POZ

# Names Will Never Hurt You?

## Just like Poltergeist, mandatory HIV name reporting is back—but this time the battle lines are redrawn

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Bob is a 52-year-old Philadelphian with a 30-year heroin habit who tested negative half a dozen times before his HIV test came back positive. Each time, he had the test done anonymously: At a city-run clinic where no one asked his name, his blood samples were numbered and he produced a copy of his test number to get his results. “I don’t believe there’s any list the state can have that can be kept confidential,” he says, adding that a lot of people he knows—young ones and injection drug-users especially—will avoid getting tested if Pennsylvania starts collecting the names of people whose results come back positive.

Bob’s other option was to get a “confidential” test at a doctor’s office or hospital, the method used for two-thirds of all HIV-antibody testing in this country. It’s called “confidential” because once the doctor or clinic has your name, they are required to hold it in confidence. But in 28 states, that “confidentiality” is extended to include—indeed, require—the reporting of those names to the state health department.

If a growing list of organizations have their way—from the Christian Coalition to the American Medical Association (AMA) to the Centers for Disease Control and Prevention (CDC)—HIV name reporting will soon be adopted by all 50 states. And if a bill in Congress sponsored by Rep. Tom Coburn (R-OK) and 100 cosponsors passes, every state will be required to send its names to a national HIV registry.

The past year has seen a resurgence of the push for mandatory name reporting (MNR) of people with HIV. In response, a storm of controversy has erupted that echoes the battles that stopped such initiatives—and even more draconian measures—from being implemented in the 1980s. But this time around, there is broader support for MNR including, surprisingly, some voices within the lesbian, gay and AIDS communities. For example, widely published gay journalist Chandler Burr criticizes what he calls “AIDS exceptionalism” that defies the “traditionalist public health approach”—MNR, routine testing and partner notification—long used for such diseases as syphilis, hepatitis-B and tuberculosis. “There will always be excuses for not doing things that are effective,” Burr contends. “This doesn’t argue against putting the right policies in place, just because a small minority of people won’t get care.”

Unlike HIV positive cases, AIDS cases have had mandatory name reporting in all 50 states since the early 1980s. But because of the new and better AIDS drugs, AIDS cases are becoming a smaller portion of the whole picture as more and more people live with HIV that has not progressed to AIDS. Keeping a tally of HIV cases may be the only way for states to get the kind of comprehensive overview of the epidemic that they need in order to target services and prevention programs effectively.

How to do this, however, is a loaded question. AIDS advocates distinguish sharply between HIV *case* reporting—the collecting of nonidentifying demographic information about people with HIV—and HIV *name* reporting. While most see the necessity for collecting HIV case data, they staunchly maintain that states don't need to collect names. The CDC and its allies, on the other hand, see MNR as the easiest and most efficient HIV case-counting method and as a means of helping people get medical care quickly.

MNR opponents have two problems with this argument. The first is that its assumption that everyone can get adequate medical care is unrealistic, especially in light of continuing inability of federal funds to cover the demand for AIDS drug assistance. "We can't for the life of us see how having names will get people into treatment," says Michelle Mascaro of the AIDS Foundation of Chicago. "The money just isn't there." In any case, the CDC's Multi-State Evaluation of HIV Surveillance (MESH) survey of 2,300 people, conducted in 1996, found that people with HIV got into care just as rapidly after being tested at anonymous sites as at "confidential" sites.

The second problem is that treatment can't possibly work if those who need it have been scared into staying away from testing. Kiyoshi Kuromiya, editor of the national treatment newsletter *Critical Path AIDS Project*, says: "Everybody should be told that there are early intervention options. But we've known since the beginning of the epidemic that mandatory anything—including name reporting—doesn't help people realize their options."

Indeed, it is the fear of driving people with HIV underground that has most fueled the public-health opposition to MNR. And evidence continues to mount that name-reporting, or even the fear that a state may adopt it, drives people away from HIV testing. The MESH study found that 19 percent—almost one in five—identified name reporting as a reason not to get HIV testing. An earlier study in California found that more than 60 percent of those tested anonymously would not have tested if their names were reported to public health officials. A report last fall by the American Civil Liberties Union (ACLU) opposing MNR, citing nine studies, concludes, "The deterrent effect of name reporting is most pronounced in the very populations with the greatest need for preventive intervention: Gay and bisexual men, people of color, intravenous drug-users and sex workers."

MNR supporters respond that these fears are no longer warranted because the 1990 Americans with Disabilities Act and other new legal protections have dramatically reduced the risk of HIV-related discrimination. But Catherine Hanssens, director of the AIDS Project of the Lambda Legal Defense and Education Fund, doesn't buy this argument, noting that Lambda's AIDS discrimination caseload keeps growing. "People aren't getting their houses burnt down, but that doesn't mean there isn't discrimination against people with HIV," she says. Besides, a 1997 decision by a federal appeals court found that an HIV positive person without symptoms is not protected by the disabilities law.

Eileen Hansen, public policy director of the San Francisco–based AIDS Legal Referral Panel and an 11-year veteran of this debate, concurs. "The stigma that many individuals and populations face prior to being confronted with AIDS actually makes for an increased likelihood of AIDS discrimination and less access to care."

MNR opponents also point out that HIV and AIDS registries have been breached. Who can forget that a computer disc containing 4,000 names from the Florida State Health Department AIDS Registry was stolen, allegedly by an employee's boyfriend, and sent to two newspapers in St. Petersburg last year? (He is currently facing criminal charges.) And the ACLU reports that, "The FBI has admittedly used improperly obtained HIV information, and local law enforcement agencies have disclosed HIV status to neighbors and prison inmates, and broadcast the names of people with HIV over police radios."

But even more sinister than individual, illegal violations, MNR opponents say, is the constant threat of government-sanctioned breaches: Confidentiality laws can be modified or repealed at will. State legislatures and courts can use, and sometimes have used, HIV registry lists for such non-health purposes as criminal prosecution, medical licensing or even custody or adoption decisions. In 1991, for example, Illinois passed a law (never implemented) requiring its state Health Department to identify HIV positive health care workers—by cross-matching the state AIDS registry against health care licensure records—and then disclose the status of those with HIV to their patients. In Colorado, the state Health Department discloses a person's HIV status to police, firefighters or other medical personnel when an incident occurs on the job that may have exposed the worker to HIV.

And most recently, in the much-publicized case of Nushawn Williams, a Jamestown, New York man charged with knowingly spreading HIV via unprotected sex with dozens of younger women, the county health department sought and was granted a court order to publicly disseminate his name (included on a list of prisoners who have tested positive). This was done under an exemption from New York's HIV confidentiality law allowing for disclosure in cases of "clear and imminent danger to the public health." Activists fear that once names are listed, such exemptions can open the door for politicians to use them against any person with HIV to create hysteria and stigma.

The fallout from the Williams case will undoubtedly be a heightened push to the proliferating trend of state laws criminalizing HIV transmission. Police and prosecutors already have wide leeway to use health department records in such cases. And a current federal proposal by Secretary of Health and Human Services Donna Shalala is likely to extend such powers by institutionalizing a dangerously flexible approach to confidentiality—exempting medical information requested "for a legitimate law enforcement inquiry" or for a public-health emergency "affecting life and safety." According to Axel Torres-Morrero, public policy director of New Jersey's Hyacinth Foundation, more than 300 people with HIV have been prosecuted nationwide (with one-sixth convicted) "because someone accused them of doing something risky.” He adds, “If you can go to jail for having sex while HIV positive, and if the police have access to the state HIV registries, who’s going to run the risk of having their name in a registry?”

For many from the communities most affected by HIV, these prosecutions only reinforce deep-rooted fears about the consequences of getting their name on a government list. Howard Josepher runs Exponents/ARRIVE, a New York City agency that provides intensive drug treatment and job training to ex-inmates with a history of injection drug use. Josepher says, “If being tested means being identified, and especially if the police have access to the records, people will choose not to be tested.”

Immigrants, with or without legal documents, are another group likely to be frightened away from testing by mandatory name reporting. Fernando Chang-Muy, a professor of immigration and refugee law at the University of Pennsylvania’s Law School, concurs. Granting the Immigration and Naturalization Service (INS) access to state HIV name registries, he says, “brings up the possibility of deporting people if they are known to be HIV positive” because of the federal HIV immigration-exclusion law.

Activists have their own theories about what’s behind the current push for HIV name reporting. For one thing, right-wing groups, which have mounted the most energetic campaigns for MNR, have multiplied in number, financing and sophistication over the past decade. This mirrors the declining membership in ACT UP and other activist groups which mobilized against MNR in years past.

But there’s also the possibility that many gay white men may now—with 11 states guaranteeing gay rights and TV’s *Ellen* symbolizing a changed popular consciousness—see themselves as better protected from discrimination, with less concern for the realities of other HIV-affected communities. Says Terry McGovern of the HIV Law Project, “I remember when the major AIDS organizations were fighting tooth and nail for the privacy concerns of people with HIV. Why are these no longer major concerns? Perhaps the perception is that civil liberties should shift as the demographics shift.”

Whatever the reasons, the softening of much of the traditional opposition to MNR has transformed the political landscape, forcing the AIDS-concerned into tough choices. Walt Senterfitt, a board member of Being Alive, a Los Angeles PWA advocacy group, says, “The train for mandatory HIV case reporting is barreling down the tracks. I believe it is time we and other AIDS organizations switch from being the track kill or the caboose for this train and, instead, become its engineers.”

Larry Gostin, a professor at the Georgetown University Law Center and a vigorous opponent of MNR in the mid ‘80s, is one of many former MNR opponents to jump track. Gostin asserts that there are strong legal protections now in place against HIV-related discrimination, and so he argues that “name reporting with confidentiality protections is justifiable,” provided that the option of anonymous testing is also preserved.

Mark Senak, public policy director for AIDS Project Los Angeles (APLA), says the organization’s historic opposition to HIV name reporting hasn’t changed. But an APLA White Paper, recently issued to promote community discussion, includes the statement: “If a program of HIV surveillance by name is implemented carefully and with full participation by the communities affected by HIV, better information on the spread of the epidemic can be obtained without unreasonable risks to individual confidentiality.”

On the other hand, several organizations—including the AIDS Action Council, the ACLU and NAPWA—still oppose MNR. “Under no circumstance does NAPWA support HIV named reporting,” its Position Paper proclaims, adding that NAPWA “guardedly” supports HIV case reporting only if it is done “using unique or coded identifiers that insure the privacy and confidentiality of the individual.”

Using unique identifiers (UIs)— codes of letters and numbers (including, for example, such individual data as gender, race, birth date and Social Security number) that unlink a medical record from a name—is an alternative that many activists and advocacy organizations prefer. Finding a UI system that eliminates duplicates effectively and that is usable by all testing providers is not easy. But, proponents argue, a good UI system offers the best of both worlds: Case-by-case epidemiological data without privacy endangerment or testing avoidance. Of the two states that have adopted the UI approach, Texas has had difficulty getting cooperation from doctors and local health departments, while Maryland rates its experience a success. And contrary to opponents’ claims, the cost of Maryland’s UI system appears to be roughly comparable to that of MNR.

Of course, any code can be cracked. But UI advocates say there are computerized methods of scrambling the information so that it’s virtually impenetrable, although these safeguards slightly boost the system’s costs.

With the sides clearly drawn, the battle over name reporting is now in full swing. Three-quarters of all HIV positive Americans live in one of the “high incidence” states and territories that have, so far, resisted name reporting: California, Georgia, Illinois, Maryland, New York, Pennsylvania, Puerto Rico and Texas.

The CDC, mainstream medical authorities and right-wing allies are turning up the heat on the 20 states not yet engaged in HIV name reporting. At presstime, a CDC statement on its preference for how to record HIV cases is imminent, but its nationwide presentations on “Why We Need Name Reporting” and its co-authored New England Journal of Medicine article criticizing UIs suggest a bias. And if past practice on AIDS name reporting is any indication, it’s likely the agency will enforce a call for MNR by making this practice a condition of future grants to the states. (For three years now, the CDC has rejected Maryland’s application for funds to support its shoestring UI system budget.)

What the CDC has said, however, is that it wants case reporting adopted in all 50 states by January 1999. This will allow the agency to compile national HIV data by the time the next CARE Act re-authorization battle gears up in the year 2000. AIDS case statistics then are likely to suggest a waning epidemic, but HIV case data, particularly if collected in high-incidence states, will show the opposite. This may make it easier to convince Congress that HIV remains a crisis requiring continuing large-scale federal funding.

So what does all this mean for Bob, the HIV positive heroin user, and thousands of others who fear name reporting? One near certainty is less access to anonymous testing—despite the lip-service paid to that option by many MNR supporters. In many states, numbers of no-name test sites have dropped sharply following adoption of MNR. And ten states have eliminated anonymous testing so far, since the CDC does not require states to offer anonymous test sites as a condition for receiving funds.

If people live in a state without MNR, they will probably access testing and care as readily as their counterparts have in the past. If they live in a state that does HIV case reporting by unique identifier, demographic data about them will become a part of their state's larger epidemiological picture. And if they get tested in a state that collects names, their names will be on a list in the health department—potentially available to law enforcement, potentially subject to legislative manipulation and judicial subpoenas, potentially at risk of being leaked.

The debate is raging, the clock is ticking and some big dominoes are falling. Florida adopted MNR in 1997 and New Mexico plans to do so in 1998. Nineteen more states are on the line.

Eileen Hansen of the AIDS Legal Panel says, "There's a planned effort to move this thing along as quickly as possible without generating any more community opposition than they can avoid." So, state by state, the battles are unfolding quickly—with the fate of thousands of HIV positive people hanging in the balance.