

# AIDS and the American Health Polity: The History and Prospects of a Crisis of Authority

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**I**N 1981 WHEN AIDS WAS FIRST RECOGNIZED, THE American health polity was changing more rapidly than it had in a generation. The individuals and institutions that comprise the health polity had a growing sense of discontinuity between past and present. They were poorly prepared to take aggressive, confident action against a disease that was infectious, linked—in the majority of cases—to individual behavior, and expensive to study and treat, and that required a coordinated array of public and personal health services.

The unconventional phrase “health polity” encompasses more individuals, institutions, and ideas than the words usually used to describe health policies and politics. A polity is broader than a sector or an industry. It includes more people than providers and consumers of health services, more institutions than a health care delivery system, and it is more than an aggregation of policies. According to the *Oxford English Dictionary* (1978), a polity is “a particular form of political organization, a form of government . . . an organized society or community of men.” I use the phrase “health polity” to describe the ways a community, in the broad sense of the OED definition, conceives of and organizes its response to health and illness.

My thesis is that, when the AIDS epidemic began, a profound crisis of authority was transforming the American health polity. The roots of this crisis reached back in time—some for decades, others for just a few years. They included: changes in the causes of sickness and death and, therefore, concerted efforts to adapt facilities and payment mechanisms in order to address them; ambivalence about the recent progress of medical research, reflected in slower growth in research budgets and

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efforts to make scientists more accountable to their financial sponsors and the media; a growing belief that individuals should take more responsibility for their own health and that public health agencies should encourage them to do so; a sense that the cost of health care was rising uncontrollably and should be contained; and an increase in the power of the private sector and the states within the health polity. Everyone who worked in the health sector knew that a crisis was occurring; so did attentive consumers of print and television news. Uncertainty about priorities, resources, and, most important, leadership pervaded the health polity. The AIDS epidemic was an additional element in an ongoing crisis.

I write first as a historian and then as an advocate. This article has three parts. The first two analyze contemporary history. First, I describe the origins of the crisis of authority; then, I describe how the crisis has influenced the response of the polity to AIDS. In the third part, I identify shortcomings in how the American health polity responds to illness; these flaws have been revealed more clearly by this epidemic.

## The Health Polity in 1981

### *The Declining Importance of Infectious Disease*

The most profound change affecting the health polity in the late 1970s and early 1980s was a major shift in patterns of illness—a shift with consequences for every individual and institution within the polity. For more than a century, public health officials, physicians, medical researchers, and hospital managers had accorded priority to preventing, diagnosing, and treating infectious disease. Now, they were increasingly managing conditions that were chronic and degenerative. When priority had been accorded to infectious disease, most of the resources allocated to the health polity had been spent to manage acute episodes of illness. The new prominence of chronic degenerative disease was stimulating a profound reallocation of resources, new assumptions about the responsibilities of individuals and institutions, and considerable concern about rising costs.

In the 1970s, physicians, health officials, and journalists frequently described infectious diseases as problems that had been, or soon would be, solved by scientific progress and an improving standard of living.

They usually defined the most pressing health problems as cancer, heart disease, mental illness, and infant mortality among the poor. In contrast, almost everyone knew the history of success in the struggle against infectious diseases during the past century. Smallpox would soon be the first infectious disease to be eradicated; measles would be the next target (Russell 1986). Controlling an infectious disease now seemed to be a routine process of discovering its cause and cure. It was no longer necessary, in the United States at least, to crusade for proper sanitation, housing, and diet in order to reduce the incidence of infectious disease. There was considerable evidence that, from the early nineteenth century until at least the 1930s, changes in diet and living conditions had been more important than medical intervention in bringing most infectious diseases under control (McKeown 1976). As a result of rapid scientific advance since the 1940s, moreover, many diseases that had once been leading causes of death had become brief, if unpleasant, episodes of illness. According to leading medical scientists, this success proved that research in basic science should have higher priority than efforts at care and cure (Thomas 1974). By the early 1980s, infectious disease accounted for "less than 5 percent of the costs estimated for all diseases in the United States" (Rice, Hodgson, and Kopstein 1986).

Sexually transmitted diseases were now accorded lower priority as threats to health. Syphilis and gonorrhea were amenable to drug therapy. In public health practice, treatment was now considered a method of controlling venereal disease. The availability of treatment, whether in public health clinics or the offices of private physicians, created opportunities for education as well as cure (Last et al. 1986). Although public health agencies still conducted vigilant surveillance, physicians reported a smaller number of their cases than they did in the past, in large measure because they perceived venereal disease as less of a threat to the community (Cleeve et al. 1967).

Just a few years later, some people would recall the general attitude toward infectious disease in the late 1970s. In 1986, for instance, a third-year resident, who had entered medical school at the end of the 1970s, lamented that "many of today's residents spent their formative years in medical training during an era when the ability of the scientific community to solve health care problems seemed limitless" (Wachter 1986). The chief of the infectious disease bureau of a state health department recalled that, before the AIDS epidemic began, he had been considering a

job with the World Health Organization because his work in the United States had become routine (see Acknowledgments).

### *Increasing Priority to Chronic Degenerative Disease*

For more than half a century, a growing number of experts had urged that more attention and resources be allocated to chronic degenerative disease. In the 1920s and 1930s, a handful of medical specialists, clinical scientists, statisticians, and public health officials had insisted that chronic disease—then often called incurable illness—would become more important as average length of life increased. They urged their colleagues to accord higher prestige and priority to long-term and home care, but without much success (Boas 1940).

Chronic disease attracted increasing attention in the 1940s and 1950s. A privately organized Commission on Chronic Illness (1956–1959) issued what were later regarded as landmark studies. Some medical specialists began to shift their emphasis from infectious to chronic disease. Among the first to do so were specialists in tuberculosis, who broadened their emphasis to diseases of the respiratory system after streptomycin was introduced as a cure for tuberculosis in the late 1940s (Fye 1986). The new specialty of rehabilitation medicine gained widespread publicity as a result of its success during and after World War II and vigorous support throughout the 1950s from the Eisenhower administration and Congress (Berkowitz 1981). By the late 1950s the Hill-Burton Act had been amended to encourage the construction of facilities for long-term care and rehabilitation.

Nevertheless, priority within the health polity continued to be accorded to acute rather than long-term care—either for infectious disease or for acute episodes of chronic illness. There were several reasons for this. Physicians' prestige among both their colleagues and the general public continued to be a result of their ability to intervene in crises rather than their effectiveness as long-term managers of difficult cases. Moreover, most of the money to purchase health services was paid by Blue Cross and commercial insurers on behalf of employed workers and their dependents, whose greatest need was for acute care. Organized labor had little incentive to negotiate for fringe benefits for people too old or too sick to work. Since the inception of group prepayment for medical care in the 1930s, Blue Cross and commercial

companies had resisted covering care for chronic illness, most likely because they feared that it would lead to adverse selection of risks and undesirably high premiums. A constituency for long-term care of chronic illness was, however, created in the 1950s by the campaign for Social Security Disability Insurance and then in the early 1960s by efforts to create what in 1965 became Medicare (Berkowitz and Fox 1986; David 1985).

In the 1960s, debates about national policy focused attention on unmet needs for health services in general and especially on care for chronic illness. Some advocates of health insurance for the elderly under Social Security, enacted as Medicare in 1965, emphasized the need for long-term as well as acute care. But Medicare insured more comprehensively against the costs of acute episodes of illness than for outpatient, nursing home, or home health care (Benjamin 1986). Medicaid, however, which had been conceived mainly as a program of acute care for recipients of categorical public assistance, quickly became a major payer for nursing home and home health care for the elderly. By 1965 there was little controversy about the inception of the Regional Medical Program of grants by the federal government to diffuse the results of academic research about the major chronic diseases—heart disease, cancer, and stroke (Fox 1986).

Federal leadership in shifting priority to chronic degenerative disease continued during the Nixon administration. In 1970 the president declared war on cancer (Rettig 1977). Two years later, an amendment to the Social Security Act nationalized the cost of treating end-stage renal disease by covering kidney transplants and dialysis under Medicare.

### *Individual Responsibility for Health*

By the 1970s there was considerable evidence that progress in controlling and preventing disease, especially chronic disease, could be achieved by changing personal behavior—"lifestyles" was the euphemism. Accordingly, health professionals and the media admonished individuals to modify their behavior in order to prevent or delay the onset of heart disease, stroke, and some cancers. To the surprise of many cynics, these pleas were effective (Knowles 1977). Millions of people stopped smoking, drank less, exercised more, and ate less salt and fatty food. Preventing chronic illness had become a popular cause and, for some entrepreneurs, a lucrative one. For the first time since the nineteenth century, commercial

food products were advertised as improving health, with the sanction of medical scientists. Manufacturers of healthier bread, cereals, and even stimulants, in turn, promoted exercise. Some of the new emphasis on individual behavior was a result of concern to reduce or shift the cost of health services. But much of it was associated with a spreading interest in fitness, and with the belief that individuals should exert more control over their own bodies.

The promotion of individual responsibility was linked to increasing emphasis on the rights of patients, particularly their right to be treated with dignity and after giving informed consent. Individuals were urged to take more responsibility for their own health status in part so that they could demand more timely and efficient attention from the individuals and institutions of the health polity (Levin, Katz, and Holst 1976). Critics of this point of view described it as another instance of "blaming the victim," of making individuals responsible for the results of inadequate income and education (Crawford 1977). The new emphasis on individual responsibility for health strengthened existing oversimplifications of cause and effect in the spread of disease. Individuals could be held responsible for behavior they engaged in before it was known to be dangerous. Moreover, individuals could be artificially abstracted from the social groups that formed their values and influenced their behavior.

Reflecting the new emphasis on individual behavior, state and local public health agencies joined campaigns to persuade individuals to reduce smoking and substance abuse. Even vaccination became a matter of individual choice. Public health officials, who in the past had insisted that children be required by law to be vaccinated, now educated parents to make prudent choices.

Control of environmental pollution was an important exception to the increasing individualization of public health services. Public officials at the local, state, and federal levels exercised collective responsibility and evoked hostility from industry. Assisted and sometimes provoked by voluntary groups, public health officials called attention to the hazards of lead-based paint, fertilizers, chemical dumps, and atomic wastes. For reasons which are still obscure, the emphasis on collective rights and responsibilities in protecting people from diseases which had environmental origins was not translated into other areas of public health practice. Diseases were increasingly categorized as subject either to individual or to collective action.

*The Unfulfilled Promise of Science*

Another reason for urging individuals to take more responsibility for their own health was frustration at the inability of medical science to keep some of its implied promises of the 1940s and 1950s. The great advances against infectious disease of the 1940s, especially the development of effective antibiotic drugs, had been widely publicized as the beginning of a permanent revolution in medicine. During the 1950s, the budget of the National Institutes of Health and the expenditures of voluntary associations that sponsored research grew faster than ever before. Congressmen, philanthropists, the press, and the general public expected that the causes of and cures for chronic diseases would soon be found, as a result of research on basic biological processes (Strickland 1972). But medical scientists proved to be better at basic research and at devising new technologies for diagnosis and for keeping very sick patients alive than at finding cures. This technology was disseminated rapidly because third-party payers eagerly reimbursed hospitals for purchasing it, which they did at the request of growing numbers of physicians in each medical specialty. The Regional Medical Program, as it was originally conceived, proved to be redundant. But the vast expenditure for technology had little discernible impact on overall mortality from particular diseases. In the absence of new miracle drugs, the responsibility of individuals to reduce their risks was accorded greater importance.

By the 1970s, moreover, scientists were losing their privileged status within the health polity. Their success in the struggle against disease was no longer taken for granted. They were frequently admonished to propose ways to solve practical problems and to be more accessible and forthcoming to representatives of the press and television. Moreover, scientists were no longer assumed to be virtuous as well as effective. What was called the bioethics movement had begun a strenuous critique of medical scientists, especially clinical investigators, some years earlier. To many participants in this movement, protecting patients and research subjects from harm was the highest ethical goal. For some, autonomy took precedence over beneficence as goals (Pellegrino 1985). This concern was embodied in federal regulations for the protection of human subjects in research. Similarly, the venerable antivivisectionist controversy was reactivated by a new animal-rights movement. In part as a response to external criticism of science, but also because of general economic problems, research priorities and budgets

were scrutinized more carefully than ever before by federal officials and congressmen.

For a generation, the resources allocated to the health polity grew because everyone assumed that the nation's health would improve if more money was spent for research, hospitals, physicians' services, and educating health professionals. Public subsidies helped to create an increasing supply of hospitals, professionals, and research facilities. Blue Cross/Blue Shield and commercial insurers, using the premiums paid by employers and employees, stimulated demand for care. After 1965, when Medicare and Medicaid were established, the federal government became the largest third-party payer. In the early and mid-1970s, there was broad agreement that access to basic medical care for the poor and the elderly was a diminishing problem (Anderson and Aday 1977), that the next problems to solve were improving the quality of care and expanding the coverage of insurance and public entitlement programs. But the consensus that had unified the health polity since World War II was now eroding.

### *From Comprehensive Services to Cost Control*

The broad coalition that had dominated the health polity broke apart in the 1970s. The labor movement, weakened by declining membership, ceased to lobby forcefully on behalf of broad social policy. Executives of large corporations, who for thirty years had provided their employees with generous health insurance benefits, found it increasingly difficult in the economic conditions of the 1970s to pay the cost of health care by raising the price of goods and services. The comprehensive first-dollar insurance coverage available to workers in the largest industries began to be described as a luxury that must be sacrificed in order to avoid increasing unemployment. Community rating, which had been endorsed by labor and business leaders in the 1940s as a way to increase equitable access to comprehensive health care, had been sacrificed to experience rating, which shifted costs to the groups that could least afford to pay them. Moreover, generous health insurance benefits seemed to encourage unnecessary surgery and excessive hospital stays. Evidence that numerous hospitals and physicians inflated their charges because third parties would pay them provided business, labor, and government leaders with additional justification for cost containment. As tax revenues declined in the recessions of the 1970s, the federal government and the states



changed the emphasis of health policy from providing access to more comprehensive services to cost control.

Advocates of cost control also argued that generous subsidies and reimbursement policies had created an oversupply of physicians and hospitals. Many of them wanted to reallocate the resources of the health sector to take account of the increasing incidence and prevalence of chronic illness. They contrasted excess capacity to provide acute care with the lack of facilities for long-term care.

### *The Crisis of Authority*

The new emphasis on cost control and reallocating resources was evidence of a profound change in the distribution of authority within the health polity. Since World War II, authority in health affairs, as in social policy generally, had been increasingly centralized in the federal government, though considerable power remained with state government and with employers. Centralized authority was frequently displayed in programs that required local initiative to meet federal standards, for example, the hospital construction program created by the Hill-Burton Act of 1945 and the community mental health and neighborhood health centers of the 1960s. In 1978 a political scientist, looking back at health policy since the mid-1960s, wrote that “in no other area of social policy has the federal government been so flexible, responsive and innovative” (Brown 1978).

But the federal role in social policy generally, and especially in health, narrowed after 1978. National health insurance, which many people believed to be imminent a few years earlier, was politically moribund by the late 1970s (Fox 1978). In Congress and federal agencies, there was active discussion about containing health care costs through tax policy and new reimbursement strategies that encouraged competition and offered incentives to physicians to use fewer resources (Meyer 1983). Prepaid group practices, which for half a century had been the favorite strategy of liberals for increasing access to medical care, were renamed health maintenance organizations (HMOs) by the federal government and used as a mechanism to control costs (Brown 1983). Diagnosis-related groups (DRGs), a mechanism to control hospital costs by setting prices based on the intensity of resource utilization, were devised by researchers at Yale in the mid-1970s and were initially implemented in New Jersey (Thompson 1978).

At the same time, many state health departments or rate-setting commissions were becoming, for the first time, active managers of the health industry. The goal of state and regional health planning changed from promoting rational growth to encouraging shrinkage or consolidation. "Regulation," a word that had once been associated mainly with the responsibility of the states to implement health codes and license professionals, was now used more often to refer to setting reimbursement rates and issuing certificates of need for construction and new equipment.

Other states, however, chose to withdraw from active regulation of health affairs. Their leaders adopted the rhetoric of deregulation and competition that was heard with increasing frequency in discussions of national economic and social policy.

Business leaders began to claim new authority in the health polity. They perceived the cost of health benefits as an impediment to competition with foreign firms and a stimulus to dangerously high rates of inflation. In the United States, unlike other industrial nations, health insurance was linked to employment and was, therefore, a cost of production. A growing number of employers were choosing to self-insure in order to reduce costs. Many of them took advantage of a 1978 amendment to the Internal Revenue Code that permitted individual employees to select from a menu of benefits that often included less generous health insurance (Schmid et al. 1985). Responding to pressure from employers, Blue Cross and commercial insurance companies began to write policies with larger deductibles and copayments, to scrutinize claims more rigorously, to require second opinions and preadmission screening before hospital admissions, and to reduce beneficiaries' freedom to choose among physicians.

The health polity was experiencing a crisis of authority. Assumptions about the balance of power in the health polity that had been accepted, though often grudgingly, since the New Deal were now challenged. In health affairs, as in social policy generally, increasing centralization was no longer regarded as inevitable. Many congressmen and federal officials were eager to devolve authority over health affairs from the federal government to the states and the private sector. Business leaders were taking more initiative in health affairs. Devolution would soon be accelerated by the Reagan administration. The health polity in 1981, when AIDS was first recognized, was more fragmented than it had been at any time since the 1930s.

## The Health Polity Responds to AIDS

### *The Modern Response to Epidemic Disease*

The health polity had, however, devised a set of responses to epidemics during the twentieth century. These responses had been increasingly effective in controlling infectious disease (Dowling 1977). At the beginning of the AIDS epidemic there seemed no reason to doubt that the problems posed by this new infection could be solved promptly and efficiently by applying the well-tested methods of surveillance, research, prevention, and treatment. These methods had recently been used, with comforting success, to control Legionnaires' disease and toxic shock syndrome. In 1981, despite the crisis of authority in the health polity, AIDS did not seem to be an unusual challenge.

Widely shared assumptions about recent history generated confidence in these responses. For a generation, scientists had rapidly identified new infectious agents and devised tests for their presence, vaccines against them, and drugs to treat their victims. Most physicians and hospitals reported most cases of life-threatening disease, and public health officials held these reports in strict confidence. Although mass screening programs were sometimes controversial and were only partially effective in identifying new cases, there were widely accepted techniques for managing them. Since the early 1970s, moreover, it seemed possible to prevent disease through education and advertising, which had persuaded many people to modify their diets and habits of exercise and to stop smoking in order to reduce their risk of hypertension, heart disease, and lung cancer. Finally, despite the problems of high costs and fragmented authority, more Americans than ever before had access to medical care as a result of insurance or public subsidy.

Five years later, many public health officials remain confident that AIDS will eventually be controlled by the conventional techniques for responding to epidemic disease. In support of this position they note that there have been no documented breaches of confidentiality in reporting or screening; scientists have identified the infectious agent, devised a test for antibodies to it, and report progress in the search for a vaccine; many gay men have modified their sexual practices in response to education; no one is known to have been denied treatment for AIDS because of inability to pay for it; and, in several major cities, innovative programs of care are being offered to AIDS patients.

Other observers dispute this optimism, claiming that the conventional methods are inadequate to address AIDS (Altman 1986a). They point to events or policies that appear to be a result of hostility or insensitivity to gay men and intravenous drug users. Many gay men, for instance, fear that their privacy is threatened by reporting and screening policies that offer confidentiality, which could be breached, instead of guaranteeing anonymity. This administration, unlike earlier ones, has been reluctant to request funds from Congress for research and services during an epidemic; President Reagan did not even mention AIDS in public until January 1986. Despite education in "safe" sex, much of it financed by public funds, the percentage of gay men who have positive antibodies to HTLV-III virus continues to increase. Moreover, public agencies have been reluctant to reach out to drug users in illegal "shooting galleries" or to provide them with disposable needles. Many third parties are reluctant to pay the additional costs of treating patients with AIDS. Although programs to create separate hospital units and community facilities for AIDS patients have been presented by their sponsors as positive steps, some critics view them as the beginning of segregation, the modern equivalent of leper colonies.

Without denying the persistence of discrimination, I believe that the conventional responses to epidemics are now inadequate mainly because of the crisis of authority in the health polity. A polity that is focused on chronic degenerative disease, that embraces cost control as the chief goal of health policy, and in which central authority is diminishing cannot address this epidemic as it has others of the recent past. In the following paragraphs I describe how the crisis of authority has influenced the actions of the health polity in surveillance, research, paying the cost of treatment, and organizing services for AIDS patients.

### *Surveillance*

Disagreements about policy for surveillance have highlighted problems of cost and fragmented authority. The definition of a reportable case of AIDS used by the Centers for Disease Control (CDC) excludes cases of AIDS-related complex (ARC). Since all but three states have adopted the CDC definition, the incidence and prevalence of ARC can only be conjectured. The absence of information about ARC has impeded accurate study of the onset and duration, as well as the cost, of the AIDS continuum. Reporting policy, on the surface a straightforward problem

in public health practice, in fact understates the severity and the cost of the epidemic.

Moreover, legal standards for the confidentiality of case reports vary among the states. Four of them—Colorado, Wisconsin, Montana, and Minnesota—mandate that names of individuals who have antibodies to the AIDS virus be reported to state health departments (Intergovernmental Health Policy Project 1986). Moreover, because AIDS—as of the summer of 1986—is classified as a communicable disease everywhere except in Idaho and Puerto Rico, case reports are not protected as strongly by statutes as they are for sexually transmitted diseases. They can, for example, be subpoenaed, although there is no evidence that they have been.

The lack of uniformity among the states in standards of confidentiality is an old problem that is made worse by the absence of national leadership in health affairs. On the one hand, surveillance policy has always been the responsibility of state governments, except for Indians, immigrants, and the military. On the other, standards of confidentiality affect civil liberties, an area of policy over which all three branches of the federal government had, until recently, been exerting increasing authority for a generation.

The absence of encouragement to the states by federal officials to adopt common standards to protect confidentiality increases the fear of many gay men that they will be stigmatized and persecuted. This fear, already intense, grew after the publication of a survey commissioned by the *Los Angeles Times* according to which “most Americans favor some sort of legal discrimination against homosexuals as a result of AIDS” (Shipp 1986). Fear became rage when columnist William F. Buckley wrote in the *New York Times* that “everyone detected with AIDS should be tattooed in the upper forearm, to protect common needle users, and in the buttocks, to prevent the victimization of other homosexuals” (Buckley 1986). The fear is so intense that it embraces the entire range of public policy: the irrational—Lyndon Larouche’s proposal to screen every American for antibodies to the HTLV-III virus; the dubiously effective—bills in several states to put AIDS patients in quarantine; the debatable—proposals to identify children or employees with AIDS to school officials; and the extension of traditional techniques of venereal disease control—tracing the sexual contacts of persons with AIDS.

Very little has been written or said to date about the effect of AIDS on the stigmatization of users of intravenous drugs. Unlike homosexuals, they do not organize to assert their rights, and they do not receive much

public sympathy when they claim to do no harm by their private behavior. Drug users are generally stereotyped as pariahs who alternate between preying on innocent victims and receiving treatment and support at public expense. Moreover, many of them are also stigmatized because they are black. Addicts who die of AIDS may use fewer public funds than those who survive to receive treatment for their drug problems. Although several landmark civil liberties cases in the past have involved addicts, their rights—unlike those of gay men—have not yet been a subject of litigation during the AIDS epidemic.

### *Research*

The brief history of research on AIDS has been influenced by the disinclination of the Reagan administration to assert central authority in the health polity (Arno and Lee 1985). In 1985 the Office of Technology Assessment, a congressional agency, reported that “increases in funding specifically for AIDS have come at the initiative of Congress, not the Administration.” Moreover, “PHS agencies have had difficulties in planning their AIDS related activities because of uncertainties over budget and personnel allocations” (U.S. Congress. Office of Technology Assessment 1985). In January 1986, President Reagan called AIDS “one of the highest public health priorities,” but at the same time proposed to reduce spending for AIDS research by considerably more than the amount mandated by the Gramm-Rudman-Hollings Act (Page 1986; *Blue Sheet* 1986; Norman 1986).

As a result, at least in part, of the administration’s reluctance to fund research on AIDS, voluntary contributions and state appropriations for laboratory and clinical investigation have been more important than in other recent epidemics. Foundations to sponsor medical research established in New York City and, after Rock Hudson’s death from AIDS, in Los Angeles have recently merged to form the American Foundation for AIDS Research. In several cities, community-based organizations began to raise funds for research within and outside gay communities using techniques similar to those invented many years earlier by the National Tuberculosis Association and the National Foundation for Infantile Paralysis. The states of California and New York appropriated funds for research. These appropriations may be the first significant state expenditures for research related to a particular disease—except, perhaps, mental illness—in a generation.

Similarly, state and local health departments, frequently in collaboration with community-based organizations, took the initiative in programs to prevent AIDS through public education. If the epidemic had occurred in the 1960s or even the early 1970s, the federal government might have established a program of grants for community action against AIDS. Consistent with the social policy of those years, such a program would have included guidelines for citizen participation. In the 1980s, in the absence of federal initiative, the leaders of community-based organizations in each major city combined goals and strategies from the gay rights, handicapped rights, and anti-poverty movements of the recent past. Because they do not receive federal funds, some community groups have been free to move beyond educational programs and mobilize political action on behalf of patients with AIDS (Needle et al. 1985). However, without a national program, community-based organizations are unlikely to emerge or to be influential in cities with small, politically weak gay populations.

### *Cost of Treatment*

Because the epidemic began when government and private payers were restraining growth in the health sector, responsibility for the costs of treating patients with AIDS became a controversial issue. Many groups within the health polity had incentives to publicize and even to exaggerate high estimates of the costs of treating patients with AIDS. Prominent hospital managers were uncomfortable with the new price-based prospective reimbursement and were under pressure to offer discounts to health maintenance and preferred provider organizations. They encouraged speculation by journalists that the cost of treating patients with AIDS was 40 to 100 percent higher per day than the average for patients in their institutions. Many insurance executives embraced the highest estimates, perhaps because they wanted the states or the federal government to assume the burden of payment. A few insurance companies tried to obtain permission from state regulatory agencies to deny initial coverage to persons at risk of AIDS (Shilts 1985). Officials of the federal Health Care Financing Administration have avoided discussing the cost of treating AIDS and have ignored suggestions that the two-year waiting period for Medicare eligibility be waived for persons with AIDS who qualify for Social Security Disability Insurance. When persons with AIDS qualify for the less generous disability provisions of

the Supplemental Security Income program, they are eligible to receive Medicaid; the states have become the payers of last resort.

The actual costs of treating patients with AIDS are difficult to estimate because responses to the initial research on the subject are heavily political. The authors of a study conducted by the Centers for Disease Control in 1985 estimated that the cost of hospital care between diagnosis and death averaged \$147,000 (Hardy et al. 1986). They derived this figure by using charges as a proxy for cost and multiplying them by an average length of stay that was unusually long because it was disproportionately weighted with data from New York City municipal hospitals, which treated large numbers of intravenous drug users who had multiple secondary infections and few home or community alternatives to hospitalization. Then, they compared hospital expenditures for AIDS with those for lung cancer and chronic obstructive pulmonary disease and found that they were “similar,” despite the obvious differences in the course, duration, and incidence of these diseases. Whatever the authors intended, the exaggerated estimates alarmed insurers—now prohibited by insurance regulators in several states from denying coverage to victims of AIDS—public officials, hospital executives, and the media. Another study, conducted at San Francisco General Hospital in 1985, has alarmed some hospital executives because its estimate of the cost of hospitalization, between diagnosis and death, \$27,857, was so low that it undercut their demand for higher reimbursement for AIDS patients (Scitovsky, Cline, and Lee 1985).

In the spring of 1986, two New York studies confirmed that most of the speculative earlier estimates were probably exaggerated. The state health department found that the cost of ancillary services for patients with AIDS in 1984 was 20 percent higher than for other patients whose diagnoses were classified in the same diagnosis-related group. A study conducted for the Greater New York Hospital Association by the consulting firm of Peat Marwick and Mitchell concluded, to the surprise of its sponsors, that routine costs for AIDS patients were only about 20 percent per day above the average for all patients.

Moreover, hospital managers complained less frequently about the cost of treating patients with AIDS as the institutions' occupancy fell, in large measure as a result of cost-control policies. For a variety of reasons—including reimbursement penalties for low occupancy and the desire to avoid layoffs—hospital leaders preferred expensively filled beds to empty ones.



*Organizing Services*

In no previous epidemic have variations in lengths of hospital stay for patients in different cities been discussed so widely. Most of the variation seems to be a result of the availability of nonhospital services—particularly ambulatory medical care, skilled nursing facility beds, housing, hospice, and home health care. A few city and state health departments have tried to coordinate services. In San Francisco, the city-county health department, allied with voluntary associations in the gay community, organized a network of inpatient, outpatient, and supportive services (Arno and Hughes 1985; Arno 1986). In order to achieve similar goals in a different political environment—one that is larger, has more competition among institutions, and has no tradition of coordination by consensus—the New York State health department is establishing AIDS treatment centers. In this program, state officials will select hospitals that agree to meet specified criteria for managing a continuum of services (State of New York, Department of Health 1986). Each hospital will receive a higher reimbursement rate based on its proposal. Moreover, every hospital in the state will receive a 20 percent higher rate of reimbursement for each patient with AIDS treated since 1984.

The New York State health department requires that its AIDS Centers, like San Francisco General Hospital, dedicate beds for AIDS patients. The rationale for the requirement, according to a principal author of the New York program, is that patients will be treated better if they are clustered. He defined treated better to mean that, as in San Francisco, AIDS patients would be served by nursing and social service staff who had volunteered for their roles, and that there would be greater attention for continuity of care. Moreover, the dedicated beds in San Francisco seemed to be related to shorter lengths of stay and lower utilization of intensive care.

A substantial number of hospital administrators and physicians in New York were enraged by the requirement to dedicate beds. They insisted that segregated patients and their hospitals would be stigmatized. Moreover, dedicated beds created new burdens for overworked nurses. Perhaps most important, the health department was intruding on the domain of physicians and hospital staff. In the final regulations, a compromise was arranged which, health department officials hope, will lead most of the designated centers to dedicate beds. In fact, many teaching hospitals in New York already cluster their AIDS patients for

convenience in managing them. This dispute, like so many others during the epidemic, was less about AIDS than about the changing distribution of authority in the health polity.

In October 1986, the Robert Wood Johnson Foundation made the first awards in a \$17.2 million program to encourage case management for AIDS patients. Funds were granted to applicants from 10 of the 21 standard metropolitan statistical areas with the most cases of AIDS. Announcing the program, in January 1986, a foundation official described the federal government as if it were another philanthropic organization: "If an anticipated federal grants initiative for similar purposes materializes, the Foundation and the Department of Health and Human Services are planning to coordinate the two programs as closely as possible" (Altman 1986b). In 1985 Congress had appropriated \$16 million for AIDS Health Services Projects in the four cities with the greatest number of cases. However, the administration sequestered these funds. For the first time since the 1950s, a foundation program may well serve as a surrogate for, rather than an example to, the federal government.

The absence of national policy to organize and finance treatment for patients with AIDS may be appreciated by state and local officials who prefer to avoid responsibility for treating these patients. After a generation in which barriers to access to health services were gradually lowered as a result of federal programs, geographic inequities may be increasing more rapidly for persons with AIDS than for victims of other diseases. AIDS patients in states or cities with relatively unresponsive health departments and no Robert Wood Johnson Foundation money may receive considerably less or lower quality care than patients in other jurisdictions. The programs funded by the Robert Wood Johnson Foundation may be emulated elsewhere because, according to evidence from San Francisco, coordination reduces the length of hospital stays and the utilization of intensive care. But earlier discharge from hospitals can also be combined with inadequate outpatient, nursing home, and home care. In many places, that is, superficial or cynical emulation of the policies of San Francisco or New York could produce results similar to what has happened when mental patients were deinstitutionalized.

There are many historical precedents for superficial acceptance or cynical distortion of strategies to improve health and social welfare in the United States. Since the 1930s, officials of many state and local agencies have accepted the policies urged by experts with national visibility only when adopting them was a precondition for receiving federal funds or

under court order. The possibility that these officials will resist pleas and even incentives to coordinate services for AIDS patients is enhanced by the unwillingness of the Reagan administration to insist on particular actions by state governments and by the recent retreat of the federal courts from mandating states to improve the care of particular classes of patients.

The public officials and staff members of voluntary associations who coordinate treatment for patients with AIDS have benefited from the gradual reorganization of services to emphasize chronic illness. Like tuberculosis, the most lethal disease of the nineteenth century, AIDS is an infectious disease that requires services outside the hospital. Reimbursement incentives offered by Medicare and private insurance since 1981 have stimulated a substantial increase in the number of home health care agencies and skilled nursing facilities. Techniques for case management have been elaborated and tested in the past few years under waivers from the Health Care Financing Administration and by Blue Cross plans and commercial insurance companies. Moreover, recent interest in substituting palliative for heroic measures in treating patients whose illnesses are terminal has increased reimbursement for and thus the availability of hospice services.

AIDS is, to date, the only disease for which institutions are receiving grants and special reimbursement to coordinate inpatient and out-of-hospital services. The only comparable disease-specific case management is for end-stage renal disease—mainly for the procurement and distribution of organs. It is too soon to know if the interest groups organized around other diseases and conditions—people with multiple handicaps, for example—will demand similar services.

What is certain, however, is that the response to the AIDS epidemic by the American health polity has been shaped by fundamental changes that were occurring simultaneously. The most important of these changes, which I described in the first part of this paper, were according priority to chronic degenerative disease, emphasizing the responsibility of individuals for their own health, and controlling expenditures for health services. A crisis of authority was transforming the health polity. The future of the AIDS epidemic will be shaped, not only by the number and distribution of cases and by the results of research, but also—and perhaps most importantly—by how that crisis is resolved. If the polity responds to AIDS as it has done since 1981, it is likely that the epidemic will be another incident in the gradual decline of collective responsibility for

the human condition in the United States. Because I hope for a different result, I describe next how the American health polity might reconsider its response to AIDS, or to any other life-threatening disease.

## AIDS and the Future of the Health Polity

### *A Polemical Interpretation of Recent History*

During the late 1970s and 1980s, the health polity broke sharply with long-term trends in American social policy. For most of the century, there was a gradual shift in assigning responsibility to care for the sick from individuals and families toward collective responsibility and entitlement. Individualism was regarded as a weak basis for social policy in an industrial society. For most of the century, authority in the health polity was gradually centralized in national institutions—notably the federal government, large insurance companies, international labor unions, and professional associations. Fragmentation was considered to be inconsistent with a just and efficient society. The centralization of authority in national institutions was never complete in any area of social policy. State and local institutions, both public and private, continued to exert enormous power. A health insurance system that was based almost entirely on employment and retirement from it created considerable insecurity and inequity. But the trend was clear; until the late 1970s those who opposed centralization, particularly the ideological right, considered themselves a minority group.

The AIDS epidemic coincided with a concerted effort within the polity to reverse the trends toward centralization in social policy. Authority within the polity was devolving from the federal government to the states and to private corporations.

The AIDS epidemic provides evidence that this reversal of social policy threatens the public interest in security against illness. I summarize that evidence and its implications in my concluding paragraphs.

### *The Persistence of the Unexpected*

AIDS should provide convincing evidence that, despite the achievements of biomedical scientists, epidemics of diseases of mysterious origin and long latency will continue to occur, even in industrialized countries. Some of these diseases will be infectious; most will probably be linked in some way to behavior or location or work. Science will continue to

comprehend nature incompletely. The individuals and institutions who comprise the health polity should, therefore, accept the need to study and treat a greater variety of diseases than anyone can now imagine. Pressure to contain costs should be offset by a sense that there are limits to how much the resources allocated to health care can be reduced in a society concerned about its survival.

The epidemic should also lead to better understanding of some practical implications of the platitude that all diseases are social as well as biological events. In the years before the AIDS epidemic, the health polity accorded priority to biological factors in disease because its members were optimistic about the progress of medical science. The social basis of disease was not so much denied, as some critics charged, as it was ignored because of enthusiasm in the health polity about the results of laboratory research. However precisely social factors in disease were identified, they did not contribute as effectively to diagnosis or therapy as the study of diseased tissue. The AIDS epidemic makes it difficult, however, to deny that many pathogens only cause disease when people facilitate their transmission. As a result of AIDS there may be increased willingness to speak openly about sexual behavior and to provide more systematic education about it. There is already evidence that, in some schools, teachers are being more explicit about the risks of sexual behavior in response to students' fears about AIDS (Rimer 1986). The media have been more explicit and accurate in reporting about AIDS than about any disease in the past that was linked to sexual behavior.

### *The Limits of Individual Responsibility*

The epidemic also offers evidence that contradicts the assumption that it is desirable or even possible to substitute individual for collective responsibility for social welfare. For more than a decade it has been fashionable among some politicians and policy intellectuals of both the left and the right to assert that, if individuals are given proper incentives, they can provide adequately for their own health and welfare. A plausible extension of this argument is that removing people who have positive antibodies to the AIDS virus from insurance pools would, in the short run, save money for other people in those pools. Proponents of individualizing risk do not seem to care that removal would also prevent those with positive antibodies who do not get AIDS from subsidizing health care for other people.

Individualizing risk reinforces a short-sighted view of what is rational social policy. Consider a society in which everyone who is considered a poor risk is denied insurance or forced to enroll in a group composed entirely of people with expensive afflictions. In such a society, the premiums for the oldest and sickest people would be prohibitively high, forcing them to seek public assistance or charity. Since most people are likely to become very old, very sick, or both, the consequence of smaller, more homogeneous risk pools would be widespread pauperization. The political response to such a perverse policy might be broader support for a federally financed program of insurance against the catastrophic costs of illness.

AIDS also challenges the wisdom of offering incentives to apparently healthy young people to choose the least comprehensive health insurance. The beginning of the epidemic coincided with the decision of many employers to offer their employees so-called flexible benefit plans. Under these plans, employees who considered themselves to be in excellent health could substitute other benefits or in some instances cash for the most expensive health insurance. There are no data about how many AIDS patients, most of them in their thirties and with no previous history of serious illness, chose such substitutions.

The epidemic emphasizes the limitations of social policy that links entitlement to health insurance to employment rather than to membership in society, and that provides benefits as a result of bargaining rather than entitlement. Since World War II, most Americans of working age have obtained health insurance from their employers or their unions. Federal income tax laws encouraged the link between insurance and employment and prohibited firms from discriminating among workers at different levels of pay in awarding benefits. The tax laws cannot, however, remedy disparities in the coverage offered by different firms. Moreover, state governments have been reluctant to mandate coverage and have done so mainly in response to pressure from members of new provider groups who wanted to be reimbursed. In addition, many employers now escape mandates by self-insuring. As a result, the extent and duration of coverage varies enormously among workers with different employers. A disease which, at the present time, mainly affects people of working age and drug abusers, many of whom do not work at all, reveals the limits of an insurance system that does not offer a set of uniform and adequate minimum benefits.

The epidemic has exposed the fragility of the networks of personal support that are frequently promoted as substitutes for services that are

provided, at higher social cost, by insurance, philanthropy, or public policy. People who are at risk of contracting AIDS may be only slightly more isolated than everybody else. Americans increasingly live in small households, or alone; in the future, families and friends may be less frequently available during crises than ever before. Most of us may need sympathetic case management by professionals during our catastrophic illnesses.

### *The Reassertion of Central Authority*

Finally, the AIDS epidemic may demonstrate that the American health polity best serves the public interest when institutions within it struggle to assert central authority, when they do not accept fragmentation as the goal as well as the norm of health affairs. The unwillingness of the federal government to exert strong leadership in response to AIDS has been criticized by congressmen, journalists, and victims since the beginning of the epidemic. In the absence of federal assertiveness, however, the health departments of several cities and states have coordinated the response of the health polity to the epidemic. These health departments have tried, in different ways, to counter fragmentation by linking their traditional responsibility for surveillance with their more recent mandate to manage the health system. To the extent that similar linkage of the responsibilities of public health officers occurs elsewhere, it may be a partial substitute for the abdication of federal leadership and, perhaps, a model for future national administrations.

Such lessons could be drawn from the history to early 1986 of the response to AIDS of the American health polity. If they are not, we may recall the 1980s as a time when many Americans became increasingly complacent about the consequences of dread disease and unwilling to insist that the individuals and institutions of the health polity struggle against them.

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