

On Oct. 16, the American Civil Liberties Union issued a 22-page document entitled "HIV Surveillance and Name Reporting: A Public Health Case for Protecting Civil Liberties," which blasted HIV names reporting and argues that such a plan would undermine both public health and civil liberties.

The report also concludes that HIV names reporting would discourage a significant portion of the public from being tested, thereby hampering HIV tracking.

"Although there are many vexing questions raised by the epidemic, HIV names reporting is not one of them," says Michael Adams, a staff attorney with the ACLU's AIDS Project and one of the report's principal authors. "Proponents of aggressive HIV surveillance are shooting themselves in the foot by advocating names reporting, because doing so will shrink the pool of people who would get tested for HIV."

The ACLU says it recognizes that the emergence of promising new medical treatments and improved legal protections have shifted the focus of epidemiological surveillance to the "front end" of the AIDS epidemic—HIV infection—and that the benefits of early medical intervention, which didn't exist just a few years ago, have placed greater emphasis on learning people's HIV status.

The ACLU also notes that proponents of names reporting argue the passage of the Americans with Disabilities Act has strengthened legal protections for people with HIV, easing concerns that names reporting will expose individuals to discrimination by employers, insurance companies and government agencies.

The ACLU says, however, that while these developments may warrant better HIV tracking, they do not justify names reporting.

According to one of the nine comprehensive studies cited in the ACLU's report, more than 60 percent of individuals tested anonymously would not have tested if their names were reported to public health officials. The group says similar conclusions were reached by the other studies, strongly suggesting that names reporting would obstruct efforts by public health officials to better track HIV cases.

The ACLU's report also found legal protection against HIV discrimination to be far from secure, despite the passage of the ADA.

It notes two recent federal appeals court rulings that strictly limit the reach of the ADA in barring discrimination based on HIV status. In a ruling by the 4th U.S. Circuit Court of Appeals, the court held that the ADA does not cover people with HIV who are free of AIDS-related symptoms. The 6th Circuit, meanwhile, ruled the ADA does not protect people with either HIV or AIDS from discrimination in insurance.

"In sum, the fears that drive people away from HIV testing with names reporting are not groundless. To eliminate them, we need more than edu-

cation; we need solid antidiscrimination protection and real availability of treatment for the poor and uninsured," the report says.

Doug Zeh, of the Portland-based Cascade AIDS Project, says CAP receives many calls from people who think they may have been discriminated against because of their HIV status.

"We get at least one a week, which is enough to cause concern," he tells *Just Out*.

The Human Rights Campaign, the nation's largest lesbian and gay political organization, meanwhile, is calling upon the CDC to address a number of issues as the agency proceeds in developing an expanded HIV surveillance system.

Seth Kilbourn, HRC's senior policy advocate

input from the public.

Stoltenberg also criticizes OHD for scheduling a recent public meeting on the issue at the same time as an AIDS summit featuring many consumers. The meeting was held in Northeast Portland, while the conference (which was cosponsored by OHD) was held in Beaverton.

"That wasn't an accident," she says.

As for HRC, Kilbourn says anonymous testing must be accessible to anyone who seeks it, and surveillance systems at the local, state and national level must be separated from any partner notification and contact tracing systems.

"In a perfect world—in which gay people had full civil rights protections—names reporting would not be controversial," he says. "But as long as people can lose their jobs, their homes or their

some find especially troublesome—particularly for people in rural areas who may not seek testing for fear word will get out.

"Let's say you're living in a little town in Eastern Oregon: Everyone knows everybody. People will worry their neighbors or families will somehow find out," says one gay man living with HIV.

The man, who is an HIV/AIDS consumer advocate, has lived nearly his whole 30-plus years in a rural community about 30 miles from Portland.

He says he was the victim of a violent hate crime in his own yard a few years back, clubbed by a band of young men who called him "faggot" as they beat him. He asked that his name not be revealed, because he still worries about discrimination and harassment.

"It's different in smaller communities," he says.

With respect to names reporting, he says even if confidentiality is guaranteed, the perception alone of a possible slip is enough to deter people from getting tested.

He also notes that some people within ethnic minority populations are already distrustful of bureaucratic institutions and harbor strong fears of ostracism within their own communities.

Others say immigrants and undocumented workers—now the target of an aggressive government crackdown—may also balk at getting tested or seeking treatment for fear of deportation.

"Latinos, African Americans, street people—all are distrustful of public health," says longtime consumer advocate Jack Cox, who tested positive for HIV a dozen years ago.

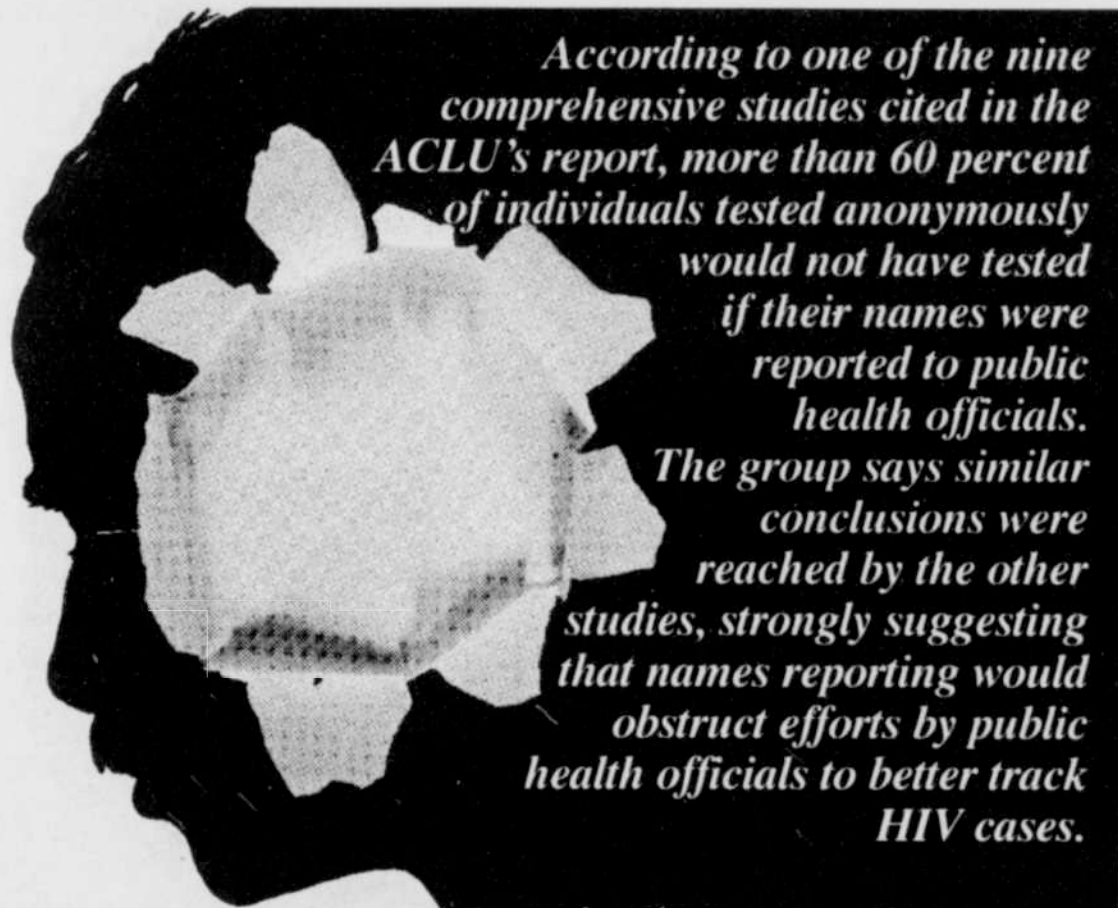
He says had names reporting been the order of the day back then, he might not have sought testing. "I would have been scared," he says. "I think in the gay community we've come a long way in terms of fears about stigma, but my guess is other communities now are where the gay community was 10 years ago."

In 1994, Cox organized the HIV Advisory Council of Oregon and Southwest Washington, which works to improve HIV/AIDS services and give a voice to consumers.

"In an ideal world names reporting may work, but this is the real world—there are too many social risks," he says.

Back at OHD, Modesitt says it's imperative that his agency's plan has the support of county health authorities.

"This is a collaborative effort," he says. "We won't move forward unless we're in agreement." Modesitt says OHD hopes to have a proposal that is endorsed by county health departments by January; he would like to see a plan implemented by April 1998. Modesitt says that since the proposal could be adopted via an administrative rule change, there would likely be just one hearing for public discussion.



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for health issues, says the need for an expanded HIV surveillance system must be fully explained and justified, and that the CDC must demonstrate that the benefits of expanded HIV surveillance will outweigh the costs, both in terms of resources and increased risk of confidentiality breaches.

Additionally, Kilbourn says confidentiality and privacy concerns are legitimate, and argues that the use of coded identification must be fully explored as an option. If names are to be used, he says, the CDC must demonstrate that they are an essential part of the surveillance system.

Some in Oregon echo that sentiment. Susan Stoltenberg, CAP's executive director, says OHD has provided no evidence that names reporting will lead to better data collection.

"It's just a theory," says Stoltenberg, who criticizes the agency for failing to solicit broad-based

children merely for being gay, privacy concerns are legitimate."

Adopting a names reporting plan in Oregon would simply require an adjustment of state administrative rules, not a legislative act.

Modesitt says OHD representatives have been meeting with county health officials as well as community advocates to discuss the proposal, which calls for expanding confidential physician and laboratory-based disease reporting to include all HIV-infected people. Laboratories would have to report antibody testing, viral load and other tests indicative of HIV infection, and physicians would have to report all newly diagnosed HIV-infected people as they do AIDS cases.

But it's the component that calls for names to be reported to county health departments that

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