THE AIDS EXCEPTION: PRIVACY VS. PUBLIC HEALTH

by CHANDLER BURR

It's time to stop granting "civil rights" to HIV—and to confront AIDS with more of the traditional tools of public health

EPIDEMIOLOGY, which encompasses both the systematic study of infectious disease and the implementation of the means to contain it, is something of a medical oddity. As dependent on statisticians and politicians as it is on medical-care providers, and often used at times of desperation, by practitioners who have been accorded police and in certain cases military powers, epidemiology has sometimes had to strike a balance between the harshness that may be required to control infectious diseases and the civil liberties of people whose rights may be subject to abridgment.

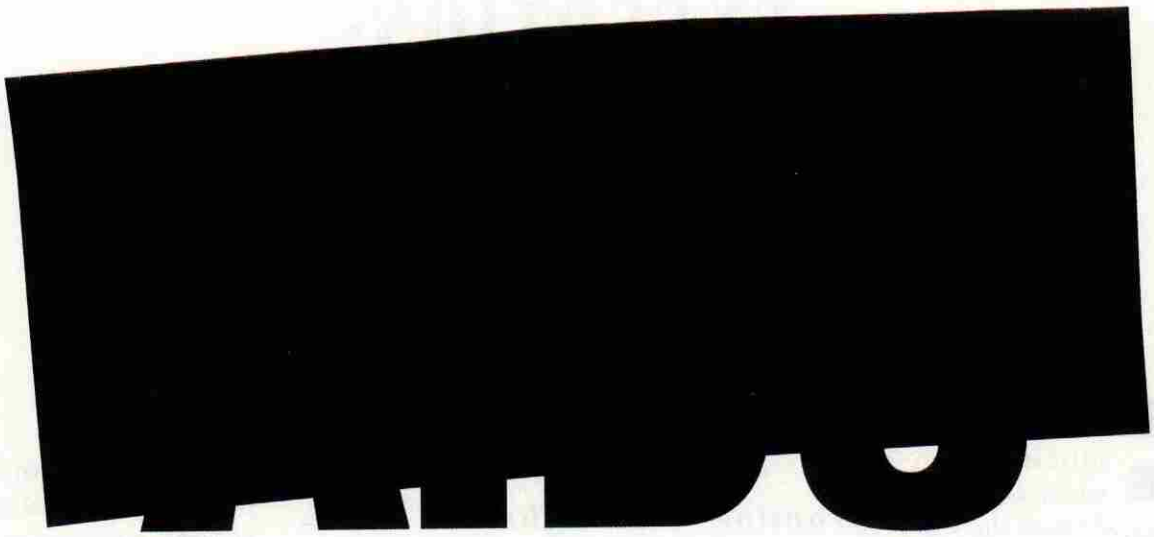
Since the turn of the century, with the introduction in this country of bacteriological testing and the establishment of boards of health, standard public-health measures have been deployed against infectious diseases. These measures, leaving aside the extreme step of holding people in quarantine, have typically included at least some of the following: *routine testing* for infection, often undertaken without explicit patient consent; *reporting* to local health authorities of the names of those who test positive for infection; *contact tracing*, or the identification of any people who may have been exposed to infection; and *notification* of these possibly infected people that they may have been exposed. Some combination of these four practices has been commonly applied against outbreaks of infectious diseases, including typhoid, diphtheria, and tuberculosis, and against upsurges in sexually transmitted diseases. It would be surprising if, out of all the viruses and bacteria that can do us significant harm, one was exempted from the scope of these measures. It would be even more surprising if the one chosen pathogen was responsible for an epidemic that today constitutes the leading cause of death among all Americans aged twenty-five to forty-four.

This very thing has, of course, happened, largely in order to accommodate civil-rights concerns. The practice of tradi-

Illustrations by Ivan Chermayeff

tional public health has been to a great degree suspended for acquired immune deficiency syndrome and for human immunodeficiency virus, the virus that causes it. Although various traditional public-health steps are being taken against AIDS and HIV, in differing combinations from state to state, the result is a chaotic patchwork—one that is inadequate, a growing number of critics say, to the task of containing and eradicating AIDS.

"We have convinced ourselves," Ralph Frerichs, a prominent epidemiologist at the University of California at Los Angeles, wrote in a recent issue of the journal *Epidemiology*, "that the fight for survival can be waged in a way that is socially acceptable but not always biologically credible." Many public-health officials, he contended, "have remained steadfast in their commitment to programs and approaches that have hidden the identity of HIV carriers but have failed to halt viral transmission"—a commitment that is in the end bound to prove self-defeating, "making winners of the virus but losers of people."



THE PRICE OF COOPERATION

WHAT is known in the field of public health as AIDS exceptionalism has been maintained in legally and programmatically direct ways and also in complex and subtle ways. Its origins are not difficult to ascertain.

When AIDS first surfaced, in the early 1980s, it was indisputably a disease of urban male homosexuals (and, to a far lesser extent, of intravenous-drug users). Public-health authorities, faced with a fatal, communicable disease whose method of transmission they did not understand, desperately needed the cooperation of the infected—as they would in any epidemic. In the case of AIDS, however, the infected eventually became disinclined to cooperate. "In the first months and years of the epidemic," the journalist Elinor Burkett, the author of *The Gravest Show on Earth* (1995), recalled not long ago, "people with AIDS died in the hallways of hospitals, where nurses wouldn't touch them. They were kicked out of their apartments. Insurance companies canceled their policies. Their bosses fired them. They had no idea how to get Social Security disability payments or Medicaid."

The discovery of HIV, and the development of a test that could detect it, brought matters to a head. In the aftermath of anti-gay persecution and even violence, the price exacted by a terrified gay community for cooperation in even a rudimentary public-health effort was ironclad anonymity. In 1985, shortly before the federal government was to announce the licensing of the first test for detecting HIV, the National Gay Task Force and the gay civil-rights group Lambda Legal Defense and Education Fund filed a petition in federal court to delay this action, pending a legal guarantee that the test would not lead to widespread screening aimed at gay men. They then put pressure on the Food and Drug Administration, which along with the federal Centers for Disease Control (now the Centers for Disease Control and Prevention, and henceforward referred to as the CDC) had been made aware of eager queries from school districts hoping to use the HIV test to

identify and fire gay teachers. The FDA quickly acceded to the demand that the HIV test be used not to screen and identify *people* for HIV infection in systematic campaigns but only to screen the blood in blood banks.

Out of the threat that the HIV test posed to privacy grew a rigid resistance to almost all HIV testing without consent—and a public-health approach to combating AIDS characterized by considerable delicacy. The FDA's agreement to restrict how the HIV test could be used resolved, temporarily, a political problem. Left unanswered, as Randy Shilts, in his book *And the Band Played On* (1987), observed, was "the broader public health question of how you can control a disease if you decline to find out who is infected." Shilts went on, "In this poisoned atmosphere, the nuances of long-term consequences for control of the infection fell low on the list of gay concerns."

DOES AN ABSENCE OF ROUTINE TESTING, REPORTING, AND NOTIFICATION MEAN THAT A LOT OF UNDISCOVERED AIDS AND HIV CASES ARE FESTERING IN THE LARGER SOCIETY? YES.

The result, ultimately, was the effective suspension of traditional public-health procedures for AIDS, which is to say, there would be no routine testing for HIV; the reporting of the names of the HIV-infected would be required only in some places, and would miss the epidemic's hotspots; and contact tracing and notification would as a result be greatly handicapped, and in many places pursued in desultory fashion if at all, often in the face of opposition. All efforts were to be voluntary—dependent on educational outreach and persuasion rather than on systematic procedures. "U.S. officials had no alternative but to negotiate the course of AIDS policy with representatives of a well-organized gay community and their allies in the medical and political establishments," Ronald Bayer, a professor at the Columbia University School of Public Health, wrote in a critical retrospective some years ago. "In this process, many of the traditional practices of public health that might have been brought to bear were dismissed as inappropriate."

A NUMBER of opportunities present themselves for the routine testing of people for various diseases by public institutions, routine testing being defined as testing that can be performed without a person's explicit consent. Pregnant mothers are routinely tested for tuberculosis, hepatitis B, and syphilis; testing for chlamydia and group-B streptococcus is also common under certain circumstances. Newborn babies are routinely tested, without the mothers' permission, for phenylketonuria and hypothyroidism. Patients admitted to hospitals may undergo a variety of blood tests, depending on their symptoms, the tests being performed as a matter of course, without necessarily informing the patient or asking explicit permission. Although a patient can at any time refuse to undergo a routine test, he or she does not have to be specially notified that the test is being done or given a specific opportunity to refuse.

HIV testing, in contrast, is almost always voluntary—which means it is done either at an anonymous-testing site or with a person's explicit permission (and which usually means also that the person being tested must sign a release). At the federal level HIV testing is required only of immigrants entering the country, foreign-service and military personnel, and federal-prison inmates. At the state level routine testing is prohibited everywhere except under narrowly defined circumstances. Marcia Angell, the executive editor of *The New England Journal of Medicine*, and a proponent of routine testing in some form, says, "Having to ask specifically has a huge effect, and it is a clear difference between AIDS and many other diseases."

Making even certain subpopulations the target of routine testing would turn up large numbers of infected people who currently escape detection. In a 1992 *New England Journal of Medicine* article Robert Janssen and his colleagues at the Division of HIV/AIDS at the National Center for Infectious Diseases recommended voluntary targeted testing for HIV in certain hospitals, a policy well short of routine testing and yet one that has been implemented virtually nowhere. They wrote,

> We estimate that about 225,000 HIV-positive persons were hospitalized in 1990, of whom only one third were admitted for symptomatic HIV infection or AIDS. Routine, voluntary HIV testing of patients 15 to 54 years old in hospitals with 1 or more patients with newly diagnosed AIDS per 1,000 discharges per year could potentially have identified as many as 110,000 patients with HIV infection that was previously unrecognized.

Testing that is merely voluntary may also miss populations that disproportionately need to be reached. The people least likely to have the virus are the most likely to say yes to a test, and the people most likely to have it are the most likely to say no. In one study infection rates were 5.3 times as high among people who refused HIV testing as among people who consented to it.

One might ask, How could a study give the infection rate of those who refused the HIV test? The answer demonstrates the methods that researchers—in this case, at the New Mex-

ico Health and Environment Department—must employ in order to obtain data without violating personal rights as protected by law. Voluntary, anonymous HIV tests were offered over a three-month period to all patients visiting a sexually-transmitted-disease clinic. Eighty-two percent of the patients consented to being tested for HIV. To determine the rate of HIV infection among those who did not consent to testing, researchers located serum that had been taken from these patients for syphilis testing, removed all identifying information, and then tested the serum for HIV.

Exceptionalists argue that routine testing will "drive AIDS underground"—make people avoid the health-care system altogether. There is no empirical proof that this will or won't occur to a greater extent than it already does, under a voluntary regime. Ultimately one must ask whether people who would go underground because of perceived self-interest should dictate policy—and also whether such people would cooperate in disease-prevention efforts under any circumstances.

WHY does testing matter? The most basic epidemiology holds that early knowledge of where a virus is moving—into which populations—is essential to slowing its spread. Even if a disease cannot be cured, knowing who the infected people are may help prevent the transmission of the disease to other people. Geneviève Clavreul, a California-based consultant to the International Cancer and AIDS Research Foundation, says that because of testing and reporting restrictions the California Department of Public Health is in essence "flying blind" in its epidemiological tracking. By law or regulation, cases of certain sexually transmitted diseases and of many other infectious diseases must be reported to state departments of health, and the names of the infected are in most cases provided and are always held in confidence. HIV is the exception. Although the disease called AIDS must be reported by name in all fifty states, infection with HIV, the virus that causes AIDS, need not be: only twenty-six states mandate the (confidential) reporting by name of positive test results for HIV, and these states tend to be ones with modest caseloads. Twelve states—including California and New York, by far the two worst-afflicted states—have no broad reporting requirements for HIV.

Requiring the reporting of AIDS but not HIV seems equivalent to requiring, say, that full-blown cases of hepatitis B be reported but not any newly detected infections with the hepatitis virus. Actually, it is worse. The incubation period for hepatitis B is usually two or three months, whereas the period between infection with HIV and a diagnosis of AIDS is often longer than ten years. This means that during all this time HIV-positive people can be both infectious and outside the public-health system. The disease is further privatized by the HIV home-testing kits now on the market, which to yet one more degree put testing and reporting into the hands of individuals.

As noted, state public-health practices mandate that certain sexually transmitted diseases be reported; in part to avoid reporting HIV some states have decided not to classify HIV as a sexually transmitted disease—even though the primary mode of HIV infection is, of course, sexual. As of 1995 only twelve states had classified AIDS and HIV infection as sexually transmitted diseases. Only sixteen states had even classified them as communicable diseases. Treating AIDS and HIV infection as exceptions, twenty-three states, including New York and California, had classified them as a separate category of disease. A report prepared for the CDC by Georgetown University and Johns Hopkins University's Program on Law and Public Health observes of this situation: "Disease-specific legislation may thwart public health goals by generating separate policies, programs, and procedures for diseases that may share common behavioral risk factors and require a unified approach for treatment and prevention."

BEYOND issues of testing and reporting lies the issue of partner notification. "Partner notification" is the term used by the CDC to describe a spectrum of outreach efforts. One such effort is contact tracing, also called "provider referral," in which doctors or public-health officials locate partners of infected people (if the infected people are willing or able to provide names) and notify them of possible infection; the name of the known infected person is always kept confidential. At a further remove on the spectrum is "patient referral," in which infected people locate and notify partners on their own. Only thirty-three states have laws that explicitly allow doctors or public-health officials to notify the sex or needle-sharing partners of those with AIDS or infected with HIV. Only four states (Arkansas, North Carolina, South Carolina, and Oregon) have statutes requiring notification.

All states technically have something that they can point to as a "partner-notification program," having such a program being a prerequisite for obtaining certain federal funds.

KNOWING WHO IS INFECTED WITH AIDS AND HIV IS ESSENTIAL IN HELPING TO PREVENT NEW INFECTIONS, EVEN IF THE INFECTED PEOPLE THEMSELVES CANNOT BE HELPED.

But the effectiveness of partner-notification programs varies widely, for reasons relating as much to how the programs are implemented as to what specific steps they call for: the real difference is between states, such as Colorado and North Carolina, that actively strive to find and notify partners primarily through provider referral, and states, such as New York and California, that tend to rely on patient referral, deferring the responsibility of notification to the infected.

As one would expect, there seems to be a marked contrast between the effectiveness of well-established partner-notification programs in which provider-referral services are made available, and that of programs in which infected people themselves do the notifying if they are so inclined. One study found that active partner-notification programs offering provider-referral services get 30 to 90 percent (depending on the city or state) of people who have tested positive to cooperate in contacting those they may have infected. Ninety percent or more of those contacted agree to be tested. However, programs in which notification is left up to the infected achieve a cooperation rate of less than 10 percent. It should be noted also that by virtue of the fact that trained public-health personnel in most instances make the notifications in provider-referral cases, testing information and counseling are made readily available to possibly infected contacts. Programs that notify primarily through provider referral find a larger proportion of other infected people, and find them earlier. The sooner a person knows of his or her infection and begins treatment, and the higher that person's T-cell count when treatment begins, the better the prognosis. In a recent study conducted at a Los Angeles AIDS clinic the average T-cell count in HIV-positive women who entered the clinic through active provider-referral partner notification was found to be 411; the average for all other women entering the clinic was 157. ("T-cell count" refers to the number of T-helper cells, a kind of white-blood cell that is essential to the proper functioning of the cellular immune system; HIV attacks and kills these cells. The T-cell count is closer to 1,000 in a healthy person, though the healthy range is subject to considerable variability. A T-cell count under 200 is one of the criteria for a diagnosis of AIDS.)

Does an absence of routine testing, reporting, and notification mean that a lot of undiscovered AIDS and HIV cases are festering in the larger society? Yes. According to the CDC, the number of Americans infected with HIV is as high as 900,000; of these, the CDC estimates, perhaps half are unaware of their infection. At least a quarter of all people in whom AIDS was diagnosed from 1990 to 1995 in Los Angeles County first became aware of their infection when they came to hospitals or clinics with advanced symptoms, having never previously been tested for HIV. In all likelihood such people had been HIV-positive for years. Most cancer, diabetes, or high-blood-pressure patients have been tested for these medical problems, know their status, and have begun treatment well before admission to a hospital with advanced symptoms. The situation with AIDS means, as one Los Angeles AIDS clinic director observed during a recent interview, that "something is really wrong." Because the lifetime cost of treating HIV is so high (estimated in 1993 to be $119,000 per

patient), the CDC has concluded that AIDS and HIV notification programs pay for themselves if only one in eighty notifications prevents a new HIV infection by indicating to the notified person that a change in behavior is warranted.

AIDS has been so thoroughly exempted from traditional public-health approaches that civil libertarians have defeated in court attempts by health authorities to notify the spouses of people who have died of AIDS that their husbands or wives were HIV-infected. During the first years of the disease, legislation urged by civil libertarians prohibited physicians and public-health officials from notifying even the spouses of living people who had tested positive for HIV, some of whom continued to have unprotected sex with their partners. In some states laws have been enacted making partner notification by a physician at best discretionary under tightly defined circumstances.

National legislation on spousal notification, passed last year, mandates that states make a "good-faith effort" to notify at-risk spouses. However, in effect the law applies only to states that already require the names of infected people to be reported. And in any event, the matter of partner notification when the partners are (or were) married addresses, of course, only a small part of the AIDS problem.

WRONGHEADED RATIONALES

HOW has AIDS exceptionalism been justified? In the mid-1980s four arguments were regularly heard for exempting AIDS from standard public-health practices. 1) There had never before been a disease that seemed to constitute a de facto marker for homosexuality, with all the social stigma that this label carries. 2) The confidentiality of testing would inevitably be violated, precisely because AIDS is more stigmatized than any other disease. 3) Given the large number of sex partners of many of those who have become HIV-infected, contact tracing would be ineffectual. 4) Because there is no cure for AIDS, and no treatment to render the infected uninfectious, it was pointless to report HIV infection as is done for other infections.

However legitimate the civil-liberties issues it sought to address may have been more than a decade ago, the exceptionalist orthodoxy is now fundamentally wrongheaded as a matter of good public health and medicine.

The argument that AIDS is a unique marker for homosexuality is incorrect, and always was so. Rectal gonorrhea in men has been almost exclusively a disease of the gay population, and is a more reliable marker for homosexuality, if anyone were looking for such a marker, than AIDS ever was. And yet cases of rectal gonorrhea have appeared for decades, by name and date, in confidential case reports sent to state public-health departments.

The argument that confidentiality will inevitably be violated has met a serious counter-argument in the form of reality: the experience of Minnesota and Colorado, which have since 1985 mandated the confidential reporting by name of both HIV and AIDS cases. As of the end of last year, for example, Colorado health authorities had received the names of 5,723 people with AIDS and of 5,137 additional people infected with HIV. There have been no breaches of confidentiality. As noted, twenty-six states now require confidential reporting of all HIV cases by name. A single intentional breach of confidentiality in the CDC's AIDS surveillance system is known to have occurred (in Florida).

As for discrimination, the federal Americans with Disabilities Act (ADA), passed in 1990, a decade after the beginning of the AIDS epidemic, prohibits discrimination based on HIV status. In addition, the federal Vocational Rehabilitation Act of 1973, state discrimination laws, and state constitutions have all been interpreted by courts as protecting people from exactly the sort of discrimination that AIDS exceptionalists claim is inevitable. And courts have in most cases ruled that being infected with HIV constitutes a disability according to the legal definition of the term, even when the infected person is asymptomatic. "We've done more or less everything that can be done on the legislative front to protect people from discrimination on the basis of HIV status," says Chai Feldblum, an associate professor at Georgetown University Law School and one of the principal architects of the ADA. "The laws are there."

The argument that contact tracing will prove to be ineffectual because many of those infected with HIV have had a large number of sex partners ignores the fact that many of those infected with syphilis and gonorrhea, other diseases for which gay men are at increased risk, have also had a large number of sex partners, and yet contact tracing has been standard procedure for these diseases for decades.

The argument that name reporting is pointless because there is no treatment has always been open to question on a number of grounds. Yes, the statement may have a certain logic from the perspective of a given infected individual concerned only about his or her fate. But if infected people can be identified, education and counseling may at the very least prompt changes in their behavior which will diminish the risk that they go on to infect others; contact tracing, in turn, extends the possibility of risk-diminishing behavioral change even more widely. Knowing who is infected is essential in helping to prevent new infections, even if the infected person himself cannot be helped.

In any event, evidence shows that new medical treatments are making HIV less infectious than ever. The latest treatments are astonishingly promising for at least some of the infected population.

Some 15 to 30 percent of HIV-infected pregnant women pass the virus on to their infants. Early treatment with zidovudine, or AZT, for the woman during pregnancy and for the infant after birth, can cut the proportion to eight percent. A new class of drugs called protease inhibitors is likely to cut the rate

even further, if the drugs are used early. The key word is "early"—which means testing pregnant mothers, not just newborn babies. The American Medical Association now recommends that HIV testing be made mandatory for pregnant women. Gay and AIDS activists have denounced this recommendation.

Protease inhibitors, which in some cases have reduced the level of HIV in the bloodstreams of the infected to undetectable levels, have revolutionized care for many patients. "I think we already have the capability to make HIV infection a chronic, manageable disease like diabetes in patients who can afford the therapy and who can take it with one-hundred-percent compliance," says Joel Gallant, the director of the Moore HIV Clinic at the Johns Hopkins University School of Medicine. Protease inhibitors have provoked debate as to their long-term effectiveness, their ability to withstand viral resistance, and their price (the protease inhibitor Invirase costs approximately $7,000 for a year's supply), and also, as Gallant has noted, because of the fastidiousness required for effective administration. But the fact remains that the exceptionalist argument that no treatment is possible is losing whatever force it had.

The benefits of knowing who is infected are still more compelling today than they were in 1992, when the CDC AIDS laboratory chief Donald Francis, writing in the *Journal of the American Medical Association* in favor of more-aggressive testing and the channeling of the infected into prevention and counseling programs, brought up "the ability to deliver important new products produced by scientific research." He wrote,

> Should the day come when a vaccine or therapeutic drug becomes available, a system for immediate delivery to those in greatest need would be required. There is no system by which to do that now. But if all infected persons were being followed up in an early intervention program, delivery would be straightforward. In my opinion, early intervention should be given the highest national priority.

The fact that AIDS is not easily transmissible (it is a hundred times less infectious than hepatitis B, and incomparably less contagious than an airborne disease like tuberculosis) provides further impetus to discover who is and is not HIV-infected. The knowledge that a given person is infected, if it means that the person takes any preventive measures at all, is much more valuable in the case of AIDS than it is for other diseases.

REMEDY-RESISTANT POLITICS?

DESPITE such developments, attempts to alter the public-health approach to AIDS, though on occasion successful, have met with fierce opposition. A case in point occurred in the spring of 1995, when Gary Ackerman, a liberal Democratic congressman from New York, introduced a bill with 220 co-sponsors to "unblind" a national infant-testing program for HIV run by the CDC as a way of monitoring HIV-infection rates in women. Since 1988 the CDC had been "blind-testing" infants for HIV in forty-five states—using blood samples, collected at birth, from which all identifying tags had been removed. Testing for HIV in this way meant that the CDC knew how many infants carried their mother's HIV antibodies but not who they or their infected mothers were. Mothers, therefore, were being sent home without being informed that they and in some cases their children were infected with a fatal virus. The CDC had no choice in the matter, being legally prevented from testing without informed consent. Under the Ackerman bill mechanisms were to be instituted so that if an infant tested positive, those doing the testing would have a way of knowing who that infant was, and its mother could be informed.

The response to this proposed legislation was immediate. Virtually every gay and AIDS group, including Gay Men's Health Crisis, the AIDS Action Council, and the National Association of People With AIDS, along with the ACLU and prominent public-health experts at leading universities, opposed the bill, largely on the grounds that unblinding the tests would do nothing to help prevent HIV transmission from mothers to their infants and would violate the privacy inherent in such an anonymous surveillance study, potentially scaring pregnant women away from seeking proper prenatal care. The intensity of feeling with which such measures have been opposed should not be underestimated. Ackerman's bill was modeled on a bill introduced in the New York State Assembly by the Democratic legislator Nettie Mayersohn to unblind the anonymous infant-testing program in New York. Mayersohn, a pro-choice, feminist old-line liberal who in 1989 had been named Legislator of the Year by the New York State chapter of the National Organization for Women, was labeled a "fascist" by individuals associated with the AIDS lobby. (Last June, three years after Mayersohn introduced her original legislation, the New York legislature passed a bill allowing the state to institute mandatory HIV testing of newborns and to notify parents of the test results. Newborn testing began last February.)

In the matter of the Ackerman legislation, the head of the CDC informed Ackerman that if the bill were not withdrawn, the CDC would suspend the infant-testing program altogether. Ackerman gave no credence to this threat by a public-health agency, because the infant-testing program was demonstrably useful in tracking the prevalence and trajectory of heterosexual AIDS. But the CDC program was indeed suspended. Public-health authorities thus lost even this imperfect means of monitoring one aspect of the epidemic.

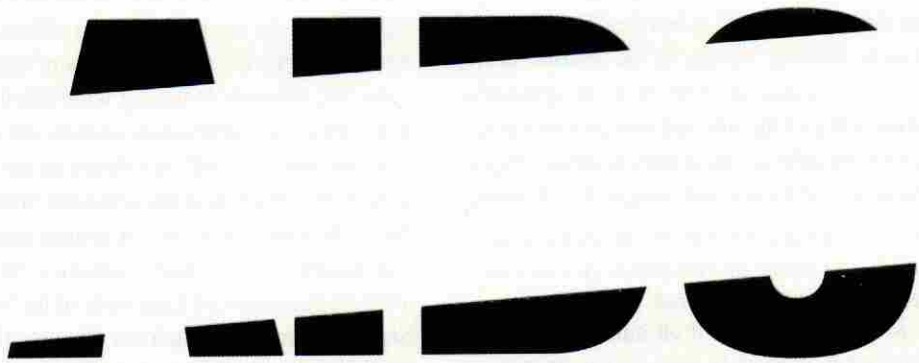
In response to the CDC's suspension of testing, Ackerman joined forces with Tom Coburn, a Republican congressman and a Christian conservative from Oklahoma, to draft new legislation that has become known as the "Baby AIDS Compromise." The legislation was enacted last May as part of a larger bill, the Ryan White CARE Reauthorization Act. The compro-

mise requires state health-care workers to offer counseling and voluntary HIV testing to pregnant women who have not previously been tested for HIV. States that by March of 2000 do not meet certain goals with respect to the voluntary HIV testing of pregnant women or to HIV incidence among newborns will have to implement a mandatory infant-testing program or lose some federal AIDS funding.

THE ultimate question for AIDS exceptionalism is this: Do the disease-containment and disease-prevention measures of traditional public health—the measures from whose full force AIDS has been significantly shielded—work? The answer given to this question by AIDS exceptionalists as well as traditionalists seems to be yes. Joel Gallant, for example, opposes routine involuntary testing for HIV and aggressive partner notification, but not on medical grounds; rather, he fears the potential for employment and insurance discrimination, domestic abuse, and breaches of confidentiality. He maintains that he would otherwise favor traditional public-health procedures for the fight against AIDS, particularly routine testing.

Lee Reichman, the executive director of the National Tuberculosis Center and a physician on the staff of the New Jersey Medical School who cares for AIDS patients, cautions that given the course that the evolution and politics of the disease have taken, traditional public-health measures by themselves may no longer be feasible, in part because of the possibility that they will drive the infected underground. As noted, this is an exceptionalist article of faith. But Reichman goes on: "Traditional public health is absolutely effective at controlling infectious disease. It should have been applied to AIDS from the start, and it wasn't. Long before there was AIDS, there were other sexually transmitted diseases, and you had partner notification and testing and reporting. This was routine public health at its finest, and this is the way STDs were controlled."

In the months ahead a national debate may well be joined over rescinding the exceptional public-health status of AIDS, owing in part to a bill introduced by Tom Coburn, the Oklahoma congressman. Coburn's bill, the HIV Prevention Act of 1997, would establish confidential HIV reporting nationwide. It would require states to inform anyone who has been exposed to HIV. It would require that all people accused of sexual offenses be tested for HIV. And it would allow health-care providers to test a patient for HIV before performing a risky invasive medical procedure. The Coburn bill contains a number of other provisions and also two nonbinding "sense of the Congress" resolutions, one urging states to criminalize the intentional transmission of HIV, the other affirming the principle that strict confidentiality must be observed in carrying out the bill's provisions. (A companion bill has been introduced in the Senate.) "The fact is that epidemiology works," Coburn says, "and public-health policies work to control disease, and they work by identifying vectors of infectious disease, and you notify people at risk. If you don't do that, you can't control the disease. And that's what we've not done with HIV."



The AIDS Action Council—a group "dedicated solely to shaping fair and effective AIDS policy," in the words of its literature—has denounced the Coburn bill as "an attempt to

federalize policies that do nothing but stigmatize and punish people living with HIV/AIDS." The act, in the view of the council, "replaces education and personal responsibility with 'Big Brother' intrusion and control." In previous statements the council has characterized measures like the ones now proposed as "failed policies that do nothing to prevent any more Americans from becoming infected with HIV."

It is hard to see how traditionalist policies can be said to have "failed" with AIDS, since they have not been systematically tried. Be that as it may, some skepticism toward legislation like Coburn's is warranted. Conservatives representing themselves as public-health advocates are certainly vulnerable to a charge of hypocrisy. Coburn's bill does not address one of the exceptionalists' central criticisms: that although traditional procedures will identify more infected people, conservatives are not prepared to offer any plan for helping those infected people (many of whom have no health insurance and little education, and many of whom are homeless) after they have been identified. The Coburn bill offers no new funds for the state public-health departments that would be obliged to carry out its testing and reporting provisions. A traditionalist approach to AIDS will cost money, and those who advocate such an approach should be making the case that more money is needed.

Exceptionalists also point out, correctly and bitterly, that the hatred directed against homosexuals, and the discrimination they experience at the hands of anti-gay conservatives, among others, are responsible in the first place for the very exceptionalist policies that conservatives like Coburn now so strongly oppose. Coburn's own outlook gives one pause. It was Coburn who elicited condemnation and ridicule when he criticized the airing on network television last winter of *Schindler's List*, complaining about the depiction of violence and frontal nudity.

As noted, epidemiology has sometimes had to weigh the issue of civil rights against the issue of effective disease control. The time has come to consider anew how these factors should tip the scales. We do not, of course, have an absolute guarantee that traditional epidemiology applied to AIDS and HIV would markedly bolster the success of public-health efforts. But such a guarantee is hardly required. Marcia Angell, of *The New England Journal of Medicine*, observes, "Nobody can document or prove that traditional methods of control would work better at containing AIDS, because nobody has done what would be necessary to get such proof—studying two populations, one in which traditional methods are applied and one in which they aren't. The reason no one has done this is that it is impossible. It is impossible because it's unethical and logically unworkable. So, as in many things in life, the default position is common sense. And I have no doubt, given the track record of these methods in controlling other diseases, that if, for example, we screened all expectant mothers, we could prevent AIDS in many cases. And if we traced partners, we would prevent AIDS in many cases. And if we routinely tested in hospitals, we would prevent AIDS in many cases."

Ralph Frerichs, of UCLA, framed the matter like this in the course of an interview: "Historically, public health has always transcended the legal system, much like the military. When you have an outside threat, you can suspend the normal rules of society. Traditionally, we epidemiologists have been granted full responsibility, but society has eroded that, and we now talk about respecting the rights of human individuals who have disease-causing viruses, bacteria, and so on, which makes it increasingly difficult to stop the spread of these diseases. This is society's choice. But this is de facto granting rights to the viruses and to the bacteria. And when epidemics are presented this way, as a matter of rights, the public has a harder time distinguishing the infection from the infected. The virus is our enemy, not the person with the virus, but at the same time that person harbors the virus, and we need to take a series of steps to prevent that virus from moving to another person.

A TRADITIONALIST APPROACH TO AIDS WILL COST MONEY, AND THOSE WHO ADVOCATE SUCH AN APPROACH SHOULD BE MAKING THE CASE THAT MORE MONEY IS NEEDED.

"In AIDS, as in all epidemics, there is a tradeoff between emphasizing detection of the virus and the civil-rights violations that detection engenders. Given that we have not pushed for aggressive testing, reporting, and partner notification, it appears that our society is willing to accept a higher amount of HIV infection to avoid interfering with the rights of HIV-infected people."

Earlier this year the Centers for Disease Control and Prevention reported that largely because of gains in life expectancy among the infected, annual deaths from AIDS had registered a significant decline for the first time since the onset of the epidemic. That they have done so is hardly grounds for complacency. It is evidence, however, that medical interventions make a palpable difference—and is all the more reason to start subjecting AIDS, from a public-health perspective, to more-systematic procedures.

In the end AIDS would be unlikely to prove resistant to good basic public-health policies. It may survive if it can circumvent good sense.