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Boston Globe

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AIDS: An Overview

Loretta McLaughlin

We stand nakedly in front of a very serious pandemic, as mortal as any pandemic there ever has been,” said Halfdan Mahler, director-general of the World Health Organization (WHO). “I don’t know of any greater killer than AIDS, not to speak of its psychological, social and economic maiming. Everything is getting worse and worse with AIDS and all of us have been underestimating it, and I in particular. We’re running scared. I cannot imagine a worse health problem in this century.” When asked to compare AIDS to other epidemics, such as smallpox, that have infected and killed over the course of history, Mahler said he “could not think of anything else that matched the estimates that one hundred million people will be infected with AIDS within ten years of its discovery.”

In the years immediately before the world learned of the baffling and deadly new disease that would come to be called AIDS, there were forewarnings that something truly ominous was stirring.

In late 1979, young New York City men, some of them in prime physical condition, had begun to manifest vague but debilitating symptoms. The men’s ailments, at first, did not seem very worrisome. Lymph glands in their neck, groin, or under their arms became swollen — and, curiously, stayed that way, although this common sign of infection is usually temporary. The men also intermittently had sore throats, transient fever, and brutal night sweats. Some had a dry cough, muscle aches, shortness of breath. They complained of being unduly tired, and many, inexplicably, lost a considerable amount of weight. They seemed to have a strange and persistent flu that they didn’t ever completely get over. They also seemed chronically run-down and open to one infection after another. They had only one thing in common: they were all homosexuals. And so the syndrome was gratuitously labeled gay-related immune deficiency (GRID), or the gay disease.

Soon, some of these men, whose smouldering illness kept worsening, began to develop different symptoms — peculiar purplish spots on their arms, legs, torso, face. Their doctors had rarely, if ever, seen such blemishes — and never on young healthy men. They appeared to have a skin cancer called Kaposi’s sarcoma (KS). While the young men’s KS was virulent, the cancer typically had been a chronic affliction of elderly middle-European Jewish men and aged Italian men. It had been slow growing and seldom killed. Portentously, an unexplained but even more aggressively malignant form of KS had recently

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turned up in central Africa. In the United States, KS had occasionally been seen in patients who were undergoing chemotherapy for some other form of cancer. These instances of KS were associated with the patients’ immune system being impaired by the cancer treatment. As a result, the KS in the New York men was thought of as an “opportunistic” disorder — one that took advantage of a person’s immune defenses being down. The men’s run-down state also was thought to account for the fungal infection (candida, familiarly called thrush) that often appeared in their mouths, and the gross cold sores (herpes simplex) that sometimes spread across their faces. These, too, were signs that what should have remained bland infections were opportunistically flourishing in the absence of a sound immune system. Strangely, all of these patients also were homosexual. So, the KS syndrome in the young New York men, whose immune systems were obviously out of kilter, though no one knew why, was first labeled Kaposi’s sarcoma and opportunistic infections (KS/01). Or the gay cancer.

During the same period, in California, a handful of cases of Pneumocystis carinii showed up — a rare and exotic form of pneumonia. The organism that causes this pneumonia is a truly primitive agent, a protozoan, which in evolutionary terms dates back to the first single-celled animals from which life derived. It is found everywhere in the world and is one of countless microbes that are carried by most people. Normally, these microbes remain innocuous, in that they are kept suppressed in the human system. Yet, in late 1979 and 1980, Pneumocystis carinii pneumonia was diagnosed in five young men in Los Angeles. All had the same sort of pre-pneumonia syndrome of fever, malaise, cough, and thrush which had been troubling the New York City KS cases and the GRID patients. Studies of the California men showed that they, too, had impaired immune systems. They all also were homosexual. Now there was “the gay pneumonia, PCP.”

What first attracted the attention of the federal Centers for Disease Control (CDC) in Atlanta, Georgia, was a flurry of requests from the Los Angeles doctors for samples of a drug, pentamidine, that was effective against the pneumonia. The drug was needed so rarely that the nation’s entire supply was stored at the CDC.

The first public inkling of the five pneumonia cases came in the June 5, 1981, issue of the Morbidity and Mortality Weekly Report (MMWR), the CDC’s widely disseminated monitor of infectious disease and deaths in the United States. Less than a month later, on July 3, the CDC was reporting the phenomenal appearance of Kaposi’s sarcoma in New York City — twenty-six KS cases over a thirty-month period. The same July report importantly noted that six of these twenty-six persons had also developed Pneumocystis carinii; there also were ten additional cases of the exotic pneumonia in Los Angeles and six in the San Francisco Bay area. Two of the ten in Los Angeles also had KS, strongly suggesting a link between the cancer and the pneumonia. All the cases still were among homosexuals. By the end of August, there were seventy more patients with both conditions from the same three cities.

Nearly a year passed before the early-phase condition, defined for no apparent reason as generalized lymphadenopathy, or chronic swollen glands, was acknowledged on May 21, 1982, by the CDC as an emerging health problem among American homosexual males; fifty-seven cases were cited. This report noted too that the men’s immune systems were abnormal. And by June 11, a second cancer, lymphoma, a rare cancer of the lymph glands, which are key players in the immune system, was added to the roster of disorders related somehow to the swollen gland syndrome in gay men. Sexual transmission was raised as a possibility, as was the use of sexually stimulating “poppers” or other illicit drugs.
It was this year-long association of an emerging new illness with homosexual men — and only homosexual men — that underlies the ease with which the illness that was to become AIDS was medically and politically ignored as a major health problem. As U.S. Rep. Henry Waxman (D-Calif.) had said earlier in April, "There is no doubt in my mind that, if the same disease had appeared among Americans of Norwegian descent, or among tennis players, rather than gay males, the responses of both the government and the medical community would have been different." Noting that copious attention, money, and research had been poured into solving the mystery of a form of pneumonia that in 1976 had struck an American Legion convention in Philadelphia, Representative Waxman concluded, "What society judged was not the severity of the disease but the social acceptability of the individuals affected with it." Yet there were early indicators, had they been heeded, that a medical storm was brewing which eventually would blow across the country — and the world — leaving no corner untouched.

As early as July 9, 1982, the first appearance of the new disease was noted outside the male homosexual community. That day, the CDC reported that the same syndrome — the Kaposi’s cancer, the Pneumocystis carinii pneumonia, and the severe opportunistic fungal and viral infections — along with an old infection, tuberculosis — had appeared among thirty-four Haitians newly residing in the United States. They, too, were mysteriously immunocompromised. It was a startling development, which the CDC in its low-key style referred to as a "new phenomenon." Nearly all the Haitian patients were heterosexual. The CDC report also noted that an unusual form of KS had recently been observed in Port-au-Prince (Haiti). Though time would reveal that the cases in the Haitians were misconstrued — causing them cruel and unwarranted discrimination — the central point was that the disease had appeared in heterosexual patients, so the cause of its spread was not limited to male homosexual practices. It was an early warning of things to come.

Although the information was not substantial enough to be published, word of other complications and of the transmission of the new disease to other groups was arriving virtually month by month at the CDC. Addicts who used, and often shared, needles to inject narcotics directly into the bloodstream were afflicted. So were the first handful of the nation’s twenty thousand hemophiliacs who rely on a product called Factor VIII, extracted from pools of donated blood, to stem their inherited tendency to bleed internally. The new disorder also had been linked to a blood transfusion. A blood recipient had become sick after receiving blood from a donor who later had become sick himself. The nation’s leading blood banks, to their later regret, imprudently resisted facing up to the danger this posed for the nation’s blood supply. Babies born to mothers who were drug-addicted or who were the sexual partners of needle-using addicts were also falling ill, signifying that the disease could be passed during pregnancy or childbirth. The pattern of the cases all supported the single idea that a new virus, an extraordinarily deadly virus, was loose. The pattern also indicated that the mysterious virus could be transmitted sexually or via blood, much the same as the hepatitis B virus. Questions immediately arose as to whether the new disease could be passed to health workers, as hepatitis can be, from needle sticks with contaminated blood. Infectious-disease experts were relieved that there were no signs the new disease was “contagious,” like measles or flu, which spread on airborne particles wherever people congregate. Nor did it seem to be easily “infectious,” like mononucleosis, the high-school and college-age disease that is marked by unrelieved fatigue and that can be spread through casual contact, through kissing, or by drinking from the same glass or Coke bottle. Nonetheless, infectious-disease experts, early in the AIDS outbreak, were privately frightened about the prospects for sexual and blood-borne
spread. Some of the infections these patients were developing were horrendous — some almost never seen before, except in animals. Further, in some patients, the disease seemed to directly attack the brain. Doctors and nurses were struck by the intensity of the patients’ illness; these were among the sickest patients ever seen in a lifetime of providing medical care.

Terribly worrisome would be the prolonged incubation period — now known to extend from two to ten years — when an infected person could look and feel well while harboring the virus and could unwittingly pass it to others. This lengthy symptom-free but infectious stage, a long period of silent transmission, is incredibly dangerous. Without knowing it, the CDC by mid-1982 had already learned the disease’s primary target groups and the most salient of its broad clinical ramifications. The final characteristic of the disease was its deadliness: it seemed to eventually kill without exception.

The era of AIDS had dawned. The syndrome was first defined and given its name in the CDC’s September 3, 1982, weekly morbidity and mortality report: “This group of clinical entities, along with its specific immune deficiency, is now called acquired immune deficiency syndrome (AIDS).” By that time, there were 593 confirmed cases in the United States, and 243 were already dead. As of February 1988, nearly seven years into the epidemic, yet probably still nearer the beginning than the end, the worst fears of those early days had been realized. Nearly 55,000 cases of AIDS had been logged, and 30,000 had died of AIDS in the United States. A broader definition of AIDS now includes twenty-four infections and ten cancers. The definition also now covers the sickest of those patients with a chronic progressive form of AIDS called ARC (AIDS-related complex) and three other conditions when they develop in people infected with the AIDS virus: dementia, tuberculosis, and a profound, irreversible, eventually fatal weight loss called “wasting” syndrome.

A great deal of scientific progress has been made — more learned, more rapidly than ever before about a single virus. But few doubt that more could have been done had more research funds become available sooner. Too little has yet been done in any coherent or comprehensive way through public education to limit the spread of the disease; to prepare the public for the onslaught of cases that are already in the pipeline; or to rally funds, prepare facilities, or organize the means to deliver medical care to the tens of thousands in the United States and the millions across the world who will need AIDS care in the immediate years ahead.

On the plus side, the cause of AIDS is now known, officially designated human immunodeficiency virus (HIV). A more cunning virus is hard to imagine. It has more genetic material with which to constantly redesign its surface than any other known. It can and does change somewhat, individuate, in virtually each person infected. When activated, it can replicate by making copies of itself many times faster than any other known virus. And, like a fifth column agent, it attacks the very cells in the human system which call forth and orchestrate the defenses that each person relies on to protect against disease.

Discovery of the virus in 1983 by a French team at the Pasteur Institute in Paris — an achievement later duplicated by an American team at the National Cancer Institute — led fairly quickly to development of a test. An indirect test, in that it detects antibody response to the virus rather than the virus itself, was officially released on March 2, 1985. Henceforth, blood could be protected. Though it was loudly argued that the test did not specifically indicate a person was carrying the virus, the finding that a person once infected apparently remains so forever signifies that a positive AIDS antibody test actually does diagnose infection. Thus, those who are infected can be identified. Search for treat-
ment already has elucidated one medicine (AZT) that can at least prolong life for AIDS victims, though it is highly toxic. Dozens of other drugs or treatment approaches are under study. A cure still seems remote, considering the virus’s capacity to make itself part of the genetic material of its human host and to take sanctuary in the brain, where most drugs do not reach, or not at full strength. A vaccine is being sought, but the capacity of the virus to change and in other ways to outwit the immune response upon which vaccine protection is predicated diminishes the likelihood that an effective vaccine will soon be available.

From all indications, AIDS will be with us for a long time to come. “AIDS is out of the box,” says Dr. James Chin of California, a World Health Organization consultant whose primary work is maintaining global surveillance of the disease. “Even if we had an effective vaccine to protect new cases today, it is something the world would have to live with over the next century.” Before it is conquered, AIDS has the potential to disrupt the social and political equanimity of the United States and to wreak havoc on less fortunate parts of the world.

AIDS is seen as a slow plague, one that will probably take a generation to unfold. The United States’ capacity to bear this new health burden, though it will be strained, is light-years ahead of that of Third World countries, where the annual outlay for health care amounts to a few scant dollars per person, or less. Yet it is in Third World nations, most notably so far in Africa, the Philippines, the Caribbean, and Central and South America, that the AIDS epidemic is spreading rapidly. These are areas already beset by other dire health, economic, and social problems — from malaria, tuberculosis, and parasitic disorders to malnutrition and poverty, illiteracy and industrial backwardness, rampant population growth and financial dependency.

With the very first case, AIDS was an epidemic. In modern epidemiology terms, that designation applies to any unusual outbreak of a disease, even one more case than should be expected. Because the disease never existed before, AIDS, then, was automatically an epidemic. Though the subject is in dispute, some think that the disease originated in Africa. A virus that is highly similar to the human AIDS virus is found in green monkeys in Africa, though it does not make the monkeys sick. And the first evidence of AIDS — identified much later — were traces of the virus which were coaxed out of human blood samples (stored and frozen for research purposes) collected in Kinshasa, Zaire, in 1959. Though co-exposure to malaria confused the AIDS status of some early blood samples, sporadic cases of what are now known to be AIDS-related diseases clearly date back to the mid-1970s in central and east Africa. Among the earliest victims was a Danish woman surgeon working in Zaire, whose first signs of illness, as was later reported in the British medical journal *Lancet*, began as early as 1973.7 (A 1969 case is under study in the United States.)

Though it is unproven and probably unprovable where and when the AIDS virus first mutated and infected humans, there is more than theoretical reason for wishing it could be known. If AIDS began in Africa, then it is reasonable to look at the African experience with AIDS as providing some timetable of the epidemic, despite many differences in our experience with the disease.

Currently, the World Health Organization estimates that about fifty thousand cases of AIDS have occurred in Africa, though the official number is only about one-eighth that high. More telling, as a measure of the scope and spread of the disease on that continent, are the crude gauges of the number of Africans who are infected with the AIDS virus.
WHO roughly estimates that more than 3 million Africans may be infected with the AIDS virus — as 10 million people may be worldwide — though the actual numbers could be twice as high. The hardest hit countries are still concentrated in central and east Africa, even though AIDS has now spread throughout the continent. Further, a second AIDS virus, HIV-2, has been found extensively in west Africa; a third, labeled SBL 6669 V-2, was identified in west Africans being treated in Sweden; and a fourth virus that causes AIDS-like disease has been isolated from Nigerian cases. African and World Health Organization specialists, along with European and American medical teams, have carried out blood samplings in capital cities among prostitutes, blood donors, adult and pediatric patients, pregnant women, and health workers at large public hospitals and clinics in many central and east African nations. Updated surveys indicate that up to 20 percent of men and women in the twenty- to forty-year-old age group and 10 percent of hospitalized children in some urban areas are already infected with the AIDS virus. At some large maternity clinics, 20 to 25 percent of pregnant mothers are infected and infant mortality from AIDS alone is high. The findings are difficult to assess, because it is unknown whether those who are using hospitals are sicker or just better informed; thus the groups studied may be selectively high for AIDS. In various cities, however, 1 to 18 percent of the blood donors are positive for AIDS. Other studies indicate that hospital workers are infected at about the same rate as the patients, not from taking care of them but from the same cause as the patients. Infection rates among African female prostitutes range from 27 to 88 percent. Every new sampling shows higher figures, a rate of AIDS infectivity that is still rising at about 1 percent a year. Hard-won gains against a multitude of health problems in Africa threaten to be undone by AIDS. “Millions of deaths occur every year in the Third World because of diseases that could be prevented by vaccines,” says WHO director-general Mahler. “Now AIDS comes along and there is the risk it will overshadow all the other diseases.”

AIDS is different in terms of symptoms and patterns of spread in Africa than in the United States, which may partially account for why it went unrecognized there so long. One form the disease takes in Africa was labeled “slim disease” — an irreversible wasting away. These AIDS patients look as if they are starving to death for lack of food, and some were confused with those who truly had. Other African AIDS cases, as elsewhere, manifest the viral, fungal, and bacterial infections that their previously healthy immune systems had held in check. AIDS also allows latent tuberculosis to reestablish itself. Recent samplings found that 40 percent of patients in TB sanatoria were infected with AIDS. In countries where underlying TB infection is widespread, the arrival of a disease that can activate TB has a ripple effect. AIDS is such a disease, and while it is not spread casually, TB is, raising the specter of renewed infection with TB among coworkers, family members, community contacts, and health care teams. Further, with AIDS, many patients have severe reactions to anti-TB drugs. Exotic fungal infections that are naturally more prevalent in equatorial countries add to the AIDS burden in such climates. A Massachusetts Institute of Technology study suggests that the speed at which a person infected with the AIDS virus converts from silent to overt disease is governed by the frequency of other infections. If this is so, then Third World people whose lives are peppered with the diseases that thrive in heat, humidity, and squalor are in terrible jeopardy.

In Africa and elsewhere in the Third World, AIDS is indisputably a heterosexual disease, spread primarily through ordinary sexual intercourse, as well as in pregnancy from mother to child, and by breast feeding. As Halfdan Mahler points out, these modes of transmission “touch on the most intimate contacts of family life.” Thus, interrupting the
spread of AIDS in the Third World will be exceedingly difficult. The incidence of standard sexually transmitted diseases (STDs) also is very high, and these infections often are inadequately treated (there and here), leaving multitudes of STD victims prone to secondary infection with AIDS. Lack of disposable hypodermic needles and syringes contributes to the spread of AIDS in the Third World. Needles are scarce and must be reused; often, they are inadequately sterilized, even though household bleach readily kills the AIDS virus. In some STD clinics, it is common practice for a large syringe to be filled with multiple doses of antibiotics. When the same syringe needle is used to inject a row of patients, if one patient is infected with AIDS, the infection may be passed to the rest — as with needle-using drug addicts in U.S. cities. Pressure-gun injections are also now suspected of being able to spread AIDS. Blood transfusions remain a serious source of AIDS transmission. Testing blood for AIDS currently costs $5 to $10, an impossible expense. New, simple, and inexpensive blood tests will soon be available, but they are less sensitive. Moreover, with the discovery of additional AIDS-causing viruses, tests will have to detect all of them. With limited electric power, there is little opportunity to freeze and store blood. In most of the world, blood drawn in the morning is often transfused before nightfall — “so urgently needed,” says one CDC physician, “it is often still warm.”

Demand for blood is high in Africa and wherever children are prone to sickle-cell anemia, malaria, and parasitic diseases that thin the blood.

The heterosexual spread of AIDS has many catch-22 characteristics in Africa and other Third World countries. High-risk groups, outside of prostitutes and long-distance truck drivers, are not easy targets of prevention campaigns. In many of these countries, polygamy is legal as well as religiously and culturally sanctioned. A polygamous husband with AIDS risks transmitting it to more than one wife: the availability as well as the acceptance of contraception is limited; condoms are the least favored means. In Africa, the average woman bears more than six children. If she is infected, her progeny are likely to be infected during pregnancy or childbirth. Outside the First World, breast feeding is predominant; infected mothers can transmit the AIDS virus in breast milk. Immunization with live virus vaccines, such as for polio, measles, and mumps, carries new risks. Given to AIDS-infected children who inefficiently make antibody, the virus-laced vaccines may give them the actual disease; immunizing other children who may shed live virus from the vaccine may also expose an AIDS-infected child in the family to the infection. Choices with a high social cost lie ahead: cutting back treatment for STDs versus paying for higher priced sterilization procedures; limiting breast feeding versus providing needed nutrition; curtailing immunization versus controlling childhood diseases; restricting blood transfusion versus maintaining life support.

While there was nothing that African nations could have done in the absence of knowledge about AIDS to protect their already hard-pressed people, heroic efforts are now under way. Almost every African nation has appointed an AIDS advisory commission, and education campaigns are gearing up. Yet, on top of intrinsic social problems, many African nations are caught up, directly or indirectly, in political, military, and economic upheaval that involves great movements of troops, workers, displaced families, and refugees. Vast numbers of tradesmen, truckers, food suppliers, and camp followers crisscross the continent, moving back and forth from city to village to encampments. There also is constant relocation of workers from the countryside along the roads and railroad tracks into cities and a consequent mushrooming of slums and informal households. The AIDS virus now travels with all of it.

There is great anxiety that some African countries may lose a key segment of their
young adults, along with part of the next generation of children. In one capital city, the rate of infection is about 30 percent among the educated young men — the group that carries out much of the city’s daily business and commerce. Professor Charles Myers of the Harvard Institute for International Development (HIID) estimates that by 1995, AIDS will have killed so many productive young adults in Zaire that the nation’s gross national product may drop by 8 percent — the equivalent of a $292 billion loss in GNP for the United States. “The mind boggles at the numbers,” Myers said of his projections of the impact of AIDS on many central African countries. “On economic grounds alone, the case for very high levels of preventive expenditures — even if success is limited — is extremely strong.” Currently, the World Health Organization estimates that it will need $1.2 billion in extra funds to combat AIDS in countries that do not have enough to do it themselves. Yet, the United States is not fulfilling its share of the bargain, despite long-established policy in support of WHO. Dr. William Foege, former head of the CDC, notes that the United States spends on its own health care “in seventy minutes of one day” the $61 million that was assessed as its share of the 1986 WHO budget. Only $10 million has been paid, “while the Soviet Union, China, Japan, and the Western European countries have all paid in full. I am personally embarrassed that our government has weakened the chances of solving the world AIDS problem,” Foege says. It will prove to be extremely costly economizing in the long run.

I have devoted considerable attention to AIDS in Africa because more is known about what is happening there. But the AIDS factors and forces at work in Africa apply widely across the Third World. Brazil now ranks second to the United States in incidence of AIDS among single countries in the Western Hemisphere. Though the official number of cases there is two thousand, the actual number is probably ten times greater. The Brazilian government says it is testing donated blood in public hospitals, but some 90 percent of blood for transfusion is collected and sold by private companies, which have not been testing at all, according to U.S. AIDS experts who recently visited there. Other factors in Brazil which are singularly relevant to AIDS spread are the nation’s week-long, sexually wanton, pre-Lenten Carnivale; religious bans on condom use in an overwhelmingly Catholic nation; surveys that point to a bisexual spread of AIDS ten times greater than in Western Europe; and a well documented, culturally accepted practice of anal intercourse by heterosexuals.

Though Haiti’s tally of cases is unofficially set at about fifteen hundred, Haiti’s case rate is estimated to be higher, about thirty per one hundred thousand — twice that of the United States as a whole. As here, cases are congregated in cities. Dr. Jean Pape, a Haitian physician who is a member of the Cornell University Medical School faculty, has been researching AIDS in Port-au-Prince since 1982. His research suggests that 10 percent of the adults in urban areas, 66 percent of the city prostitutes (many from the neighboring Dominican Republic), and 3 percent of Haitians in rural areas are infected with the AIDS virus. In a culture where folk medicine predominates, AIDS may also be spread through ritualistic cutting and “injection” of innocuous substances on dirty needles. In the most impoverished nation in the hemisphere, haunted by starvation and now caught up in political turmoil, the prospects for controlling AIDS are dim.

No Central or South American country is without AIDS, nor any island of the Caribbean. And not the Latin American country of Mexico, which appears on its way toward a significant AIDS problem. The effects of sporadic AIDS-prevention campaign blitzes are not long lasting. In many of the countries, strong anti-American protests are being voiced. Many see the United States as the source of their AIDS problem — as is also felt
in Europe — believing the disease is spread not only by the U.S. members of the international jet set — American gay males and heterosexual swingers — but also by AIDS-contaminated blood and blood products from the United States.

Informal reports from Cuba indicate that AIDS-infected military personnel returning from Angola are being "held" at one end of the island, where they may be joined by family members if they so wish. Two Cuban hospitals have established AIDS wards, and the Cuban government has established a new AIDS prevention and control program, according to Radio Marti, which operates under the direction of the U.S. Information Agency.

In the Philippines, outbreaks of AIDS have centered in bars and brothels frequented by U.S. servicemen. Beyond trying to cope with their own incipient AIDS problem or to ward off its taking root — especially in Asian countries, where AIDS has appeared later and only minimally — some countries are taking drastic steps to identify and ship home any foreigners found to be harboring the AIDS virus. In China, Japan, and India (as well as the Soviet Union, several Soviet Union bloc nations, Belgium, and Germany), all foreign students already are required to take AIDS blood tests. If the tests are positive, the students' scholarships are revoked and the students are sent home. Since many foreign students in these countries are Africans, concern is growing that AIDS is being used as a new foil for racism. Thailand and Iraq mandate that all visitors — and natives returning from abroad — be AIDS-tested. Belgium is considering the same for visitors from African countries. China is weighing a law that would require any foreign visitor who planned to stay for six months to undergo medical examinations for AIDS.

Similarly, the United States has now made an AIDS test a prerequisite for the 530,000 to 600,000 immigrants seeking permanent residence each year in this country. There is bitter irony in the newly ordered AIDS testing of the estimated 2 million to 4 million illegal aliens who may hope to remain in the United States under the revised resident alien law. If they have been residents here since before 1982 — which the law now requires them to prove — the great probability is that they became infected here. If sent back to their native countries, they will take AIDS — and the potential for spreading it — with them. In San Salvador, health officials are alarmed that hundreds of thousands of Salvadorans now living in the United States will be deported and will bring an AIDS epidemic home with them. All seven cases of AIDS which had been registered in El Salvador by May 12, 1987, were in Salvadorans who contracted AIDS in the United States and "came back to their country to die," says Dr. Lidia de Nieto, a member of the nation's Health Ministry. While great attention was paid to the U.S. decision to test all recruits for military service as well as all members of the armed forces, almost none was given to U.S. State Department testing that began on January 1, 1987, of all Foreign Service personnel and their dependents, including thousands of members of the Peace Corps and the U.S. Agency for International Development. The Foreign Service chapter of the American Federation of Government Employees has filed suit to protest such "routine" testing; court documents revealed that seventeen Americans in the Foreign Service had already contracted AIDS and that five of them had died. AIDS thus has become a new job hazard for Americans working overseas, particularly where there is risk of being injured, requiring transfusions, and getting the AIDS virus from contaminated blood. The future significance of AIDS as a deterrent, not only to government foreign service, including the Peace Corps, but to the army of missionary workers across the world, is scarcely recognized. Nor has the portent of the disease been evaluated in terms of international trade and world economics, political, and even military operations. Kenya has requested that U.S. naval ships no longer allow their crews to disembark at Mombasa; the Philippines have linked
their AIDS problem to bar girls working near the U.S. naval base at Subic Bay or Clark Air Base north of Manila, the largest installations used by U.S. forces outside the United States. Very slowly but surely, AIDS is moving into these larger contexts. This past March, an international conference (at the Barbican Center, London, organized by the London School of Hygiene and Tropical Medicine) on the global impact of AIDS met to assess the social, economic, and political AIDS issues, including travel restrictions, employment problems, population dynamics, and volunteer work.

Nowhere has AIDS become so much a part of daily life as in Europe, where the pattern of the outbreak most closely resembles the U.S. pattern. Though they have far fewer cases (eight thousand cases in twenty-seven countries) than the United States, European countries moved quickly into public education campaigns. Direct mailings have gone out to a vast number of households; anti-AIDS messages emblazon subway walls, billboards, taxicabs, and buses; radio, TV, and newspapers carry public service announcements. Near U.S. military bases, AIDS is still commonly referred to as the “Yankee” disease. Yet, despite early efforts, there are indications from Europe that the education campaigns are gaining only limited response in changing personal sexual behavior.

The story of AIDS is far different in the United States, one of its most tragic characteristics being the needless loss of time in the beginning. Many forces, blindly or deliberately, converged to permit the AIDS virus to take a deep hold in this country before any meaningful steps were taken to combat it. Since time is the great enemy in the fight against AIDS, this important, early advantage was lost.

The central failure concerning AIDS is that it was not — and still is not in some quarters — perceived as what it fundamentally is: a disease with potential for destruction of great magnitude, not a form of supernatural retribution. The overriding focus of early social and political attention was its male homosexual spread — too often on judgmental, moralistic terms.

AIDS origin here, primarily among homosexual men, made the disease not only distasteful but dismissable to many, most notably the Reagan White House, which has been unduly influenced by ultraconservative fundamentalists. Representative Waxman is on solid ground when he says, “I am convinced that had the first victims of AIDS been members of the Chamber of Commerce, the Reagan Administration would have responded immediately and forthrightly. Because the male homosexual population was first affected by AIDS, the Reagan Administration thought of this group as dispensable and didn’t respond as quickly as it could have and should have. The Administration has handled this whole thing in an irresponsible way. As a matter of fact, I think that when people look back historically at the Reagan Administration, aside from the huge deficit that we have run up over the last six years, the other comment on this Administration will be its failure to deal with the AIDS crisis, which unfortunately will have gotten out of hand and affected maybe millions of people.”

To the credit of the gay male community, it organized much needed, early support services and was the first to generate self-help, safer sex materials. But the homosexual stigma that was attached to AIDS was the factor, above all others, that fostered political and social neglect, while encouraging the expression of pseudo-religio-political prejudice and vindictiveness. The “gay” label also permitted a paucity of funding and a transference of attention to nonmedical economic and social issues — mandatory blood testing, insurance screening, job discrimination, health benefit eligibility, entitlement to Social Security Disability coverage. Though these issues are
significant, the effect was diversionary — a begging of the question: What should the United States be doing to combat the greatest threat to public health in modern times?

None of the major public policy issues surrounding AIDS has yet been resolved.

Essentially these issues can be broadly summarized under three headings: mobilizing to fight the disease, through funding and organizing research and medical care; civil rights, in the sense of safeguards against discrimination within the conflict between public and private rights; and prevention, through education and public health programs.

Mobilizing to Fight the Disease

When the proposed $790 million AIDS budget for FY'88, which covers research, epidemiology, public health services, and information programs, is included, the federal government will have spent or allocated $1.676 billion for AIDS since mid-1981. (On February 18, details of the FY'89 federal budget indicated an administration request for $1.7 billion for all AIDS-related federal programs, including the U.S. Public Health Service [PHS], Medicare and Medicaid, the Department of Defense, and the federal Bureau of Prisons.) The glaring flaw in that funding picture is that the sum did not even amount to $100 million prior to FY'85 — four years into the epidemic. It also should be noted that in each fiscal year since 1983, it has fallen to the Congress to increase the AIDS budget by 76 to 115 percent over the previous year, markedly exceeding the administration's request.21

Nearly $485 million in additional monies is budgeted for 1988 to underwrite the federal share of Medicaid, Medicare, Social Security, and Veterans Administration costs for the care and support of AIDS patients, and for massive, mandatory AIDS-testing programs for recruits and members of the armed forces, Job Corps enrollees, Foreign Service employees, and federal prisoners.

Through the end of 1987, individual states had allocated an additional $200 million, primarily for support services and education, though some funds for research were specified. Five states alone (California, New York, Florida, New Jersey, and Massachusetts) accounted for 85 percent of this money.22

Insofar as AIDS research is concerned, a number of problems stem from the lack of clear policy. Until 1988, funding was woefully inadequate. Even next year, federal funds for research will approximate only half a billion dollars — the remaining $250 million is earmarked for education and prevention. Whatever excuses may be offered for early failure to recognize the need to fully fund AIDS research, none remain. In October 1986, the National Academy of Sciences (NAS) and the Institute of Medicine (IOM) concluded in their joint study on AIDS that funding for AIDS research should be set at a billion dollars a year by 1990 — two years hence — and, further, that another billion dollars should be spent for public education and prevention, through a combination of federal, state, and private funds. Moreover, NAS-IOM underscored the need for such funds to be new funds — not siphoned from existing Public Health funds, as has chronically been the case in previous years.23

A second research problem, in the view of some scientists, has been the lack of a comprehensive, coherent approach to AIDS research. While it is agreed that new knowledge is needed to understand the AIDS virus and its biologic activity in humans — knowledge that can come only from basic research — it is nonetheless arguable that the components
of that research can be far better focused and integrated. The National Institutes of Health (NIH) could and should better coordinate in-house and externally assigned work and industrial projects. Much more could be done to bring together the groups involved in these projects. NIH is still authorizing research without first consulting the teams most likely to do the work. While NIH has identified the major lines of research—vaccines, anti-AIDS drugs, and virus investigations—it has not fully asked the research community what it sees as the best approach, the best targets, or the best way to organize. Among those scientists who subscribe to the view that greater coordination is both possible and necessary is Dr. David Baltimore, a Nobelist in medicine and physiology who received the prize for his work in virology, and director of the Whitehead Institute at the Massachusetts Institute of Technology.

One research area that has become better coordinated is the testing of new anti-AIDS drugs under the aegis of the National Institute of Allergy and Infectious Diseases. Such evaluations are now under way at nineteen centers across the country. While much has been done and fresh efforts are being made to enlist the nation’s front-line scientists in the research drive to unravel the mystery of AIDS, the public policy issues of how large the federal commitment to AIDS research should be, how fast it can be deployed, and how that research will be organized—perhaps even targeted—are yet to be fully aired or addressed.

Of at least equal importance is the public policy issue of assuring all AIDS patients medical care, and how that care is to be funded. Estimates of the direct medical care costs of AIDS vary widely. The best guess most widely cited is $8.5 billion to $16 billion a year by 1991, calculated for the Centers for Disease Control by economist Anne Scitovsky of the Palo Alto Medical Foundation/Research Institute and her colleague Dorothy Rice of the University of California at San Francisco.24 Their projections, however, are based on 1985 and 1986 data and on a U.S. Public Health Service forecast that estimates the United States will experience 270,000 cases of AIDS by 1991. Dr. Stephen Joseph, New York City health commissioner, has stressed that in 1991 alone, there will be more new AIDS cases than cumulatively in all the years from 1980 to the present. These projections do not reflect the unexpectedly large explosion of AIDS infectivity in needle-using drug addicts (or any significant spread of AIDS into the heterosexual population), which makes the upper estimate of $16 billion by 1991 more likely. Further, a forecast by the Rand Corporation, a California think tank, considers the PHS projection (of 270,000 cases between 1981 and 1991) low and offers a mid-to-high-range estimate of 400,000 to 750,000 cumulative cases in that period.25 Rand says its mid-range estimate would boost medical costs for AIDS to $38 billion by 1991.

For comparative purposes, even the low estimate of $8.5 billion a year for AIDS in 1991 rivals or exceeds the medical costs associated with other major health care expenditures: by 1991, $8 billion for caring for auto accident victims; $4.9 billion for digestive cancers; and $3.9 billion for lung cancer.26

While $8.5 billion to $16 billion in AIDS medical costs adds only a small percentage increase to the national health care expenditure, it should be kept in mind that AIDS is a completely new cost burden. Further, most AIDS patients are young adults, who historically are in an age group with the lowest medical expenses. Moreover, the costs will not be evenly distributed, any more than the patient load will be. Though U.S. AIDS cases have been concentrated in five major cities (Los Angeles, San Francisco, New York, Houston, and Miami), the CDC predicts that 80 percent of the growth by 1991 will occur outside these areas. Nonetheless, the heaviest case loads will continue in cities, and a
disproportionate number of cases will increasingly be among minorities, who dominate the populations of inner-city, urban poor.

Some 50 million Americans have inadequate health care coverage, and 30 million under the age of sixty-five have none.\textsuperscript{27} The federal Health Care Financing Administration estimates that 40 percent of AIDS patients’ care is currently being paid under federal/state Medicaid programs, though in some inner-city areas the figure rises to nearly 80 percent. To be eligible for Medicaid, of course, AIDS patients must first be impoverished.

The availability of Medicare for AIDS patients, under Social Security Disability coverage, is relatively meaningless. Disabled AIDS patients must “qualify” first by having made payroll contributions; then, they must prove that they are unable to work for a continuous period of at least twelve months. Though the eligibility period for receiving cash benefits has been shortened, patients must wait an additional twenty-four months for Medicare benefits.\textsuperscript{28} Only 1 to 3 percent of AIDS patients live long enough to qualify for Medicare, though this could change if new therapies prolong survival.

In view of these medical-cost calculations, the AIDS epidemic requires new public policy on how the costs are to be met. Private insurance pools have been recommended, as have other publicly financed reimbursement strategies. But it is clear that only the federal system can deal with the huge expenditures that AIDS care will entail, and that only federal policy can set the course. The health care system in the United States is disjointed and uneven, owing to the disparate mechanisms under which it is funded, and many health care delivery planners believe that it cannot withstand the financial burden that will be imposed upon it by AIDS. Many of these planners feel that only a national health insurance program, drawing on the widest base possible, will be able to aggregate and dispense sufficient funds in timely enough fashion to meet the challenge of AIDS.

Almost all studies so far have limited their consideration to overt AIDS, according to the old CDC definition. The broader definition put into effect in September 1987, which includes seriously ill ARC patients and other AIDS-related conditions, is expected to raise all estimates by at least 15 percent.\textsuperscript{29} Further, new analyses of New York City’s experience find that 46 percent of patients hospitalized with AIDS infections are chronic ARC patients, many of whom become sick and die without ever having met official AIDS definitions. The CDC itself has said that its AIDS figures may be underreported by 40 percent. Whatever the actual case loads ultimately prove to be, they are much more likely to be higher, not lower, than current analyses indicate.

Money is not the only AIDS medical care problem. Shortages of nurses and of appropriate facilities, such as hospices for dying AIDS patients and inpatient services for those with dementia, further complicate the picture. Studies indicate that AIDS patients require at least 40 percent more nursing care than other medical/surgical or pediatric patients. This translates into eight or more hours of direct nursing care per day. At these high levels of care, it is estimated that at least thirteen thousand additional nurses will be needed for AIDS patients alone by 1991, at a time when nurses will still be critically scarce. The nursing requirements also preclude the possibility that many AIDS patients will be able to be cared for in nursing homes, since the patients need far more nursing care than is available in a skilled nursing facility. Studies have further shown that AIDS patients, because of physical and mental disabilities, also place high demands on social services. While models for flexible, alternative approaches to AIDS care (most notably developed in San Francisco), such as residences, hospices, and home care, should be pursued, they are not readily available. Shortages in home care staff and in funding for home care already are tying up services for the elderly. A new (October 1987) Massachusetts Hospital Associa-
tion study identified the “most pressing” gaps in the health delivery system as the unavailability of secure inpatient psychiatric services for AIDS patients suffering neurological and other mental disturbances; an inadequate number of drug abuse programs, particularly methadone treatment centers; and a shortage of home health and hospice services, which already “appear seriously strained.”

What is certain is that there will be no quick fix for the medical care requirements of AIDS patients. The hardest hit states already are reaching the limits of their financial ability to cope with the disease. States may be a “laboratory” for devising better medical delivery responses, but AIDS is a national health crisis and the major responsibility for funding and for gearing up the health delivery system to respond lies with the federal government. Such action is fraught with difficulty. Yet, public policy decisions on AIDS medical care issues cannot be avoided much longer.

**Civil Rights**

At the heart of public policy considerations concerning AIDS is the conflict between individual rights and the need to protect the public health. The AIDS outbreak here began and persists in three groups — homosexual men, drug addicts, and prostitutes — who, regrettably, are classic targets of discrimination and neglect.

Though pockets of public hysteria over AIDS have calmed down as confidence grows that the disease is not casually transmitted, it should be remembered that there were sporadic early and continuing calls from some political-fundamentalist groups for quarantine, including the recommendation that Boston Harbor’s Peddocks Island, the former home of a now-abandoned leprosy sanatorium, be used as the site. The 1986 political campaign waged by Lyndon LaRouche in California embodied similar ugly proposals.

Artificial importance has been given the topic of mandatory blood tests for AIDS, as if by identifying all AIDS virus carriers, some easy solution for dealing with the epidemic would emerge. Copious energy has been devoted to the issue of AIDS testing, hardening the lines between advocates and opponents. As Adlai Stevenson said of nuclear weaponry, “There is no evil in the atom,” only in what society does with it.” So it is with AIDS testing: the problem lies in the use made of it. No problem would exist at all were it not for the stigma that some have assigned to AIDS. In despicable judgments, AIDS is dismissed as a disease of the sexually perverted, depraved junkies, and pariah prostitutes who deserve what they get. Though more subtly expressed, stigma still misshapes much of society’s — and the government’s — response to AIDS.

The second social force feeding reaction to AIDS is fear. AIDS patients have been evicted from apartments and fired from their jobs; a few have even been ousted from hospitals. Even when the AIDS victims have been children, surely unwitting victims of the disease, fear has turned otherwise reasonable adults into brute-faced protestors, refusing to allow AIDS children to attend school, shunning them and their parents, and even acting out violently against them. Despite the protection afforded by standard precautionary measures, some doctors, dentists, and nurses have refused to care for AIDS patients, and some undertakers have refused to bury them.

Fear and the prejudice born of fear are one thing. Toleration of discrimination against AIDS patients and carriers is another. Education can minimize fear and defuse prejudice, but law and the enforcement of law are needed to prevent future AIDS discrimination.
Such legal protection falls within the realm of public policy. While some states have specifically outlawed AIDS discrimination, here, too, there is need for a national stance. U.S. Sen. Edward Kennedy (D-Mass.) and Rep. Henry Waxman are cosponsoring federal legislation to ban discrimination against people with AIDS, to guarantee confidentiality of AIDS-related records, and to assure privacy. Their bill was filed on June 23, 1987, in the aftermath of the Third International Conference on AIDS, during which police in Washington, D.C., donned heavy, yellow rubber gloves in a fear-mongering reaction to a march by AIDS victims. Though two hearings have been held on the bill, no action is expected until later this year. Some of the delay stems from a persistent, negative undercurrent about AIDS, abetted by the Reagan administration’s political position that such legal protection is a state matter. Until destigmatizing legal protection is in place, progress on the whole roster of civil rights issues concerning AIDS will be stalled. These reach into the rights of homosexuals to fair and impartial treatment; of drug addicts and prostitutes to life-saving preventive and curative services; of prisoners whose AIDS infectivity can diminish their prospects for release; of military personnel whose careers may be thwarted because of their AIDS status; of public and private employees to job equity; of children to attend school; and of all people with AIDS to obtain housing, social services, and adequate and compassionate medical care.

Alongside these rights stand the conflicting issues of whether those in sexual contact with AIDS carriers are entitled to know they have been placed at risk; whether insurance companies should be allowed to test applicants; the limits under which public health officials can detain AIDS carriers who deliberately continue behavior that can transmit the infection to others; and how workers in direct care or contact with AIDS patients and AIDS carriers are to protect themselves from infection.

These are formidable public policy issues, ones that are “unlikely soon to be met,” says Dr. Harvey Fineberg, dean of the Harvard School of Public Health. As a guideline, he urges that the least restrictive means be sought to protect the community and that a graded series of responses be devised before public policy steps are taken “that run the risk of infringing upon the rights of individuals.” A national agenda of AIDS-related civil rights issues needs to be set.

Prevention

Of all the sorry aspects of the AIDS epidemic in the United States, none is sorrier than the slow and inept efforts of the federal government to prevent the spread of the infection. While it is impossible to calculate how many people acquired the infection because they did not know how not to — or, more to the point, had not been told in persuasive ways how to avoid doing so — the number has to be very large, and it is still growing.

The nub of the problem, of course, is that to educate the public about safer sex as a modality for preventing AIDS entails informing people about sexual matters. Sex education is a topic that the U.S. government historically, and this administration particularly, has shrunk from, as if the subject itself were a carnal sin. Beneath the torrents of hypocritical preaching about the need to be sensitive to religious teachings, family values, and traditional morals, the basis for much of the resistance has been the viewpoint that those who violate the bounds of chastity and fidelity should pay for their transgressions. On such terms, AIDS can be dismissed as a form of moralistic retribution, visited upon the
willful or, at least, the weak. However desirable strong moral codes may be for the conduct of society, they are weak weapons for combating a disease like AIDS, especially in an era marked by sexually frank commercialism and increasingly open sexual behavior.

Arguments against telling people how to prevent AIDS through the use of condoms rest on the same questionable point that has precluded telling teenagers about responsible (pregnancy-avoiding) sexual behavior: the fear that it would encourage the very behavior that was not wanted — promiscuity — even though extensive pilot programs prove otherwise. The barriers to educating the American public about AIDS are nowhere clearer than in the brouhaha that erupted in 1986 when television networks were confronted by public service announcements that used the word *condom*. Condoms are more openly spoken of now, though still more frequently on news broadcasts than in public service ads.

It was Rock Hudson’s death that drove the message home as nothing else had. But until 1986, the source of AIDS preventive education remained almost exclusively the gay male community. AIDS action committees and other similar forums assembled and distributed the first and only booklets, posters, and fliers that advised people how to continue to engage in sexual activities — more safely. Since these messages were directed to homosexual men, they were not generally regarded as appropriate for heterosexuals, though safer sex practices apply universally. Heterosexuals went on blindly unconcerned for a prolonged period, and government agencies did little to instruct them otherwise.

The number of AIDS cases reached a dramatic height (sixteen thousand) in January 1986, and the infection was making inroads among intravenous drug users and prostitutes in major cities. These latter groups not only were largely heterosexual, but also were seen as bridges for the spread of AIDS to the broad general public. Transfusion cases were growing, and more than two-thirds of the estimated twenty thousand seriously afflicted hemophiliacs in the United States had acquired the infection through contaminated blood products. In early 1986, the National Academy of Sciences and the Institute of Medicine decided to undertake a special assessment of the problems and to propose an appropriate national response. Public pressure for action was mounting.

In February 1986, President Reagan called for a report on AIDS from the U.S. surgeon general, Dr. C. Everett Koop. A spokesperson for the U.S. Public Health Service at that time estimated that the report would be ready by May or June, but it was not issued until two weeks before the NAS-IOM report; many felt the timing was deliberate to counteract the complaint that the president had yet to comment or act directly on AIDS. Koop’s thirty-six-page, plainspoken report about the medical facts and sexual aspects of AIDS drew heavy fire from the fundamentalist religious contingent and from ultraconservative congressional and White House factions. His pamphlet remained, until October 1987, the only major administration document on AIDS. It has yet to be distributed directly to American households. An influential opponent of sexually specific AIDS education in the schools and of Koop’s report is the stolidly conservative U.S. secretary of education, William Bennett. Further, Bennett’s former associate Gary Bauer now heads the Domestic Policy Council in the White House. In the aftermath of the Third International Conference on AIDS in June 1987, Congress appropriated $20 million for a mailing of Koop’s report to every American household. Instead, a folder was prepared for Dr. Otis R. Bowen, U.S. secretary of health and human services, by the CDC as part of its so-called America Responds to AIDS project. In his introduction, Bowen calls the response “inspiring.” With only scant reference to condoms and none to homosexuality, the folder advocates the sharing of family moral and religious values, monogamous relationships, and, for teenag-
ers, saying no to illicit drugs and no to sex. This booklet was to substitute for Koop’s
forthright report. Some 45 million copies are “targeted” for distribution by states, local
health departments, YMCAs, and selected corporations. Congress has officially re-
quested the General Accounting Office to investigate “the Administration’s failure” to
carry out Congress’s mandate to mail AIDS data to every household;” other countries,
including Great Britain, have done such mailings. The administration, meanwhile, had
indicated that it intends to use the $20 million for other purposes. A different pamphlet
is now being readied for household mailing this summer, Bowen says, and the U.S. Public
Health Service plans to comply with the congressional mandate. Rep. Gerry Studds (D-
Mass.) contends that “the White House blocked the widespread distribution of Koop’s
report, even now, because it deemed the information within the report too explicit for the
general public. The Administration’s abject failure to fulfill its public health responsibili-
ties now verges on criminal negligence.”

While the squabbling over Koop’s and Bowen’s reports continues — a reflection of the
AIDS policy struggle within the White House — cities and community organizations are
left to try to combat the spread of AIDS on a local level. Cities like New York, San Fran-
cisco, Los Angeles, and Miami have gone public with the AIDS message — on billboards,
buses, rapid transit ads, and through extensive use of news media. Some states, including
Massachusetts, are sending out their own household mailings and have prepared class-
room curricula on AIDS (the CDC is now preparing its version). But there’s a lot of slippage
between the teaching guides and their use. Communities control what is taught in
their schools, and many have denied the introduction of AIDS materials. Though a few
cautionsary spot announcements have been prepared, federally and at the state level, the
broadcast media have largely been slow to use them. The CDC regularly issues medical
advisories on AIDS infection control, but these do not reach broad public audiences.

Yet, continuing surveys show that Americans are highly aware of AIDS. Radio and TV
news features and documentaries, and stepped up reporting and special AIDS sections in
newspapers and magazines, along with plays and movies, have been the purveyors of
AIDS information for the public. Among the difficulties in such an arrangement are the
information, language, and cultural impediments, and the hit-or-miss nature of the pub-
lc’s reading and viewing habits. Further, the degree of public attention paid the topic of
AIDS, as is true of most subjects, waxes and wanes with little consistency.

In terms of public policy, the United States has failed so far to address the need for
massive, persuasive, public education aimed at prevention on any long-term basis. Not
only has the federal government failed to spell out in precise language the nature of the
disease, but it has not yet even recognized that it lacks a mechanism for speaking directly
to the public. In Europe, Mexico, Canada, and Australia, as in China and India and Soviet
bloc nations, the governments have direct avenues for public communication — through
socialized health services and socialized radio and television. Although they are helpful,
mailings to households, public health agencies or community organizations do not begin
to address the need to persuade people to change their behavior. This involves more than
an occasional booklet. What is needed in the United States is some new, direct line of
communication — from the federal or state government, or both, to the citizenry. To con-
tinually update information about AIDS, as it changes, requires a ready means of getting
the information out — quickly, thoroughly, accurately. This is the AIDS education public
policy issue that demands immediate attention.

Some still would have it that AIDS has struck like a freak storm, blowing across areas
of the world that lie powerless in its path. AIDS, indeed, may be a new whirlwind, but its
impact is worsened by the pervasive social neglect that now leaves the United States in a weakened position to cope with it. AIDS is extracting a heavy penalty for our failure to overcome homophobia, drug addiction, and prostitution; to establish a credible system for funding health costs and providing health care; to attract, train, and fund sufficient medical and research personnel and to keep pace with the need for advanced research laboratories; to create an adequate network of home care, nursing home care, hospices, and health communication; to surmount the barriers that place inner-city minorities at risk for every successive medical-social hardship; and to accept the validity of public sex education. That is the landscape onto which AIDS has moved, a setting ill-prepared for its assault.

Though lack of presidential leadership does not fall neatly into a category of public policy, national mismanagement of the AIDS epidemic does. As early as 1984, Congress’s Office of Technology Assessment chided the handling of the AIDS outbreak.39 As recently as August 1987, the U.S. General Accounting Office, in a Briefing Report to Sen. Lawton Chiles, chairman of the Senate Subcommittee on Labor, Health and Human Services, Education and Related Agencies and of the Senate Budget Committee, presented the views of a broad range of American experts on AIDS. It expressed deep concern about a general lack of federal leadership, citing a “patchwork” of federal and state funding for AIDS prevention programs and cumbersome processes for awarding research grants. It also concluded that “within the context of current health policy-making . . . the federal response to AIDS appears uncoordinated and insufficient.”40 Six years into an epidemic of the proportion and severity of AIDS, this conclusion borders on an indictment of the Reagan administration, which has held the reins of federal power since 1981: AIDS played out “on their watch.” The latest Reagan ploy has been the naming of an AIDS Commission, originally predominated by AIDS amateurs, to report on the ramifications of the epidemic. Although the commission leadership has been strengthened and is making a diligent effort to assess the AIDS outbreak and the response to it, it is late in the day to do so.

To all appearances, Congress is now taking AIDS out of the administration’s hands. Despite the gloomy predictions, it is still possible to marshal the great scientific might and vast social resources of the nation. “To have an impact on what happens in the mid-1990s,” warns Dr. Stephen Joseph of New York City, “we will have to take action now.”41 The ultimate public policy question regarding AIDS is whether enough public will and government support can be mustered to act in time. The leviathan of AIDS will not wait.

Perspective

Two rules of thumb are helpful for understanding the AIDS phenomenon.

The first has to do with the pace of infection. It holds that although it takes years for the first 1 percent of a population to become infected, after that a doubling phenomenon sets in — whether the doubling time is six months, a year, or more. Studies of a large cohort of homosexual men show that it took several years for 1 percent of the group to become AIDS-infected, as they were by 1978. It then took only one more year to double to 2 percent, and another year to reach 4 percent. The percentage reached into the teen figures by 1980, the mid-20 percents by 1981. By 1982, 47 percent (almost half) were infected. This happened before there was much awareness of AIDS and little change in behavior to contain its spread. Today the number infected in that group is around 78 percent.
The other rule of thumb relates to how many persons infected with AIDS will convert to illness, and how soon it will happen. At first it seemed that only some few would convert; others would be spared. In the beginning, the conversion rate seemed to be 1 to 2 percent a year, then 3 to 5 percent a year, then 5 to 10 percent. The conversion rate seemed to slow down between the third and fifth years. Now, it appears that after the fifth year of infection, the number of those who convert to illness seems to speed up again. Of eighty-eight California men who have been infected with the AIDS virus for seven years, 90 percent have fallen ill. Rather than escaping the disease state of AIDS, it seems more likely to be a matter of time. Incubation may extend far longer than ten years. These two indices of AIDS — spread of infection and conversion to illness — are of vital importance. The first suggests that if the spread of AIDS is not kept below a critical point, it will continue largely because there will be so many AIDS-infected people available for sexual or blood-related contact with the noninfecteds. In other words, as the pool of virus grows, so does the likelihood of encountering it. The second index, of conversion, indicates that the ultimate number of AIDS cases may be nearly all of those persons now infected. Cases today are a snapshot of the spread of AIDS two to seven years ago. Future cases will be a reflection of failure to act, now.

**Details of the AIDS epidemic and the extent to which it was mismanaged on almost every front are documented in a new book, And the Band Played On: Politics, People, and the AIDS Epidemic, by Randy Shilts, a reporter for the San Francisco Chronicle who has been writing about AIDS since 1982. The book stands as an indictment of the interlocking process whereby the early spread of AIDS can be traced to the fractious divisiveness within the male homosexual community; an imperious lack of interest by major science centers; the torpid response of public health officials, voluntary blood banks, state and federal agencies, and most elected officials; and the brittle resistance of the Reagan administration.**

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**Notes**


7. Dr. Ib Bygbjerg, State University Hospital, Copenhagen, Denmark. Letters to the Editor, Lancet, April 23, 1983.

9. Ibid.
10. Ibid.
13. Ibid.
17. Personal interviews, October 1987.
22. Ibid.
28. Ibid.
31. Adlai Stevenson, speech as Democratic presidential candidate, Hartford, Connecticut, September 18, 1952. “Nature is neutral. There is no evil in the atom — only in men’s souls.”
33. Centers for Disease Control, Atlanta, Georgia. AIDS updates.


38. Ibid.

