls "novel health emergencies." There would be generous, centrally controlled, multiyear funding, with substantial discretionary authority for expenditure; central management of research, drawing in the nation's best scientists; long-term strategic planning; and early public education.

Many of these recommendations are echoed in the report of the Presidential Commission chaired by Admiral James Watkins. And many of them make sense. Who could argue against emphasizing education—particularly when, in the absence of either a vaccine or a cure, it is the best public-health strategy available? Yet Panem errs in assuming that the design of a federal AIDS policy is simply a matter of applying the neutral calipers of public management, cost-benefit analysis, and public health to a flawed bureaucracy. In fact, wherever one looks in the annals of AIDS, political considerations dominate: these are among the items on the Watkins Commission's lengthy list of "obstacles to progress."

The shortcomings of federal AIDS policy during the early years of the epidemic, when most could have been accomplished to slow its spread, are not due primarily to inadequate communication, to hyperproceduralized mechanisms for distributing money, or to antiquated working conditions at the Food and Drug Administration. Although all those impediments did exist, and many still do, they could have been overcome, given sufficient will. But the problem is at once broader and narrower than bureaucratic structures: it has to do with both the design of health policy and the specifics of AIDS.

Critics of federal AIDS policy, such as Randy Shilts in And the Band Played On, write as if the Reagan administration was uniquely hostile to AIDS research. As it happens, each increase in AIDS-related appropriations was foisted by Congress on an unwilling White House. But in this respect AIDS fared no worse—indeed, fared rather better in dollar terms—than any other health initiative. With the significant exception of cost containment, there was little interest on the part of the Reagan administration in

exercising leadership on any health issue. Health-care budgets were cut generally. Responsibility was shifted from Washington to the states and private enterprise. The idea of comprehensive health insurance, bruited about in the 1970s, was a nonstarter in the 1980s.

AIDS raised both the level of the demands on Washington and the level of resistance to them. The assertedly unmet needs associated with AIDS seemed endless. In the litany of the Watkins Commission and in *Confronting AIDS*, the generally like-minded report from the National Academy of Sciences published in 1986 and updated in 1988, such needs included education; scientific research into new forms of medical treatment; new methods of treatment, such as at-home and hospice care; and vastly expanded drug-treatment programs.

Not surprisingly, the Watkins Commission presented the White House with a stupendous bill. Equally unsurprising was the Administration's studied lack of enthusiasm. For conservatives, this latest recital of unmet AIDS needs amounted to empire building by self-interested scientists and program padding by constituent-driven congressmen. They saw it as an emotional shout for "more," not rigorous analysis; in their view, such shouts should be met with calls for more cost consciousness and local responsibility. For liberals, on the other hand, the commission's report only confirmed that the Reagan administration's emphasis on localism and privatization, as well as its hypersensitivity to the moral connotations of illness, threatened the public's security against infectious disease.

Hardball politics has been played at each moment in the debate over the proper federal response to AIDS. In *And the Band Played On*, Randy Shilts offers telling tales—of Assistant Health and Human Services (HHS) Secretary Edward Brandt, defending the Administration's budget proposals on the Hill while pleading privately with his bosses for funds to let the CDC and NIH do their jobs; of Susan Steinmetz, New York congressman Ted Weiss's AIDS staffer, being shut out of the CDC on the flimsy pretense of the Centers' protecting the privacy rights of patients; of HHS Secretary Margaret Heckler claiming Administration credit for developing an AIDS vaccine, without any basis and against the advice of her aides.

Shilts also documents the extent to which the Reagan administration's response was premised on the understanding that AIDS primarily targeted homosexuals and drug addicts, two groups for
which the White House had little regard. In May 1984 Assistant HHS Secretary Brandt was obliged to renege on a commitment to present an award to the Blood Sister Project of San Diego. During a profound crisis in the blood banks, with homosexual men and misinformed members of the general public staying away, the group had persuaded hundreds of lesbians to donate blood. This was Reagan-style voluntarism, but right-wing allies of the Administration insisted that Brandt's acknowledgement of the Blood Sisters was "an outrageous legitimization of a lifestyle repugnant to the vast majority of Americans."

Antagonism to homosexuals and drug users shaped the substance as well as the symbols of federal policy. AIDS education was designed as the cornerstone of this policy. Yet in 1988, at the insistence of Senator Jesse Helms (who threatened to block the first comprehensive federal AIDS legislation) the education campaign was gutted. No federal funds can be spent now "to promote or encourage, directly or indirectly, homosexual sexual activity and intravenous drug use." The CDC, which disburse the funds, read this requirement to mean that no safe-sex instruction for homosexual men and no advice on sterilizing needles can be underwritten by Washington. Nothing more useful than counsels to abstinence may be offered. "Demeaning, disgusting garbage," Helms called one safe-sex video that caught his eye. "We should not allow the homosexual crowd to use the AIDS issue to promote and legitimate their lifestyle in American society." Not even the plea of Utah Senator Orrin Hatch could budge Helms. "I do not agree with their sexual preferences," said Hatch. "But that does not mean I do not have compassion for them, that I am just going to write them off and tell them to forget it, go ahead and die, because they differ from me."

The other health emergencies that Panem identifies—the predicted 1976 influenza outbreak, the threatened depletion of diphtheria-pertussis-tetanus (DPT) vaccine in 1985—did not generate such diatribes. In the AIDS debate, differences in tastes have taken precedence over concern to save lives. Any effective AIDS policy has to confront not just the bureaucratic but the emotive as well—the fear and loathing, the taint of association with the deviant that the disease conjures up in the popular imagination. Responding to AIDS means more than spending more dollars or building better bureaus. It requires emphasizing care for the sick on one side, and social responsibility on the other.
AIDS and civic-mindedness

Let there be an AIDS "emergency czar," Panem urges. "[T]he responsibility must be placed with knowledgeable public health officials...[who can] coordinate diverse health activities during an emergency." The goal of this proposal (which the National Academy of Sciences report and Admiral Watkins, though not his commission, also advanced) is to develop a fact-based strategy untainted by politics and ideology.

But centralization is not value-free. It spells power, and so does coordination, for someone is always "coordinating" someone else. The critical question remains the purpose for which that power is exercised. As Ronald Bayer points out in Private Acts, Social Consequences, there is no such thing as an apolitical health policy, and "facts alone do not dictate the course of public health action." Bayer's thesis is not the obvious one that, in matters of social policy, the facts are often uncertain. Rather, he is arguing that negotiation with the body politic—with people who are often (and blessedly) fractious, suspicious, distrustful—is critical to crafting a workable response to AIDS.

Because AIDS is transmitted by intimate behavior whose details cannot be routinely regulated by government, cooperation with those at risk must be the first line of defense—unless, that is, one is willing to adopt the Cuban approach of quarantining everyone with the HIV virus. Difficult questions arise when a course that promotes social welfare infringes upon individual liberty. Sensible responses, says Bayer, fall between the two extremes. They require official actions—aimed at changing individuals' behavior and attitudes to nurture a "culture of restraint"—as extraordinary as AIDS itself.

In writing about AIDS, one easy temptation is to reconfigure the past and settle scores, charging with stupidity or venality those who failed early on to grasp the disease's full implications. But Bayer recalls the complexities, even when detailing debates over matters that today scarcely seem debatable: Should the homosexual bathhouses be closed? Should members of high-risk groups be discouraged from donating blood? In doing so, he reminds us that while the particulars have now been settled, the underlying concerns—over privacy in the first instance, social stigma in the second—remain significant.

Private Acts, Social Consequences takes the reader through the major policy controversies regarding the reporting of AIDS tests,
the content of AIDS education, the need for mandatory screening and quarantining. Restraint, says Bayer, is required from those at increased risk of transmitting the virus—hence the value of closing the bathhouses, venues of promiscuity, in order to encourage radical changes in private behavior. Restraint and responsibility are also needed from the political and public-health leadership, which has generally opposed alarmism, inviting changes in behavior rather than trying to compel them.

Although the Reagan administration pressed for widespread AIDS testing, most politicians and public-health officials (including, notably, then-Surgeon General Koop) have preferred voluntarism. This was both sensible public-health policy and sensible politics, they argued. Widespread testing would produce an alarming number of false positives among populations with a low incidence of the AIDS virus; it would arouse suspicion and resistance in those most at risk, who most need to acknowledge the value of restraint. In the states hit hardest by AIDS, California and New York, state and local health officials forged ties with homosexual groups, which early on were already offering AIDS-prevention education. Those connections promoted trust between care-givers and those needing care, as well as encouraging sensible allocations of turf between public and private agencies.

Despite massive publicity about how AIDS is transmitted, nearly one American in four still believes that AIDS can be spread by a handshake, a hug, or a doorknob. Yet despite these misperceptions, the populace has resisted extremists’ urgings to paranoia, exercising a remarkable collective restraint. Nowhere is this more evident than in California, the state with the largest number of AIDS cases, where in 1986 and again in 1988 voters defeated measures to exclude AIDS-carriers from schools and work places. Thus far, proposals to discriminate have been rejected. But proposals to protect people with AIDS against discrimination have not been enacted either, despite the urgings of the Watkins Commission and Bayer. The Reagan White House was opposed to such measures, but with George Bush having gingerly offered support, federal nondiscrimination legislation may pass this term.

Bayer is critical of certain strategies of homosexual activists—in opposing even voluntary AIDS testing, for instance—even as he acknowledges the well-grounded fear from which those strategies spring. He repeatedly points out the deficiencies of an approach to AIDS centered entirely on rights; and he seriously considers pro-
posals that would restrict rights, as by punishing irresponsible at-risk blood donors or by quarantining infected people who knowingly endanger others. While such sanctions are very difficult to impose fairly, it is discourse more than decision that most concerns Bayer. The refusal even to acknowledge these options in public represents "a failure to recognize how public health officials could shape a culture of responsibility by focusing sharply and publicly on the social consequences of personal moral irresponsibility."

Bayer's book emphasizes neither funding nor management, but moral leadership by a tutelary government. A 1987 report prepared by the Office of Technology Assessment, based on interviews with state and local officials, reaches the same conclusion. This is not how we usually think of responding to epidemics—dollars, technology, delivery systems, and legal liability are more familiar concerns—but the implications of AIDS make such leadership necessary.

In Ronald Reagan, the nation had a President who repeatedly used the power of the bully pulpit to exercise moral suasion on matters ranging from school prayer to the Contras. But on AIDS President Reagan had almost nothing to say. Never were compassion or social responsibility his themes; such counsel as he offered focused almost exclusively on expanded AIDS testing, the politicians' easy and imperfect panacea. Waiting in the wings, as Shilts and Bayer convincingly detail, was the occasionally discussed and ever-present specter of quarantine.

Historically, quarantine has never been an effective response to highly contagious diseases; but it has manifested a deeply felt need to separate the tainted ill from the respectable well. So too with AIDS. But the Reagan administration never forswore quarantines as irrational, unworkable, and morally unacceptable. Fixated on minimizing the remotest risks of spreading AIDS, the White House never understood the far greater risks to national character posed by the us-versus-them mentality that widespread testing and quarantine would foster.

In August 1987 in Arcadia, Florida, the Ray family's home was torched when the parents insisted on sending their three HIV-positive hemophiliac children to public school. Imagine the bene-

fits to public tranquility and civic responsibility of a televised presidential fireside talk on how AIDS is and is not transmitted, with the Ray children sitting by that fireside. That talk was never given; indeed, during the first decade of AIDS it was unthinkable. Such was the price exacted by the absence not of a czar but of a moral exemplar.

Things will only be harder in the next decade. *Private Acts, Social Consequences* ends with a series of modest proposals: education “freed from the strictures of moralism” that conveys “not only knowledge but an appreciation of the moral claims imposed by the threat of HIV infection”; universal treatment for drug users that demonstrates “that social neglect is incompatible with a vigorous campaign against AIDS”; needle-provision programs aimed at users who refuse treatment, to “underscore the willingness to place the prevention of HIV transmission above the dictates of convention”; confidential and anonymous screening programs “to advance the public health while simultaneously protecting the privacy of those who come forward”; legislation to defend the social rights of the infected against discrimination, to create a “climate of trust”; and parallel measures to control those who recklessly endanger others, to “establish the moral priority of protecting the public health as a social norm.”

Yet it is unclear that we, as a nation, are up to the task. How much harder it will be to mold a popular culture of restraint and responsibility—how much harder it will be to provide the needed support, rather than malign neglect—as AIDS is increasingly ghettoized. More and more, most of those who carry the disease will be neither telegenic young hemophiliacs nor articulate white homosexuals, but black and Hispanic intravenous drug users, their sexual partners, and their progeny. Will the rest of us pay attention to their plight?