

The Emperor Has Never Looked Better: The Case for HIV Reporting

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ABSTRACT

Any proposed surveillance system must be assessed according to what it reasonably can expect to accomplish in the promotion of behaviors we wish to encourage in HIV testing, treatment, and prevention. There is no reason to believe that the name reporting of persons with positive HIV test results will provide an accurate picture of the epidemic. Most public health experts believe that a significant number of people who are HIV positive avoid testing and have no idea of their status. And there is reason to believe that significant numbers of those considering testing, particularly those who are members of racial and sexual-preference minorities, will be deterred if they are required to provide their name.

INTRODUCTION

The state-by-state reporting of positive HIV test results to state health departments, and the forwarding of summarized data on these results to the U.S. Centers for Disease Control and Prevention (CDC), seems largely a done deal. Despite considerable public opposition, in December 1999 the CDC officially finalized its proposal for a national system of HIV test reporting,¹ and some form of HIV case reporting now is in effect in most states.²

A nationwide adoption of mandatory HIV case reporting is a development of enormous consequence. It represents a substantial commitment of time, money, and other resources to the collection, compilation, and analysis of this data; and it marks a significant shift in policy that, until now, sharply scrutinized any proposal to expand the collection or sharing of identifiable information on individuals' HIV status. Whatever the reasons may have been for the lack of organized protest against mandatory AIDS reporting—whether the relatively short period from diagnosis to death in the early and mid-80s; the belief that AIDS case reporting was the least of the concerns of a community largely ignored during years of extraordinary death rates among young gay men (and perhaps even a sign that government was beginning to take notice); its occurrence before the development of an advocacy force sufficiently to fight state and federal initiatives of this kind; a “near universal recognition that an understanding of the new disease required complete [sic] surveillance data”;³ or something else that might be revealed by careful, peer-reviewed research of the matter—it is undeniable that many people with HIV may, for the first time, be identified in government lists maintained for the primary purpose of identifying them (as compared to identification in the course of providing medical care or other benefits and services), for potentially a much longer part of their lives.

Having acknowledged in 1998 that “public support is critical to the success of public health programs and agencies,”⁴ why did the CDC, and so many state officials, move ahead with an HIV reporting system that is widely opposed not only by the vast majority of consumers of HIV-related services, but by a host of AIDS-seasoned doctors; organizations such as the International Association of Physicians in AIDS Care, the San Francisco Department of Public Health AIDS Office, New York's Callen-Lourde Community Health Center; and by former U.S. Surgeon General Jocyelyn Elders, MD?⁵ What are the benefits of investing years of effort and millions of dollars to support a reporting system that is vehemently opposed by major organizations representing the populations most at risk for HIV, such as the National Urban League,

the National Minority AIDS Council, the National Black Lesbian and Gay Leadership Forum, Gay Men of African Descent, the AIDS and Adolescents Network, AIDS Action, and Gay Men's Health Crisis?⁶ The CDC offers the following as a rationale for the program:

The expansion of national surveillance to include both HIV infection cases and AIDS cases is a necessary response to the impact of advances in antiretroviral therapy, the implementation of new HIV treatment guidelines, and the increased need for epidemiologic data concerning persons at all stages of HIV disease. Expanded surveillance will provide additional data about HIV-infected populations to enhance local, state, and federal efforts to prevent HIV transmission, improve allocation of resources for treatment services, and assist in evaluating the impact of public health interventions.⁷

The CDC maintains, in other words, that the availability of more effective antiretroviral therapies has significantly slowed the progression to AIDS and has reduced the number of AIDS cases; as a consequence, the national AIDS case reporting system no longer tracks the size and scope of the epidemic, and appropriate targeting of treatment and prevention resources hinges on securing data that HIV test reporting will provide. But does this rationale hold water?

Unfortunately, the heart of the debate about HIV case reporting—one that has been contentious and fraught with drama—ignores this question, consistently skirting the heart of the matter. It is true that better data could serve the goals of better targeting prevention and treatment resources where they are needed most, although matching dollars to actual need with any kind of precision would itself mark something of a sea change. More data might also help convince the public and public officials that the epidemic is not over and that it merits the attention of increased public resources. From the outset, however, the issue of HIV surveillance has been framed as a choice between the supposed merits of reporting those who test positive, through the traditional use of names and other identifying data, versus reporting through use of “unique identifiers.”⁸ This is hardly a non-issue—and one which name-reporting advocates have yet to address adequately—but both sides of the reporting debate seem largely to take as a given not only that more information about the epidemic is necessary, but that collecting data on positive HIV tests will provide this information. Required reporting of positive HIV test results will give us more data; but, in this case, is more data necessarily better? Are the CDC's stated goals and related benefits of surveillance reasonable and realistic, and, to the extent that they are, is HIV case reporting likely to serve these goals?

These are questions worth asking. Opponents of case reporting proposals have been criticized for squandering energy on trivial or unfounded concerns; but funds to end the HIV pandemic are finite and lives are in the balance. With approximately \$41 million of CDC funds made available during funding year 2000 for HIV/AIDS surveillance and HIV incidence and prevalence studies, and with about \$28 million of that dedicated to the continuation or implementation of AIDS and HIV case surveillance,⁹ the question is more than academic. However, a larger principle is also at stake. It is the duty of public health officials to base policy on science and sound data, not on “tradition,” politics, or administrative concerns, and it is the right of the public to insist that they do.

Unfortunately, state and federal officials have utterly failed to demonstrate why HIV case reporting by name will be more effective overall than the less intrusive alternatives of anonymous seroprevalence surveys or even case reporting with coded identifiers. At the very least, public health officials should have convincing data to demonstrate that a chosen alternative will not actually undermine its stated goals. There is disturbing evidence that name-based HIV case reporting deters testing by exacerbating complex fears about the societal consequences of testing positive for HIV, and there are fundamental concerns about the privacy of sensitive medical information. Even so, there is considerably more at stake than these important concerns. When need outstrips available resources, allocation of millions of dollars to an initiative with questionable utility for ending the HIV pandemic should be vigorously challenged. And when the public health officials who have been charged with serving as leaders in science-based policy stray from that mandate, they undercut the focus on controlling and preventing disease.¹⁰ The failure of most public health officials and mainstream HIV/AIDS organizations to examine the legitimacy of the starting assumption in the debate has fairly ensured that alternative systems of surveillance are not discussed by policy makers, let alone seriously entertained.

The purpose of HIV surveillance—“to gain more reliable information about the prevalence, incidence, and future directions of HIV infection and the impact on specific populations such as racial and ethnic minorities and women”¹¹—is an important one. There is little reason to believe, however, that HIV reporting will serve this goal. As a long-time AIDS and policy expert once observed, and as is discussed more fully below:

HIV reporting does not serve our purposes of describing current HIV incidence or prevalence, since, in order to be reported, people have to seek healthcare (and be assessed for HIV infection) or have to seek counseling and testing for HIV at a non-anonymous testing site. Many people with HIV infection might not seek healthcare until they are aware that they are ill. That delay would range from weeks to years—even more than 10 years—after infection. Among those with HIV infection who seek healthcare for non-HIV related reasons, some will not be evaluated for HIV. A cross-section of those who seek healthcare or who seek HIV testing will not closely represent a cross-section of those who are HIV infected. The inner-city poor . . . are likely to be less represented than those with adequate health insurance who are also not alienated from the healthcare system. Thus HIV reporting will provide some picture of HIV prevalence, but not of HIV incidence in a community. Data on the prevalence of HIV infection will be inaccurate because of delays in seeking care or testing; incidence will really not be measured at all. . . .¹²

STATISTICAL SHENANIGANS

The misuse or absence of data has become a hallmark of the HIV test reporting debate. The primary problem with the push for HIV test reporting is the shocking shortage of data showing that it will work; that is, that it will provide a good picture of the scope of the HIV epidemic.

In its proposed *Guidelines for National Human Immunodeficiency Virus Case Surveillance* (1999) the CDC stated:

In the absence of effective therapy for HIV, AIDS surveillance data have reliably detected changing patterns of HIV transmission. . . . Because of these attributes, AIDS surveillance data have been used as a basis for the allocation of many Federal resources for HIV treatment and care services. . . . With the advent of more effective therapy that slows the progression of HIV disease, AIDS surveillance data no longer reliably reflect trends in HIV transmission and do not accurately represent the extent of the need for prevention and care services.¹³

In support of the claimed efficacy of AIDS surveillance data in “reliably detecting changing patterns of HIV transmission,” the CDC’s proposed *Guidelines* cited one 1989 study of persons infected through blood transfusion, and another study of a cohort of HIV-infected men who participated in an 11-year follow-up study—but neither study relied on AIDS surveillance data. In support of the assertion that more effective therapy has slowed the progression of HIV disease and AIDS case surveillance no longer reflects trends in HIV transmission, the *Guidelines* cited two small trials of combination therapy in men already diagnosed with AIDS, reported in 1996 and covering a short period of time well in advance of the wider availability of these therapies to the general public.

The CDC and many state officials relied primarily on two studies to support the contention that HIV case reporting systems have no significant impact on testing behavior. The first is a CDC-sponsored study of tested populations in the 12 months preceding and following the adoption of name-based HIV test reporting in six states: Louisiana, Nevada, Michigan, Nebraska, New Jersey, and Tennessee.¹⁴ The authors of this study concluded that HIV reporting by name did not appear to affect use of HIV testing in publicly funded counseling and testing programs, based on the total number of tests reported in each state before and after the adoption of name reporting.

The meaning of the actual number of tests “before and after,” and the foundation of the authors’ conclusion, appear debatable at best, when facts and factors are considered that the authors either discount or completely ignore in infusing raw testing numbers with this significance. While the test populations increased overall in four of the six states, they decreased in two, and there was a significant decline in the number of injection-drug users (IDUs) who were tested in Louisiana and Michigan. The study also reported that testing among Whites increased in all states but one, but two states had significant reduction in testing by Hispanics and Blacks. The authors had access to information on percentages of persons who chose anonymous testing only in Louisiana and Nebraska (in Nebraska, 50 percent of those who were tested chose to be tested anonymously), and offered no information on what percentage of those who were tested were HIV positive, as opposed to the number of persons who were tested who were HIV negative and/or in a group that was at low risk for contracting HIV. With no information on the existence, or absence, of prevention programs or other HIV education campaigns that were available or that had been expanded during the study period in each state, or the likely percentage of persons who were actually at risk for HIV infection who had been tested before, as opposed to after, the institution of name-based HIV test reporting, it is impossible to gauge whether a steady number of persons tested during the 25-month period in question

actually represents an increase, a decrease, or maintenance of the status quo. It is additionally troubling that the authors went to great lengths to explain away the decrease in actual testing numbers in Michigan, particularly among minorities, but gave no consideration to the web of mandatory testing provisions in existence in each state, the existence of which conceivably could have affected testing levels.¹⁵

The second study consists of data collected during another CDC-sponsored survey comprised of multiple choice questions, in which subjects were asked to choose and rank a list of possible factors that influencing a decision to seek HIV testing.¹⁶ In view of the very high number of subjects who gave as a primary reason for avoiding testing (1) a fear of knowing their HIV status or (2) a belief that they were not at risk, it is puzzling that the authors of the study did not appear to consider the importance of these answers in determining the significance of other answers. The presumptive significance that the authors attached to the subjects' misunderstanding of HIV testing and reporting laws in their states is also intriguing. Putting aside for the moment the question of whether subjects understood the difference between "confidential" and "anonymous" testing,¹⁷ the survey results suggest a deficiency in the performance of the testing counselors at publicly funded sites, whose pre- and post-test counseling responsibilities include providing an explanation of the consequence of testing for HIV and what happens with positive test results. Hanging their rationale for name-based HIV reporting on this questionable data, proponents of name reporting ignore the significant number of studies that have reached the opposite conclusion.¹⁸

PUTTING THE CART BEFORE THE HORSE

A September 1997 editorial in the *New England Journal of Medicine* by Robert Steinbrook, MD, received press attention as an endorsement of name-based HIV reporting.¹⁹ The author's endorsement of national HIV case name reporting, however, was only one element of a four-point proposal "for a more comprehensive and coordinated approach" to battle HIV, which included: (1) a national standard for HIV reporting, (2) greater access to effective medication, (3) improved access to physicians experienced in treating the disease, and (4) protection of patients from violations of privacy and discrimination.²⁰ According to Steinbrook, the four elements of this proposal must be addressed simultaneously.²¹ In addressing the issue of access, Steinbrook noted that many state AIDS drug assistance programs (ADAPs—primarily funded through the federal government), while providing anti-HIV drugs to people without adequate insurance or the means to pay for them, are unable to offer recommended combination antiretroviral therapies to already-eligible patients.²² And although he pointed to the Americans with Disabilities Act (ADA) as a source of many protections for people with AIDS and HIV, Steinbrook suggested that nationally guaranteed access to health insurance also may be necessary.²³ AIDS physicians and legal advocates who responded to Steinbrook's proposal endorsed many of his recommendations, but pointed out the lack of political will to allocate needed resources to ensure treatment for all those known to have HIV, and the inadequacies of the ADA in preventing discrimination.²⁴ Indeed, more than three years after the Clinton administration announced that it would consider expanding Medicaid to cover low-income people with HIV before they developed disabling symptoms,²⁵ this expansion has yet to materialize.

The chosen strategies for prevention and the ways they have been funded reflect a lack of resolve to direct proven prevention methods to already-identified, long-unmet needs—as does the continued use of moral judgment and politics to trump science and surveillance data as the basis for dedicating resources. The federal government has virtually ignored existing data on the increase in infection rates among young adults and the efficacy of syringe-exchange programs in slowing transmission among IDUs, as it has failed to support aggressive prevention measures targeting these groups; and, to date, relatively few state and local jurisdictions have allowed or supported such measures.²⁶ In fact, in New Jersey, where the majority of diagnosed AIDS cases consistently have been in IDUs,²⁷ state officials have persisted in shutting down syringe-exchange programs and even, with the public support of the governor, have prosecuted and jailed advocates who tried to implement them—despite the growing evidence on the efficacy of syringe-exchange programs in slowing HIV transmission without increasing drug use.²⁸

We also don't need more data to know that a significant number of our youth are at high risk of HIV infection, yet national and state efforts in this regard remain abysmal. In fact, in a Kaiser Family Foundation preliminary report based on a national survey of teens on HIV/AIDS, researchers found that while most teens say HIV/AIDS is a serious problem that they are personally concerned about, more than two-thirds of them don't know where to go to be tested.²⁹ Half of all new HIV infections are estimated to occur among young people under the age of 25,³⁰ yet, in the rush to institute mandatory reporting, public

health officials have neglected to take even minimally effective efforts to first ensure that this critical population is informed about the importance of testing, let alone whether name reporting will prove a fatal deterrent if and when they decide to test.³¹

The failure of the federal government to fund and implement proven prevention strategies that are aimed at clearly identified HIV prevention needs is discussed in a recent report of the Institute of Medicine (IOM), of the National Academy of Sciences.³² The report, sharply critical of federal efforts in this area, pointed to the fact that only 8 percent of the national HIV/AIDS budget is dedicated to prevention.³³ And the failure to ensure the institutionalization of frank, effective education about HIV before insisting on counting cases of it has perpetuated an environment that can only discourage the willingness to step forward and be counted.

Professor Gregory Herek, a University of California research psychologist studying AIDS stigma, has observed that public health officials and policy makers also “may be underestimating the continuing importance of AIDS stigma in the United States” in their advocacy of new HIV case reporting and partner notification policies.³⁴ A University of California survey documented that “the public may be becoming more suspicious and less tolerant of those who contract the virus,” and that the extent to which people with AIDS are blamed for their illness and deemed to have gotten what they deserve has increased.³⁵ The same survey reported that the percentages of persons who incorrectly believe that HIV can be transmitted through various types of casual, risk-free contact actually has increased in recent years.³⁶ These types of perceptions can cause incidents of discrimination against people with HIV to increase.³⁷

The Herek study is a telling indictment of the state of AIDS education in this country, and the state and federal public health officials responsible for its failures. The parallel rates of HIV ignorance and infection should be no surprise, in view of the silence of most public health officials in the face of dangerous political approaches to HIV: laws that criminalize spitting and consensual, protected sex and bans on condom distribution and factually explicit sex education in favor of abstinence-only curricula.³⁸ The recent IOM report states that abolishing laws and policies that block the use of *proven* prevention strategies is a key step in getting needed prevention services to at-risk and infected individuals. Requiring name reporting of HIV without having adequately addressed the significant stigma that still shadows an HIV diagnosis is just another example of putting the cart before the horse.

ASSURANCES OF CONFIDENTIALITY AND LEGAL PROTECTIONS

Because public perception of and support for government health interventions are central to the success of such interventions, the government’s failure to recognize the affect of class and social group difference on citizens’ beliefs regarding the safety of government intervention is a fatal flaw in the rationale offered to support the change to name-based reporting.³⁹ Those who have had no experience in the criminal justice system, or who have never relied on government-sponsored benefits programs for subsistence or healthcare services, or who have never had their family relationships monitored and judged by a government case worker—which are common experiences for many people of color for and for the poor—cannot comprehend the contribution of these experiences to the perception of government and the legal system as a hostile force to be avoided.

People known to have HIV and AIDS are at a real risk for social opprobrium as well as housing discrimination, loss of employment, and refusal of treatment by healthcare workers.⁴⁰ HIV and AIDS are the only medical conditions other than mental illness that insurance companies routinely target for limits on benefits that are not applied to any other catastrophic illness.⁴¹ More than half of all of the states have adopted laws that criminalize sexual and other conduct by persons who know that they are HIV positive; severe criminal penalties attach to this conduct, in many instances even when condoms are used, no transmission occurs, or the criminalized act—in some cases, spitting—poses little or no risk of transmission.⁴² This kind of stigmatization and discrimination can cause people to avoid testing.⁴³

Antidiscrimination laws are a limited remedy for the problem. Not only have federal disability discrimination laws been unreliable,⁴⁴ but state law protections and remedies offer piecemeal protection.⁴⁵ As a CDC-commissioned survey found in 1996, current state laws “reveal[] significant problems that affect both the development of fair and effective public health information systems and the protection of privacy.”⁴⁶ State statutes often allow disclosures to an inappropriately large group of persons, may fail to control the purposes for which information is used, may allow inappropriate disclosures of data pursuant to court order, and may exhibit such inconsistency among states or among data types that meaningful privacy

protections are compromised.⁴⁷ Most state HIV confidentiality laws have numerous exceptions to the general requirement of consent prior to disclosure, and the standard for issuance of a court order for disclosures outside of these exceptions allows for widely subjective judgments as to when the “need” for disclosure outweighs the subject’s interests in privacy.

Disclosures of private medical information within the criminal justice system in particular are only loosely controlled. The incident involving Nushawn Williams in Chattaqua County, New York, in which Williams was linked with the infection of a number of young women, is illustrative.⁴⁸ Several local women who tested positive for HIV identified Nushawn Williams as a sexual contact, and health officials confirmed that Williams had previously tested positive for HIV. (Williams, unlike the women who identified him, is African-American, and was incarcerated at the time.) Williams’s picture was then displayed in classrooms and broadcast on national television and in the press, followed by numerous stories in tabloids and in the mainstream press on “AIDS murderers.” It was widely assumed that Williams “knowingly infected” his sexual partners. At a minimum, this incident raises troubling questions on the ability or willingness of public health officials to control inappropriate use of individuals’ HIV-related records.

Once names have been gathered, confidentiality can be breached by judicial, legislative, or administrative order or rule.⁴⁹ For example, in 1997 the Illinois Department of Health proposed an internal policy that would have allowed the disclosure of the identities of HIV-positive persons to the Illinois State’s Attorney,⁵⁰ who could then have prosecuted such individuals under Illinois’s Criminal Transmission Act.⁵¹ Illinois adopted a measure, not yet implemented, that allows use of AIDS case reports to track down infected healthcare workers.⁵² History provides additional reason to fear that the collection of names could be used, with the wave of a legislative pen, for purposes beyond monitoring the epidemic. The use of Social Security numbers offers a relevant lesson. When the Social Security number—an example of a “unique identifier”—was introduced in 1936, the federal government responded to citizens’ protests with assurances that individuals’ identifying numbers would be used only for purposes of administering Social Security, and that confidentiality would be maintained. Today, the Social Security number is the country’s most frequently used record-keeping identifier, leading to increased fraud and invasions of privacy.

Ultimately, the common, shaky assumption that current legal protections and systems are adequate to protect the confidentiality of HIV surveillance data does not even begin to address the real issue: what is the *perception* of the protections that government will afford to persons at risk of HIV infection? As mentioned earlier, public perception is important in determining whether a particular proposal such as name-based reporting of HIV test results will serve or undermine a specific public health goal. Perceptions among affected communities regarding how far government entities can be trusted to protect individuals’ confidentiality and interests are as relevant as actual confidentiality laws and policies in determining the impact of HIV surveillance on persons’ willingness to be tested. To rely on the legal protections of government-maintained surveillance data ignores not only the distinction between the letter of the law and the reality of the protection it affords, but, more importantly, it is to ignore the relevance of individuals’ *perceptions* of the law, and whether public officials are viewed as friends or as foes. For those who mistrust government or its enthusiasm for protecting them—and people of color historically have good reason to do so—reassurances about the safety of surveillance data will not be persuasive.

SOME FACTS, SOME FALSEHOODS, AND SOME REAL RISKS

Few debates on HIV policy have generated the level of recrimination that the HIV-reporting debate inspires, even among those who typically are allies. Despite the intensity of disagreement, all parties to the debate should be able to agree on at least one point: that HIV testing, first and foremost, must be a gateway to treatment and to information that reduces further transmission. In fact, those who endorse traditional public health functions and objectives should be able to agree that the ultimate goal of surveillance is to promote effective prevention and treatment strategies and to end the epidemic.⁵³ Evidence that name reporting may effect a step away from, not toward, these primary goals should be enough to stop its adoption in its tracks.

And the evidence is there. The deterrent effect of HIV test reporting has consistently been most pronounced in those populations at greatest risk of infection: gay and bisexual men, people of color, IDUs, and sex workers.⁵⁴ For example, a recent survey conducted by the Latino Commission on AIDS in New York indicated that 72 percent of those surveyed would not be tested for HIV if their name was reported to

the New York Health Department if their test result was positive.⁵⁵ The number who would refuse to be tested because of name reporting increased to 87 percent for Latinos between the ages of 16 and 25.

The *HIV Testing Survey (HITS)* and the *AIDS Patient Survey (APS)* (hereafter, the *HITS and APS Surveys*), funded by the CDC, are cited to support the claim that name reporting is not a major concern, but they actually confirm that name reporting *deters* testing.⁵⁶ Nearly one in five participants in the *HITS Survey* (19 percent) acknowledged that name reporting was a reason not to be tested. Given that approximately half of the people estimated to be HIV positive in the U.S. do not know their serostatus,⁵⁷ a measure that reduces individuals' willingness to test to this degree is a serious public health concern.

Even the CDC acknowledges that the *HITS Survey* may underestimate concerns about reporting and fail to reflect actual behavior. The real issue is whether, when informed of name reporting, people will decline to test. An individual seeking HIV testing must be informed regarding the disclosure of test results before he or she can give truly informed consent to have the test.⁵⁸ Those who participated in the *HITS Survey* were not surveyed at testing sites or at a time when they actually were seeking to be tested, and the surveys indicate that many participants were unaware of their own state's testing policy (that is, whether the state had anonymous testing, confidential testing with no name reporting, or name reporting). While this has been cited to support the claim that people are not concerned about reporting, it may more accurately reflect the quality or accuracy of counseling and information provided during pre-test and post-test counseling. In any event, and as the CDC essentially acknowledges, participants in the *HITS Survey* stated that their intent regarding testing may not reflect their actual behavior when they seek HIV testing, if they are accurately informed at that time about their state's HIV reporting law.⁵⁹

Proponents of name reporting argue that fear of disclosure or discrimination related to HIV status are unwarranted because laws protect persons with HIV from discrimination, and public health officials will not breach confidentiality. As discussed above, these assurances are inadequate and largely unreliable. In any event, they cannot overcome individuals' subjective fears of name reporting and general mistrust of governmental bureaucracy. Despite government's best efforts, there still exists a risk of illegal disclosure by individuals. As has now been widely publicized, a computer disk containing 4,000 AIDS Registry names was obtained illegally and sent to two local newspapers in St. Petersburg, Florida.⁶⁰ In California, two computers containing 60 AIDS Registry names were stolen from the California Health Department.⁶¹ There are numerous examples of smaller leaks by healthcare workers, police, and others with access to lists of names.⁶²

A response by who advocate for name reporting regarding concerns about confidentiality that has gained some currency is that these objections essentially are moot, as government officials already have the names of people with HIV through their participation in Medicaid. This argument doesn't withstand much scrutiny, for two basic reasons. First, Medicaid continues to be available only to those low-income individuals who are effectively disabled by their illness;⁶³ this requirement eliminates virtually everyone with early or asymptomatic HIV, let alone anyone who hasn't yet been tested. The majority of eligible individuals who get tested only after they have been infected or sick for a while are not necessarily demonstrating indifference to winding up on a government list; a loss of privacy in exchange for services is the unavoidable lot of the poor. Second, people expect, and generally receive, a certain measure of privacy in their medical records, as these records serve a different purpose than that of solely identifying them as a person with HIV or AIDS.

In a sense, the existence or legitimacy of fears regarding disclosure and discrimination are secondary; they only should attain relevance once the central issue is resolved: Does name reporting sufficiently serve the ultimate goal of surveillance, which is to provide a better picture of the HIV epidemic by accurately capturing its prevalence and incidence, such that it justifies the trespass of people's privacy? The issues of confidentiality and deterrence aside, name reporting of HIV cases simply will not, and can not, accomplish this primary goal. Data on HIV incidence and prevalence, demographics, and risk factors are needed to track the epidemic's course and to better target treatment services to those in need of them; but incidence data is needed to set priorities for prevention programs, and to evaluate their efficacy.⁶⁴ As the IOM report concluded, "data from the HIV reporting system are incomplete in several important ways" that fail to measure either prevalence or incidence:

the HIV reporting system collects data only from persons who choose to be tested and who do so at non-anonymous testing sites. . . . Thus, HIV case reporting data exclude individuals who are infected but have not been tested, as well as those who use anonymous testing sites or home collection test kits. . . . Because of this selectivity, HIV case reporting by name is not representative of the larger population of infected persons. Further, because reported HIV cases could represent infections that are

anywhere from a few weeks to a few years old, the data would reflect the time that individuals chose to be tested rather than when the individual became infected. As a result, HIV case reporting data provide only partial information about the number of existing cases (HIV prevalence) rather than information about new HIV infections (HIV incidence). . . .⁶⁵

Statistics from New Jersey, which adopted mandatory name-based HIV test reporting in 1992, seem to indicate the shortcomings of relying on name-based HIV case reporting. As of September 1997, for example, New Jersey had reported 13,441 individuals living with AIDS (35,681 total cases, minus 22,240 known dead) and reported only 12,955 cases of non-AIDS HIV. That is less than one-third of the CDC's conservative estimate of how many people actually are infected. Clearly, reliance on this data might suggest to policy makers that the HIV epidemic is far less extensive than other means of estimating the size of the epidemic have suggested for years.

In short, if we are to meet the goal of securing the information we need to track the epidemic, and to best plan and target treatment and prevention interventions, "a new surveillance approach is needed."⁶⁶

A LINK TO TREATMENT AND SERVICES?

While an important goal of HIV testing and counseling is to connect individuals to healthcare and other needed services, this is not a goal or even a likely outcome of HIV surveillance. It has been suggested that name-based reporting makes it easier to link those infected with HIV to healthcare services but, in truth, there is no historic support for this contention.⁶⁷ While it is standard to offer treatment for other communicable diseases, our nation still does not provide it for many of those who already have tested positive for HIV.

The contention that name-based reporting is necessary to get people into medical care and services appears to be disproved by the CDC-funded *HITS and APS Surveys*,⁶⁸ which reported that contact by a health department is not associated with access to care.⁶⁹ People who test HIV positive at name-reporting sites do not get care any faster than people who test positive at sites where names are not used (that is, anonymous sites).⁷⁰ A more recent study confirms that contact with a health department after testing positive for HIV was not associated with earlier access to care.⁷¹ In fact, another recent study reports that the contrary is true—that is, that individuals who test anonymously enter care at a significantly earlier point in their infection than do those who test confidentially (that is, with name reporting).⁷²

Name reporting also is not necessary for partner notification, nor does it ensure better follow up. The success of any partner notification system depends upon at least three things: (1) a willingness to be tested, (2) a willingness to return for test results; and (3) a willingness to identify other at-risk persons. Name reporting frustrates all three elements. Not only is name reporting likely to deter people from testing altogether, but, among those who chose to be tested, those whose were tested anonymously were more likely to return for their results than those who provided their name.⁷³ And those who tested anonymously agreed to provide the names of their partners as often as those who tested confidentially.⁷⁴

Available data indicates that people who refuse to participate in partner notification do so because of fear that their anonymity will be compromised or that their partners might retaliate against them.⁷⁵ The current trend of linking name reporting to partner notification could lead many to conclude that health officials intend to disclose names when notifying partners; certainly they will have the power to do so. Both the perception and the reality of an increased risk to anonymity from name reporting clearly could undermine state and local health officials' efforts to gain sufficient trust and cooperation for successful partner notification and other prevention interventions.

THE VIABILITY OF REPORTING BASED ON UNIQUE IDENTIFIERS

It is not entirely clear whether those who advocate the use of unique identifiers (UIs) to track HIV-positive individuals believe that HIV case reporting will provide better data, or whether they simply have conceded the underlying issue as a lost cause, and have chosen to focus instead on the least-intrusive means of collecting individual case reports. Reporting systems that use UIs are as limited as those that use names when it comes to providing a clear picture of HIV incidence and prevalence, but at least these alternatives to name reporting—UI systems where individuals are identified only by a characteristic such as date of birth, gender, risk factor, or zip code; or identification systems that "delink" an individual's name from a

unique code that is chosen by the individual, as one chooses an on-line internet alias or bank pass code—might provoke fewer fears of inappropriate disclosures. However, opponents of unique identifiers have relied on the past shortcomings of Maryland’s and Texas’s arguably flawed systems (based on birth dates and a portion of the Social Security number) to make the shaky leap to the argument that *any* UI system just won’t work.

Maryland, which uses a UI code for the reporting of HIV cases, has concluded that its system is meeting all major objectives and that it should be continued.⁷⁶ Some of what was learned there could be used to create better data-collection systems that would provide more assurances of individual confidentiality.

Both Maryland and Texas used designs that required the last four digits of an individual’s Social Security number as a mandatory part of an individual’s unique code. Liza Solomon, who directs the HIV surveillance program for the Maryland Department of Health, has conceded that the use of Social Security numbers may have been unwise because many people either do not know, do not have, or are reluctant to disclose their Social Security numbers.⁷⁷ Nor is such a traceable set of numbers truly confidential.⁷⁸ This problem could be remedied by choosing a system that does not require Social Security numbers. Using a data element other than Social Security numbers in the UI design might well result in a higher percentage of completeness.⁷⁹ In fact, a review of New Jersey’s HIV annual surveillance reports from 1997 shows a consistently high level of “unknown/other” risk categories. New Jersey’s surveillance report for July 1999 through June 2000 showed 28 percent of those testing positive as an unknown/other risk group, with the percentage of “unknowns” for women the highest reported risk category (37 percent, as compared with 34 percent for heterosexual exposure, and 27 percent for IDUs) of AIDS cases reported during that period.⁸⁰ Because of the “continuing increase in reports submitted with no indication of HIV exposure,” the annual preparation of “adjusted reports” following field investigations to assign those with unknown risk factors to actual risk categories has been necessary to provide a more accurate picture of those testing positive.⁸¹

Contrary to claims of increased costs associated with UI systems, evidence indicates that the costs associated with name reporting and UI systems are comparable. The Maryland system costs about \$100,000 to implement annually. New York’s name reporting of low CD4 counts, which handles roughly twice the number of reports as Maryland, costs \$200,000 per year.⁸²

Finally, should it ever be necessary for public health officials to return to an individual patient, this can be accomplished in a UI system by reversing the steps for reporting. A UI that incorporates the state license or tax identification number of the physician or clinic that did the testing and counseling might enhance the ability to do patient follow up, in the rare instances when it is necessary or desirable. However, “in a well-constructed system, the need to go back to individual patients for further information would be increasingly unlikely.”⁸³

In view of the high level of opposition to name-based reporting from those who are, or who are most likely to be, HIV positive, the refusal of most public health officials to explore creative alternatives is puzzling. Why did the CDC refuse for years to support Maryland’s development of a UI system, while rewarding states that adopted name reporting systems with enhanced funding and technical support?⁸⁴ Why is it that on-line internet access services easily can accommodate millions of users who create, use, and remember their own UIs, while medical and public health officials, who manage far fewer clients, claim that such systems are beyond their abilities? The seeming intractability of public officials on the issue only adds to the misgivings of the public—the reasons offered don’t explain, but obviously an explanation exists. Is this a punitive impulse against all with HIV (except newborns) on the parts of state and federal legislators—a perceived pragmatic need to placate a conservative Congress and its state counterparts who control agency and program purse strings? As inflammatory as this last suggestion may seem, there really is no less data in support of such a conclusion than there is for the adoption of national name-based HIV case reporting.

The credibility of public health guardians, and the development of a surveillance system that best serves the needs of these officials and those affected by HIV, would have best been advanced by conducting a balanced and impartial study of alternative surveillance approaches, alone or in combination, *before* instituting an HIV-reporting system that threatens to undermine the very goals surveillance should serve.

SURVEILLANCE THAT PROVIDES
THE BEST DATA—WITH LITTLE OR
NO RISK TO CONFIDENTIALITY

For the reasons discussed earlier, and because a substantial percentage of people do not get tested or typically delay testing until long after infection has occurred,⁸⁵ the value of HIV test reporting as a tool to measure the size or direction of the epidemic, regardless of how it's done, seems negligible. Another established, "traditional" method of surveillance, anonymous seroprevalence surveys (through which incidence and prevalence data can be obtained without linking a test result to a particular name), would better determine the extent of HIV infection. AIDS researchers often collect HIV-related information, unlinked to any particular individual by name, to study the prevalence of HIV and AIDS and to monitor the demographics of the epidemic.⁸⁶ Researchers—including several at the CDC—have worked to devise systems to estimate current HIV infection rates that may give us more useful data and that do not rely on name reporting.⁸⁷ In this way, researchers can track the spread of the disease and allocate time, energy, and money accordingly. To accomplish these goals, researchers need numbers, not names. Even some who support the application of so-called "traditional" public health measures to HIV acknowledge that anonymous seroprevalence studies provide better surveillance data than name reporting does.⁸⁸

Now that a body as esteemed as the IOM has rejected HIV case reporting as a reasonable method to achieve the goals that federal and state officials have offered in its support, perhaps we can move the central issue missing from past debates on the issue to the floor of public discussion. Assuming that public health officials have both the will and the political ability to ensure the allocation of resources for treatment and for proven or promising prevention strategies that address the real nature of the HIV epidemic, and not simply address political considerations (a significant assumption), we need a new approach to HIV surveillance. The IOM has proposed the use of sentinel surveillance, using incidence data from targeted samples of "sentinel" populations (employing advanced testing technology), in combination with statistical modeling, to extrapolate the incidence data to larger subsets of the population, or to the population as a whole.⁸⁹ The challenge to change the approach to surveillance that most states have put in place may seem insurmountable. But if surveillance is worth doing, it's worth doing right.

CONCLUSION

Any proposed surveillance system must be assessed according to what it can reasonably be expected to accomplish in the promotion of those behaviors we wish to encourage in HIV testing, treatment, and prevention. There is no reason to believe that mandating the name reporting of persons with positive HIV test results will provide the accurate picture of the epidemic that is missing from AIDS case reporting. Most public health experts believe that a significant number of people who are HIV positive avoid testing and have no idea of their status. And there is reason to believe that significant numbers of those considering testing, particularly those who are members of racial and sexual-preference minorities, will be deterred if they are required to provide their name. Instituting a reporting system that has little or no evidence of efficacy, in the face of evidence that it will undermine the goals of encouraging testing and of constructing an accurate picture of the epidemic on which to base the focusing of resources, seems irresponsible.

We have entered the third decade of the AIDS epidemic, yet during this time public health officials who have advocated the introduction of a potentially counterproductive surveillance system have done little to advocate for the related benefits they say will flow from this surveillance. Too many public health officials support—or refuse to publicly criticize—counterproductive HIV policies: the forced testing of persons charged with sex offenses and the incarcerated; the use of test results by criminal law enforcement authorities to prosecute, punish, and segregate prisoners; the exclusion of foreign travelers and immigrants; the prohibition of accurate, comprehensive prevention school programs in favor of the widespread use of "abstinence only" propaganda. Too many public health officials refuse to offer policy and advocacy that are based on sound science and medicine to assist healthcare workers who are forced out of their jobs or to help patients who are denied treatment on the basis of their HIV status.

We have a right to expect that the CDC, the nation's foremost public health agency, will advance public health policy based on the best medical and scientific evidence available. When the CDC lowers its standards, the public pays. It is time for leadership that will advance true alternatives to better serve the multiple purposes of HIV surveillance.

NOTES

1. CDC, "Guidelines for National Human Immunodeficiency Virus Case Surveillance, Including Monitoring for Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome," *Morbidity and Mortality Weekly Report* 48, RR-13 (10 December 1999), 1-28; <www.cdc.gov/epommwr/preview/mmwrhtml/tr4813a1.htm>.

2. At present, 33 states require reporting of all positive HIV test results by name, while six states and Washington, D.C., have adopted some form of unique identifier (UI), or alphanumeric code, to keep track of positive HIV results (Illinois, Connecticut—non-pediatric cases, Massachusetts, Maryland, Rhode Island, and Vermont). One state, Connecticut, requires name reporting of pediatric cases only; one recently adopted a system employing both names and unique identifiers (Oregon); and three additional states (California, Hawaii, and Kentucky) appear to be leaning toward HIV case reporting with unique identifiers.

3. R. Bayer, "HIV Testing and Reporting," *Journal of the American Medical Association HIV/AIDS Information Center—Policy*, March 1996, <www.ama-assn.org/special/hiv/policy/testing.htm>. Bayer does not define what he means by the need for "complete" data, nor does he cite a source or authority for his suggestion that there was broad support for AIDS reporting, or that such support explains the absence of wide-scale opposition to reporting.

4. CDC, "Public Opinion About Public Health—California and the United States, 1996," 47 *Morbidity and Mortality Weekly Report* 69 (6 February 1998).

5. See, for example, "Advocates Condemn States, National Push for Names Reporting," 17 March 1999, <www.lambdalegal.org/cgi-bin/pages/documents/record?record=388> (press release announcing opposition to name reporting initiatives and consensus statement endorsed by nearly 100 organizations). In New York State, the testimony of a physician who operates an adolescent AIDS clinic for high-risk youth in Brooklyn fell on deaf ears, despite its urgency:

[The NY name reporting/partner notification regulations] will do more harm than good in driving people most likely to be HIV infected away from the counseling and testing process. As far as the needs of adolescents at risk of being or becoming HIV infected are concerned, these regulations should be completely rethought. In particular, the issue of names HIV reporting and the mechanisms of mandatory partner notification will create an insurmountable barrier that will prevent providers working with high risk youth from being able to gain the trust required to engage them in the HIV counseling and testing process.

J.M. Birnbaum, "Comments on the Proposed Regulations Implementing Article 21 Title III of the New York Public Health Law," submitted by J.M. Birnbaum, MD, MPH, Adolescent HIV Program, State University of New York Health Science Center at Brooklyn/Kings County Hospital Center, 8 April 1999; on file with the author.

6. "Advocates Condemn State, National Push for Names Reporting," *ibid.*

At an April 1998 public meeting on HIV reporting in Washington, D.C., after approximately 100 individuals and representatives of local AIDS service organizations spoke against name reporting—with many opposing any system of reporting—John Ward, representing the CDC's HIV Surveillance Branch, said that the concerns voiced were consistent with those he had heard in forums he had attended around the country since 1997. L. Chibbaro, "Mayor Supports Unique Identifier," *Washington Blade*, 20 August 1999, 1.

7. CDC, "Guidelines for National HIV Case Surveillance," see note 1 above, p. 1.

8. See, for example, M. Johri et al., "New Approaches to HIV Surveillance: Means and Ends," in this issue of *APPJ*, (noting the polarization of HIV surveillance debate into "camps," one supporting name reporting, and one unique identifiers).

9. CDC, DHHS, Program Announcement 00005, "HIV/AIDS Surveillance and HIV Incidence and HIV Prevalence Studies, Notice of Availability of Funds," <www.cdc.gov/od/pgo/funding/00005.htm, <http://www.cdc.gov/od/pgo/funding/00005NCS.htm>>. Under this funding program, only a portion of about \$6 million was made available for a limited number of state in-progress HIV incidence and prevalence surveys, which the CDC distinguishes in its program description from "core" HIV/AIDS surveillance (the balance of the \$6 million supports laboratories performing the STARHS—Serological Testing Algorithm for Recent HIV Seroconversion—Assay).

10. The CDC's 1991 guidelines for the management of HIV-positive healthcare workers provide an apt example of the consequence of disconnecting policy from supporting science. In a bow to political pressures, the CDC rejected the overwhelming testimony of medical, infectious disease, and public health experts and adopted guidelines that permitted the restriction or removal of healthcare workers with HIV from practice, or the notification of their patients, in the event that they performed "exposure-prone" procedures. Then, as now, the CDC lacked any data that attempted to define what procedures were "exposure-prone," or data on how restrictions on HIV-positive healthcare workers would enhance patients' safety. CDC, "Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures," *Morbidity and Mortality Weekly Report* 40 (1991): 1-9 (hereinafter "1991 Recommendations"). As the title indicates, the recommendations addressed infection with hepatitis B virus (HBV) as well; they noted that hepatitis is approximately 100 times as infectious as HIV, and developed a partial definition for "exposure-prone procedures" by referring to those procedures implicated in the transmission of HBV, not HIV. *Ibid.*, pp. 3-4. The guidelines continue in force, despite the continuing lack of evidence that HIV-positive healthcare workers pose a real risk of transmission to their patients. See, for example, R.L. Chamberland et al., "Investigations of Patients of Health Care Workers Infected With HIV," *Annals of Internal Medicine* 122 (1995): 653-7, helpfully summarized in "AIDS Alert," *American Health Care Consultants* (May 1998): 50-1.

The CDC guidelines have provided the foundation for most federal court decisions upholding the firing or demotion of HIV-positive healthcare workers, despite the absence of data that any of the affected professionals posed a measurable risk to patients' safety. See, for example, *Estate of Mauro v. Borges Medical Center*, 137 F.3d 398 (6th Cir. 1998), *cert. denied*, 119 S.Ct. 51 (1998) (upholding the dismissal of an ADA discrimination suit and the firing of a surgical assistant with HIV because the possibility that he would have to put his finger near the open wound of a patient during surgery constituted an exposure prone procedure posing a "direct threat" to the patient); *Waddell v. Valley Forge Dental Assoc.*, 1:99-CV-00262-CAP (ND Georgia 14 August 2000) (dismissing the ADA suit of a dental hygienist who challenged his proposed demotion and firing after employer learned of his HIV status; fact that Waddell holds sharp instruments, and has his fingers in patients' mouths during teeth cleaning, constitutes an "exposure prone" procedure under CDC guidelines and warrants his termination as a "direct threat" to patients).

11. CDC, "Draft Guidelines" see note 7 above, p. 1.

12. A. Novick, "HIV Surveillance: What's Hot, What's Not," *AIDS & Public Policy Journal* 13, no. 2 (Summer 1998): 51-2, p. 51. See also Johri et al., "New Approaches," in this issue of *APPJ* (concluding that HIV case reporting will not effectively provide information about incidence).

13. CDC, "Draft Guidelines," see note 7 above, p. 2.

14. See A.K. Nakashima et al., "Effect of HIV Reporting by Name on Use of HIV Testing in Publicly Funded Counseling and Testing Programs," cited in CDC "Guidelines," see note 1 above, p. 8.

15. For example, in Louisiana HIV tests can be performed without consent on sex crime arrestees; children in hospitals; blood, semen, and tissue donors; and any person who exposes police, healthcare workers of any kind, or emergency response personnel to blood or bodily fluid that poses "a risk of HIV infection." La. Rev. Stat. Ann. §§40:1062.1; 40:1299; 40:1300. In Nevada, persons charged with sex offenses and all state inmates are among those subject to mandatory testing. Nev. Rev. Stat. Ann. §§441A.320; 209.305. The four other states studied have adopted similar mandatory testing provisions.

16. This kind of survey format, restricting as it does the response of the interviewee to a specified choice of "correct" answers, is inherently flawed. S. Burris, "Driving the Epidemic Underground? A New Look at Law and the Social Risk of HIV Testing," *AIDS & Public Policy Journal* 12, no. 2 (Summer 1997): 66-78, p. 71, citing D.W. Lyter et al., "The HIV Antibody Test: Why Gay and Bisexual Men Want or Do Not Want to Know Their Results," *Public Health Reports* 102 (1987): 468-74. It must be noted, however, that a number of the surveys coming to the opposite conclusion relied on similar methodology. *Ibid.*

17. Many people may view the terms "confidential" and "anonymous" as roughly synonymous; in other contexts, such as confidential communication with a lawyer, therapist, or priest, "confidential" may be understood to mean that the information provided to that individual will not be shared with anyone else.

18. For example, G. Reed et al., "The Impact of Mandatory Name Reporting on HIV Testing and Treatment" (poster presentation at the 11th International Conference on AIDS, July 1996); American Civil Liberties Union (hereafter, ACLU), *HIV Surveillance and Name Reporting—A Public Health Case for Protecting Civil Liberties* (New York: ACLU, October 1997).

19. R. Steinbrook, "Battling HIV on Many Fronts," *New England Journal of Medicine* 227 (11 September 1997): 779-81.

20. *Ibid.*, 779.

21. *Ibid.*

22. *Ibid.*, 780. Steinbrook also notes that ADAP programs vary widely in their drug coverage and eligibility criteria, and serve less than one-third of the minimum estimate of those likely to be eligible. *Ibid.*, citing the National Alliance of State Territorial AIDS Directors, AIDS Treatment Data Network, *State AIDS Drugs Assistance Programs: A National Status Report on Access: A Technical Report* (Menlo, Calif.: Henry J. Kaiser Family Foundation, 10 July 1997). See also M. Marchione, "Cost of AIDS Drug Program Doubles," *Milwaukee Journal-Sentinel* online, 11 January 1999 (reporting that many states have capped the amount they will pay for AIDS drugs under ADAP).

23. Steinbrook, "Battling HIV," see note 19 above, pp. 779-80.

24. M. Adams, C. Hanssens, and T. Lazarus, "Battling HIV on Many Fronts" (letter), *New England Journal of Medicine* 338 (13 January 1998): 198; M. Horberg and B. Schatz, "Battling HIV on Many Fronts" (letter), *New England Journal of Medicine* 338 (13 January 1998): 198.

25. R. Pear, "Medicaid May Be Extended to Early Treatment of AIDS," *New York Times*, 1 June 1997, A10.

26. See *AIDS Alert*, 73 (1 July 2000), 2000 WL9065707 (identifying jurisdictions with syringe-exchange programs and describing the flagging government interest in adoption of such programs).

27. In New Jersey, 47 percent of the cumulative cases of AIDS reported were contracted through intravenous-drug use (IDU), as compared with 20 percent through men who had sex with men (MSM); the cumulative HIV report percentages for each risk group are 46 percent IDU and 21 percent MSM. New Jersey Department of Health and Senior Services, *New Jersey HIV/AIDS Quarterly Newsletter*, 30 June 2000 <www.state.nj.us/health/aids/qtr0006.htm>. See also D. Leusner, "AIDS Council: Whitman Stalling Nominees Over Needle Swap Issue," (New Jersey) *Star Ledger*, 7 September 2000.

28. For example, the National Institutes of Health (NIH), Consensus Development Statement on Interventions to Prevent HIV Risk Behaviors (March 1997) concluded that needle-exchange programs "show a reduction in risk behaviors as high as 80 percent in IDUs, with estimates of a 30 percent or greater reduction of HIV, and that the

preponderance of evidence shows either a decrease in injection drug use among participants or no changes in their current levels of drug use.” See also *AIDS Alert*, see note 18 above (noting Governor Whitman’s public sanctioning of the arrest of syringe-exchange volunteers; recognition by NIH and AMA that syringe-exchange programs have been successful in reducing HIV infection); see also J. McLaughlin, “Stubborn State Gives ‘Tacit Approval’ to AIDS Deaths” (editorial), (New Jersey) *Star Ledger*, 5 May 2000, 2000WL21304952.

29. Kaiser Family Foundation, *Preliminary Findings from National Survey of Teens on HIV/AIDS, 2000* <www.kff.org/content/2000/3066>.

30. *Ibid.*

31. See, for example, comments of Dr. Birnbaum, see note 5 above.

32. IOM, National Academy of Sciences, *No Time to Lose: Getting More from HIV Prevention (2000)* <www.nap.edu/books/0309071372/html>.

33. *Ibid.* This figure refers to the total amount spent on prevention activities by a number of agencies, including the Department of Health and Human Services (DHHS) and agencies within it, such as the CDC and the Food and Drug Administration (FDA), and others such as the Department of Defense (DOD), the Department of Veterans Affairs (VA), and the Departments of Labor (DOL) and Justice (DOJ). See S. Foster et al., *Federal HIV/AIDS Spending: A Budget Chartbook* (Washington, D.C.: Georgetown University Law Center, Henry J. Kaiser Family Foundation, August 1999). Obviously, this figure includes a number of activities related to prevention, such as the costs of HIV case reporting.

34. “Survey Reveals Continued Public Unease About HIV,” *AIDS Policy & Law* 13 (7 August 1998), 1, 6.

35. *Ibid.*

36. *Ibid.*, 6. For example, 55 percent of those surveyed said that HIV can be transmitted by a person with AIDS sharing a drinking glass, while 54 percent believed that they could contract HIV from a cough or sneeze; 41 percent believed HIV could be transmitted through a public toilet; 28 percent would not want to use a glass if it had been used by a person with AIDS several days earlier, even if the glass had been sterilized in the interim; 27 percent would not wear a sweater worn a single time by someone with AIDS, even if the sweater had been cleaned and repackaged; and 25 percent said that they would feel uncomfortable working in the same office as someone with AIDS.

37. *Ibid.*, 1.

38. One notable exception to this silence was the testimony of Helene Gayle, MD, MPH, Director of the CDC’s National Center for HIV, STD, and TB Prevention, in opposition to provisions of H.R. 4431, the HIV Partner Protection Act, which sought, in part, the elimination of anonymous HIV testing options across the country and mandatory universal partner notification. Testimony on HIV Partner Protection Act by H.D. Gayle, Director, National Center for HIV, STD, and TB Prevention, CDC, U.S. Department of Health and Human Services, before the House Committee on Commerce, Subcommittee on Health and Environment (29 September 2008), <<http://waisgate.hhs.gov/cgi-bin/waisgat..D+4473319810+14+0+0&WAISaction=retrieve>>.

39. See, for example, Burris, “Driving the Epidemic Underground?” see note 16 above, p. 71:

A generalized sense that officialdom or society at large is hostile to people with or at risk for HIV—drug users, gay men, people of color, or poor people—may be a very important, and neglected, influence on testing behavior. Research among gay men reports a mistrust of government and its motives, particularly a fear that over the long run, HIV test information could be subject to misuse. [citation omitted] Mistrust of health authorities and government “help” has also been strong among Black people, with notoriously good reason [citation omitted].

40. See, for example, *EEOC v. Prevo’s Family Market*, 135 F.2d 1089 (6th Cir. 1998) (grocery store fired HIV-positive produce clerk); *Bragdon v. Abbott*, 524 U.S. 624 (1998) (dentist refused to fill cavity of HIV-positive patient). In a study of dental students, 53 percent of those surveyed said that they would not treat patients with HIV if they had a choice. E.S. Solomon et al., “Issues in the Dental Care Management of Patients with Bloodborne Infectious Diseases: An Opinion Survey of Dental School Seniors,” *Journal of Dental Education* 55 (1991): 594; S. Burris, “Dental Discrimination Against the HIV-Infected: Empirical Data, Law, and Public Policy,” *Yale Journal on Regulation* 13 (1996): 1, 11-15. A survey of 951 neonatologists nationwide found that many would withhold costly medical treatments from babies born to HIV-positive mothers, even if they had no idea whether the baby was actually infected with HIV. “In Brief . . . HIV Babies,” *AIDS Policy & Law* 10 (1995). In another study, almost half of those physicians surveyed reported an unwillingness to treat HIV-positive patients. C. Lewis and M.D. Montgomery, “Primary Care Physicians’ Refusal to Care for Patients Infected with HIV,” *Western Journal of Medicine* 36 (1992): 156; see also F. Christian, Jr. et al., “Open Heart Survey in an HIV-Positive Patient,” *AIDS Patient Care and STDs* 10 (1996): 210-11 (discussing “a reluctance among surgeons and especially cardiothoracic surgeons to operate on HIV-positive patients”); see also L.O. Gostin and D.W. Webber, “The AIDS Litigation Project: HIV/AIDS in the Courts in the 1990s, Part 2,” *AIDS & Public Policy Journal* 13, no. 1 (Spring 1998): 3-19 (providing a comprehensive compilation of HIV discrimination cases).

41. See for example, *Doe v. Mutual of Omaha Insurance Co.*, 179 F.3d 557 (7th Cir. 1999), *cert. denied* 145 L.Ed.2d 714, 68 U.S.L.W. 3327 (10 January 2000), 120 S.Ct. 845 (2000) (upholding insurer’s practice of limiting benefits for AIDS-related care to a fraction of that provided to other medical conditions). The addition of a recent decision from the relatively liberal Ninth Circuit Court of Appeals to the federal appeals courts rejecting ADA cases against insurers who discriminate has seriously eroded the possible use of the ADA’s Title III (governing public

accommodations) to successfully challenge disability-based discrimination in insurance policies in most jurisdictions. See *Chabner v. United of Omaha Life Insurance Co.*, 2000 WL1276794 (11 September 2000).

42. See Lambda Legal Defense & Education Fund, "State Laws Criminalizing HIV Transmission" (chart), updated June 2000 <www.lambdalegal.org>.

43. *The National AIDS Strategy* (Washington, D.C.: Office of National AIDS Policy 1997), 10 (acknowledging that fear of discrimination and stigma deters testing and demanding that testing not compromise confidentiality).

44. See D.W. Webber and L.O. Gostin, "Discrimination Based on HIV/AIDS and Other Health Conditions: 'Disability' as Defined under Federal and State Law," *Journal of Health Care Law & Policy* 3 (2000): 266-329, p. 285 (noting the "significant barriers" for plaintiffs with HIV discrimination claims under the ADA).

45. *Ibid.*, 304-5 (concluding that less than half of the population of individuals with AIDS are in jurisdictions with protections that are "clearly established," while approximately 6 percent of that population are in jurisdictions that significantly limit or have no protection for HIV infection in major areas; the remaining individuals are in jurisdictions that pose much the same "significant barriers" as are faced under the ADA).

46. L.O. Gostin et al., "The Public Health Information Infrastructure," *Journal of the American Medical Association* 275 (1996): 1921, 1924.

47. *Ibid.*, 1925.

48. A. Simones, "The Right to Suffer as Individuals or the Necessity to Survive as a Society: HIV Status and the Constitutional Right to Privacy," *University of Missouri—Kansas City Law Review* 68 (1999): 195, citing A. Nossiter, "Man Knowingly Exposed 62 Women to AIDS Virus," *New York Times*, 13 November 1997, B.1; see also L. Kennedy, "The Miseducation of Nushawn Williams," *POZ* (August 2000): 38-43, 63.

49. For example, a grand jury in Virginia indicted two sex workers for attempted murder because they allegedly were having unprotected sexual intercourse. The Virginia State Attorney General ordered this arrest after obtaining the women's HIV records from the local health department. The charges were dropped after witnesses against the women perjured themselves. A. Forbes, "'Names' Versus 'Unique Identifiers': the 'How' of HIV Case Reporting," *SIECUS Report* (February/March 1998): 4.

50. AIDS Foundation of Chicago, *Action Bulletin* 11, no. 2 (April 1998): 3.

51. On a national level, DHHS Secretary Donna Shalala recommended that proposed medical record privacy law allow police and other law enforcement officials to have virtually unlimited access on request to all private medical records. "Confidentiality of Individually-Identifiable Health Information, Recommendations of the Secretary of Health and Human Services, Pursuant to Section 264 of the Health Insurance Portability and Accountability Act of 1996, Submitted to The Committee on Labor and Human Resources and the Committee on Finance of the Senate and The Committee on Commerce and the Committee on Ways and Means of the House of Representatives, 11 September 1997" <<http://aspe.os.dhhs.gov/admnsimp/pvcrec0.htm>>.

52. Illinois Public Act 87-763, codified at 410 Ill. Comp. Stat. 325/5.5.

53. See D.N. Klaucke, et al., "Guidelines for Evaluating Surveillance Systems," *Morbidity & Mortality Weekly Report* 37, S-5 (6 May 1988): 1-18, p. 6 (epidemiologic surveillance information "is used for planning, implementing, and evaluating public health interventions and programs. Surveillance data are used both to determine the need for public health action and to assess the effectiveness of programs").

54. See, for example, E.J. Fordyce et al., "Mandatory Reporting of Human Immunodeficiency Virus Testing Would Deter Blacks and Hispanics from Being Tested," *Journal of the American Medical Association* 262 (1989): 349 (22 percent of African-American and Hispanic participants would not test if their results were reportable to public health officials); D. Hirano et al., "Anonymous HIV Testing: The Impact of Availability on Demand in Arizona," *American Journal of Public Health* 84 (1994): 2008 (name reporting and fear of discrimination discourages men who have sex with men from HIV testing.); P. Mayer, "Confidentiality in HIV Testing Remains," *WebMD Medical News* <<http://my.webmd.com/content/article/1728.50477>>.

55. Stansbury Associates, *Survey of Latino Attitudes to HIV Surveillance Case Reporting*, a study conducted for the Latino Commission on AIDS in December 1997; on file with the author.

56. CDC, "HIV Testing among Populations at Risk for HIV Infection—Nine States, November 1995-December 1996," *Morbidity & Mortality Weekly Report* 47 (25 December 1998): 1086-91.

57. J. Levi, "Rethinking HIV Counseling and Testing," *AIDS and Public Policy Journal* 11, no. 4 (Winter 1996): 164.

58. Illinois law, typical of most state laws in this regard, requires an explanation regarding the disclosure of test results prior to obtaining written informed consent to perform an HIV test. See note 52 above.

59. The CDC has acknowledged that a participant's "stated intent to test may not match actual behavior," and that participants "may underestimate concern about reporting." Excerpts from a CDC slide presentation on the *HITS and APS Survey*, see note 56 above.

60. S. Landry, "AIDS List is Out: State Investigating Breach," *St. Petersburg Times*, 20 September 1996, I-A, 10-A.

61. M. Iacobbo, "No Names Please," *Providence Phoenix*, 13 May 1994, 2.

62. ACLU, see note 18 above.

63. Under current Medicaid policy, with the exception of eligible low-income children, a person with HIV not only must meet state income and resources criteria, but also must become sick and disabled in order to be eligible for

benefits, even under states' Medicaid "medically needy" programs. U.S. DHHS, Health Care Financing Administration (HCFA), *Medicaid Eligibility*, <www.hcfa.gov/medicaid/meligib.htm>.

64. IOM, *No Time to Lose*, see note 32 above, p. 11.

65. *Ibid.*, 13. See also Johri et al., "New Approaches," in this issue of *APPJ*.

66. *Ibid.*

67. G.N. Colfax and A.B. Bindman, "Health Benefits and Risks of Reporting HIV-Infected Individuals by Name," *American Journal of Public Health* 88 (1998):876-9.

68. CDC, *HITS and APS Survey*, see note 56 above.

69. See Forbes, "'Names' Versus 'Unique Identifiers,'" see note 49 above.

70. *Ibid.*

71. D.H. Osmond et al., "Name-Based Surveillance and Public Health Interventions for Persons with HIV Infections: Multistate Evaluation of Surveillance for HIV Study Group," *Annals of Internal Medicine* 131 (1999): 775-9.

72. A. Bindman et al., "Multistate Evaluation of Anonymous HIV Testing and Access to Medical Care," *Journal of the American Medical Association* 280 (28 October 1998): 1416.

73. CDC, *HITS and APS Surveys*, see note 56 above; I.H. Picciotto et al., "HIV Test-Seeking Before and After the Restriction of Anonymous Testing in North Carolina," *American Journal of Public Health* 86 (1996):1146, 1148.

74. Forbes, "'Names' Versus 'Unique Identifiers,'" see note 49 above, p. 5 (reviewing the results of the *HITS and APS Surveys*, see note 56 above).

75. S. Crystal, "AIDS Contact Notification: Initial Program Results in New Jersey," *AIDS Education & Prevention* 2, no. 4 (1990): 284; K.H. Rothberg et al., "Domestic Violence and Partner Notification: Implications for Treatment and Counseling of Women with HIV," *Journal of the American Medical Association* 50, no. 3 (1995): 87. According to reports published in the magazine *POZ*, Amanda Carlson-Bey and her two-year-old son were brutally slain after she disclosed her HIV status to her partner, Michael Charles Stewart. "Death by Disclosure," *POZ* (March 1999), 26.

76. *Ibid.*, 7; see ACLU, *The Maryland Lesson: Conducting Effective HIV Surveillance with Unique Identifiers* (New York: ACLU, December 1997), an interview with Liza Solomon, Director of the Maryland AIDS Administration, p. 9. "Maryland has not received funds from the Centers for Disease Control to implement its HIV surveillance system. Maryland requested funds to support this program in our 1995, 1996, and 1997 surveillance cooperative agreement. All requests were denied. Maryland and Texas did receive funds from the CDC to evaluate the UI program."

77. *Ibid.*

77. *Your Social Security Number: How Secure Is It?* (San Diego, Calif.: Privacy Rights Clearinghouse, 1997) (Social Security numbers are the most frequently used record-keeping numbers in the U.S., and their easy accessibility to large numbers of people has resulted in increased fraud).

79. Maryland reported 84 percent completeness for all data elements except Social Security number. Forbes, "'Names' Versus 'Unique Identifiers,'" see note 49 above, p. 7.

Although it is rarely mentioned, name-based reporting has produced incomplete reporting of test results: names are omitted, duplicated, or erroneously entered into name-based registries, and there is considerable use of pseudonyms by people seeking HIV testing.

80. New Jersey Department of Health and Senior Services, *New Jersey HIV/AIDS Quarterly Newsletter*, 30 June 2000.

81. New Jersey Department of Health and Senior Services, *New Jersey HIV/AIDS Quarterly Newsletter*, 30 June 1997 <www.state.nj.us/health/aids/976pg8.htm>.

82. Forbes, "'Names' Versus 'Unique Identifiers,'" see note 49 above, p. 7.

83. Novick, "HIV Surveillance," see note 12 above, p. 52. The CDC "Guidelines for National HIV Case Surveillance" state, "Through follow-up with providers, the HIV/AIDS surveillance system has provided an effective means to identify rare or unusual modes of HIV transmission and infection with rare strains of HIV and to improve the prevention of HIV-related opportunistic illnesses." CDC "Guidelines for National HIV Case Surveillance," see note 1 above, p. 20. In support, the *Guidelines* cite in part a study of rare strains of HIV conducted in Los Angeles County, where there is no HIV case surveillance system, and a report into the investigation of the Acer case, the dentist suspected of infecting several of his patients, which again did not hinge on the existence of an HIV-test reporting system. *Ibid.*, notes 102-6.

84. See Johri et al., "New Approaches," in this issue of *APPJ*.

85. Gay Men's Health Crisis, "HIV Treatment and Diagnosis in the United States," *Treatment Issues* 13 (May/June 1999) <[wysiwyg://62/http://www.aegis.com/pubs/gmhc/1999/GM130501.htm](http://www.aegis.com/pubs/gmhc/1999/GM130501.htm)>, citing an unpublished survey by F. Hecht, "AIDS Patient Survey," a federally funded study of 2,801 people with AIDS across the country, which found that the time from HIV testing to AIDS diagnosis ranged from two years to less than one year; 20 percent of those surveyed had received their HIV diagnosis and their AIDS diagnosis at the same time; most of those surveyed had been infected more than five years before being tested.

86. Illinois law, for example, expressly allows this form of surveillance. 410 Ill. Comp. Stat. 305/8.

87. See Novick, "HIV Surveillance," see note 12 above, p. 53—citing R.S. Jansen et al., "Diagnosis of Early HIV Infection Using A Dual Enzyme Immunoassay Antibody Testing Strategy for HIV Incidence Estimates, Clinical Research, and Public Health"; R. Brookmeyer et al., "The AIDS Epidemic in India: A New Method for Estimating Current Human Immunodeficiency Virus (HIV) Incidence Rates," *American Journal of Epidemiology* 142 (1995): 709; R. Brookmeyer and T.C. Quinn, "Estimates of Current Human Immunodeficiency Virus Using Early Diagnostic Tests," *American Journal of Epidemiology* 141 (1995): 166; E.H. Kaplan, "HIV Surveillance for HIV Prevention: Some Preliminary Ideas, Center for Interdisciplinary Research on AIDS," (unpublished working paper, 1998, Yale University, New Haven, Conn.).

88. See Forbes, "'Names' Versus 'Unique Identifiers,'" see note 49 above, p. 4.

89. IOM, *No Time to Lose*, see note 32 above, p. 14.