



THE DAVID GEFFEN CENTER
APLA DENTAL SERVICES
NECESSITIES OF LIFE PROGRAM
Long Beach South Los Angeles
San Fernando Valley Wilshire Center

ADMINISTRATION
The David Geffen Center
611 South Kingsley Drive
Los Angeles, California 90005
Telephone 213.201.1600
Fax 213.201.1595
Website www.apla.org

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Public Statement on the Proposed Shift to Names-Based HIV Reporting In California

Funding for California's HIV/AIDS programs may hinge on whether the Legislature adopts names-based HIV reporting before the current session ends.

In early 2005, State Senator Nell Soto (D-Ontario) introduced SB 945, a bill that would allow California to shift to a names-based HIV surveillance system from the current code-based system. Although strongly supported by many community advocates and health officials, the bill is currently held up in the Senate Judiciary Committee. But this bill may be the key to maintaining or even increasing federal funding for California's HIV/AIDS programs.

Currently, federal funding for HIV/AIDS programs through the Ryan White Comprehensive AIDS Resources and Emergency (CARE) Act is allocated nationwide based on living AIDS case data. When the CARE Act was reauthorized in 2000, it called for revising the allocation formula to include HIV case data by 2007.

In June 2005, the U.S. Centers for Disease Control and Prevention (CDC) issued a letter stating that, "it is *critical* that all areas move as quickly as possible to an integrated, confidential names-based HIV/AIDS reporting system."

And just last month, the White House released its principles for this year's CARE Act reauthorization, scheduled for September, which uphold the 2007 deadline for the inclusion of HIV data.

While AIDS cases have been reported by name to the state for more than 20 years, new HIV infections in California are reported using a unique identifier, or code-based, system. The CDC considers HIV data from code-based systems unreliable, and will not accept the data. It is unlikely to confirm them for use in allocating Ryan White funds.

In 2004, California received more than \$223 million in through Titles I and II of the CARE Act. Approximately \$174 million was allocated using estimated living AIDS case data. The state could lose up to \$50 million annually in CARE Act funds - significantly reducing services to people living with HIV/AIDS - if the CDC refuses to recognize code-based HIV cases.

In 2002, AIDS Project Los Angeles (APLA) supported the establishment of a code-based HIV reporting system. At the time, this method was considered a viable means for health officials to track the HIV epidemic while ensuring an individual's right to privacy.

During its three years of implementation, however, the code-based system has proven to be more labor intensive and less accurate than a name-based system. According to Los Angeles County's HIV Epidemiology Unit, part of the Department of Health Services, there is a 40 percent error rate in code-based lab case data gathered over the last year. This error rate is only expected to increase over time. As of July 2004, there were more than 26,000 unmatched cases.

Thirty-eight states currently use a names-based reporting system. California is the only state among the five largest that uses an HIV reporting system different than its AIDS reporting system. The other four – New York, Florida, Texas, and New Jersey – use name-based systems, giving them an advantage over California when CDC confirms their HIV data for the Ryan White funding formula.

APLA has always emphasized balancing the need for continuous funding for HIV/AIDS programs with California's ability to ensure HIV case information confidentiality. We believe that the names-based AIDS reporting system in California has demonstrated the state's ability to preserve the confidentiality of people living with HIV/AIDS. During the last 24 years, 136,000 AIDS cases have been reported to the state by name with no breaches of confidentiality.

To ensure that Californians living with HIV/AIDS continue to receive CARE Act-funded treatment and services, APLA encourages the state of California to adopt a names-based HIV surveillance system, with the following requirements:

- *Penalties for disclosure must be increased.* In order to ensure confidentiality, proposed legislation should include the prohibition of disclosure of HIV test results and provide penalties for such disclosure.
- *Anonymous HIV testing must be preserved.* In order to accommodate individuals who would like to get tested but who are unwilling to give their names, alternative anonymous testing sites should be made available where personal identifying information would not (as is the case now) be reported to CDC.

Both these requirements are included in SB 945. Currently, supporters are looking to move the bill out of the Senate Judiciary Committee or bring a new bill to the Assembly before the current session ends in September.

With just over a year until the 2007 deadline imposed by CARE Act legislation, California has a narrow window of opportunity for implementing an efficient system of collecting complete HIV case data. We as a community must take the necessary step toward developing a viable public health policy that ensures the health and well-being of Californians living with HIV/AIDS. Names-based HIV reporting represents our best option for protecting resources and saving lives.

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