

# MAKING IT COUNT:

## **CALIFORNIA'S NAMES-BASED HIV REPORTING SYSTEM**

---

AIDS Project Los Angeles  
and the UCLA Center for HIV Identification,  
Prevention and Treatment Services (CHIPTS)

Funded through Generous Support from the  
**CALIFORNIA HIV/AIDS RESEARCH PROGRAM (CHRP)**

Grant #RP08-LA-604

# EXECUTIVE SUMMARY

To ensure that California policymakers and program administrators understand the current epidemiology of HIV/AIDS and to ensure that the state obtains its fair share of federal support for HIV care, the state's names-based HIV case registry must be as complete as possible. In early 2010, a report issued by the California Legislative Analyst's Office (LAO) raised the possibility that the system might be seriously deficient, with potentially tens of thousands of persons who were already receiving care not included in the registry.<sup>1</sup> To explore and assess this issue, AIDS Project Los Angeles (APLA) and the UCLA Center for HIV Identification, Prevention, and Treatment Services (CHIPTS) commissioned a study to further understand the extent of the potential problem and to identify what the deficiencies in the names-based system might be and how they might be corrected.

**Our study found that through intensive efforts at the local and state levels, California has achieved a robust names-based system in which the vast majority of persons with HIV who are in care and/or who have tested positive for HIV in California are now included in the HIV case registry.** While this is welcome news, it does not mean that the system is without flaws or that there is not room for improvement. To address these issues, our report provides the following recommendations, explained in greater detail in this paper's final section:

## GENERAL AND NATIONAL-LEVEL RECOMMENDATIONS

- On a national basis, consider eliminating the outdated distinction between HIV and AIDS in HIV-related surveillance reporting, both to reflect new medical realities and to better apply resources that are currently used for case reclassification.
  - Create new and more relevant approaches to tracking the impact and progression of HIV in relation to specific populations, regions, and groups, such as information on length of time since original HIV diagnosis, status at time of diagnosis, and regions in which persons are receiving care and for how long.
  - Request that the US Centers for Disease Control and Prevention (CDC)—which maintains national HIV case data—publish annual data showing the number of reported HIV cases in each state that have been previously reported in another state, along with demographic data on these populations and per capita calculations to assess relative impact.
- Allow limited access by states to the national CDC database in order to ascertain whether a new case has already been reported in another state, in turn reducing time and energy spent validating and reporting new HIV cases.
  - If the current distinction between AIDS and HIV is maintained, consider modifying CDC reporting to separately list state of origin for HIV cases and state of origin for diagnosed AIDS cases, and consider providing updates to states when an individual shifts from being an HIV to an AIDS case.
  - Propose introducing a new tiered provision in formula-based federal HIV funding which would to some degree take into consideration the current state in which an individual is receiving long-term HIV care.

## STATE-LEVEL RECOMMENDATIONS

- Expand funding for HIV case finding and report follow-up at the county level, and explore alternative methods for supporting and facilitating these services.
- Continue the process of giving local health jurisdictions in California limited access to the state HIV case registry for the purpose of examining whether a newly reported HIV case is already in the system.
- Explore creating a new voluntary, confidential case registry containing detailed information on individuals who receive a preliminary rapid HIV antibody test so that more extensive information is available on persons who receive a preliminary positive result through a rapid test but do not return to receive their confirmatory HIV test result.
- Consider developing new incentives to reward agencies that have high rates of return for confirmatory HIV test results or that document successful linkages to HIV care for HIV-positive individuals.
- Expand surveillance reporting by the California Office of AIDS to include separate data on people who have received an HIV or AIDS diagnosis in California and are currently receiving care in the state but who are classified as secondary cases and not currently included in statewide surveillance reports because they had previously been diagnosed with HIV in another state.

<sup>1</sup> California Legislative Analyst's Office, *Maximizing Federal Funds for HIV/AIDS: Improving Surveillance and Reporting*, Sacramento, CA, February 22, 2010, [www.lao.ca.gov/reports/2010/hlth/hiv-reporting/hiv-reporting\\_022210.pdf](http://www.lao.ca.gov/reports/2010/hlth/hiv-reporting/hiv-reporting_022210.pdf)

# MAKING IT COUNT: CALIFORNIA'S NAMES-BASED HIV REPORTING SYSTEM

## 1 INTRODUCTION TO THE PROJECT

In April 2006, the State of California introduced its names-based HIV reporting system which required that newly confirmed cases of HIV be reported to local health jurisdictions by name. The system was designed to improve the overall quality of the state's response to HIV by allowing public health agencies to better track its impact on populations and regions. The system was also a direct response to impending changes in the Ryan White CARE Act, the massive federal program that provides a significant share of the state's funding for care of low-income persons with HIV/AIDS. Under these new requirements, Ryan White formula funding will eventually be based solely on cases reported through names-based systems. This means that California—like a number of other states—would have lost a significant share of federal Ryan White monies if it had not converted from a code-based to a names-based system.

As with most systems changes, the conversion from code-based to names-based HIV reporting presented significant challenges. The greatest challenge involved the fact that persons who had originally been reported as HIV-positive under the code-based system could **not** automatically be included in the names-based system because detailed identity data on these individuals had not been obtained. Instead, these individuals would have to be re-identified and validated under the new system. To aid with this effort, California's names-based legislation included provisions requiring physicians and medical laboratories to directly report all HIV-positive test results and, later, key tests used for monitoring HIV disease progression to their local health departments. Local health departments would then follow up and verify these cases and in turn report them to the State Health Department. County health departments also worked with local agencies to encourage persons who had tested positive under the code-based system to be re-tested for HIV so they could be included in the new names-based registry.

While steady progress was made to incorporate HIV-positive individuals into the system, by early 2010 there were some signs suggesting that a large percentage of persons with non-AIDS HIV who were **currently receiving care** might not yet be included in the names-based case registry. A preliminary data analysis performed by the State Office of AIDS (OA) in 2007 using very early figures found that a significant percentage of people receiving benefits through the

AIDS Drug Assistance Program (ADAP) and/or included in the state's ARIES database of persons receiving Ryan White-funded services might be missing from the names-based registry.<sup>2</sup> Meanwhile, a report issued by the California Legislative Analyst's Office (LAO) in February 2010 suggested that as many as two-thirds of all persons with non-AIDS HIV in the state might be missing from the names-based system.<sup>3</sup> Deficiencies on this scale would have serious consequences for the state's share of federal Ryan White funding, particularly beginning in 2014 when Ryan White formula allocations will be based strictly on names-based cases.

To explore these critical issues, APLA, in collaboration with CHIPTS and through a policy research grant from the California HIV/AIDS Research Program (CHRP), commissioned a study in May 2010 to investigate the problem and explore potential solutions. The objective of the study was to determine how many persons in California who were receiving publicly funded HIV care were not included in the system, why they were not included, and what might be done to address the problem. Robert Whirry, an independent Program Development Consultant with extensive HIV/AIDS service system expertise, was contracted to carry out the study and report on its findings. This White Paper summarizes the results of that project.

<sup>2</sup> California Department of Public Health, *Response to LAO HIV/AIDS Surveillance Report for Stakeholders*, Sacramento, CA, March 10, 2010.

<sup>3</sup> *Ibid.*

## Why is a complete names-based HIV Case Registry important?

Having as complete a names-based HIV case registry as possible is important to California for a number of reasons. A complete HIV database allows more accurate tracking of the epidemic, and provides a clearer sense of the specific impact the epidemic is having on each region of the state. A complete database also allows public health agencies to anticipate emerging trends in the epidemic and to allocate resources fairly and effectively.

*At its most basic level, however, a complete HIV case registry means that California receives its fair share of federal resources to support surveillance, testing, prevention, treatment, and care for low-income persons living with HIV and AIDS.* Because federal Ryan White allocations will soon be based entirely on HIV data reported through the names-based system, it is vital that the system be as comprehensive as possible, particularly in terms of the inclusion of low-income persons who are *already receiving HIV care* in California. The care of these individuals is being financed by local governments, the State of California, and by public and private HIV/AIDS agencies, and the burden of costs will be disproportionately increased if federal funds are not available to augment these resources.

## 2 SUMMARY OF THE RESEARCH PROCESS

Information on the state of the California names-based surveillance system was obtained from **four** principal information sources:

- **Representatives of twelve county health departments** throughout the state were interviewed in one-on-one sessions. Most of these departments were located in populous counties which receive significant Ryan White funding, including Part A formula funding. These counties rely on accurate HIV case counts to ensure federal support for HIV care to low-income populations. As a result, many of these local health departments have developed and implemented aggressive approaches to include as many HIV-positive individuals as possible in their local names-based case counts. At the same time, these health departments face ongoing challenges related to the burdens of reporting under the names-based system, including the need to follow up on physician and laboratory results of HIV cases, which can sometimes lead to delays in reporting new HIV cases to the state.
- **Representatives of the California Office of AIDS** were interviewed, with additional follow-up through e-mail exchanges related to specific programmatic issues. This included numerous communications with Dr. Michelle Roland, Director of the California Office of AIDS; Dr. Karen Mark, Chief of the Office's HIV Surveillance, Research, and Evaluation Branch; and Steven Starr, Chief of the Office's Surveillance Section.
- **Representatives of three other states that had implemented names-based reporting** at around the same time as California were also interviewed. These states had developed their own approaches to ensuring a complete names-based system, although their approaches differed based on the relative size and scale of these states.
- **Data searches and literature reviews** were conducted to ascertain the true number of individuals in the state who might be in care but were not included in the names-based system. This data review was augmented by extensive interviews with specialists in HIV surveillance in California, including Lisa Murawski of the California Legislative Analyst's Office, Douglas Frye of the Los Angeles County HIV Epidemiology Program, and Arleen Lebowitz of the UCLA Center for HIV Identification, Prevention, and Treatment Services.

The consultant also interviewed other HIV planning and policymakers and received initial support in publicizing the project through the California Association of Local AIDS

Directors (CCLAD) and the organization's president at the time, Nettie DeAugustine. Early drafts of project-related calculations and findings were reviewed by many of the above individuals, all of whom generously donated their time to the current project.

## 3 QUANTIFYING THE SCOPE OF THE PROBLEM

When we first began our research to identify how many individuals with HIV were currently in publicly funded care but were not included in the names-based system, the outlook seemed bleak. The 2010 LAO report suggested that tens of thousands of persons with HIV who were aware of their status and in care might not be included in the names-based case registry. Planners and policymakers had become concerned that the state's HIV case registry would be woefully incomplete by the time the federal government began relying on these numbers to make key formula-based funding allocations in 2014. The situation seemed to require an urgent response that would involve a concerted effort from both the private and public sector.

**However, as our research progressed, it became clear that significant progress had been made and was continuing to be made in incorporating persons living with HIV into the names-based registry.** Despite a shortage of resources, local health jurisdictions had become increasingly adept at working with providers and laboratories to follow up on new HIV case reports. Over time, the system had also incorporated more and more persons in care through enhanced and more regular physician and laboratory reporting, often brought about by local health department outreach and education. Active case follow-up at the local level had also identified many individuals who had formerly been included in the code-based system and had fallen out of care but were added to the names-based system when they were re-linked to care. There were also backlogs of potential new HIV cases reported in some counties that had not yet been followed up on because of a shortage of resources. These backlogged cases included persons with HIV in publicly and privately funded care who will likely be incorporated into the names-based registry at a later date. HIV/AIDS surveillance data from the State Office of AIDS also continued to show steady and significant increases in the number of persons with HIV and AIDS included in the names-based system for the first half of 2010. For example, the total number of HIV cases included in the California names-based registry grew by **2,153** cases, or **5.6%**, between September 30, 2009 and June 30, 2010 alone. Meanwhile, the number of persons reported to be living with HIV in the state grew from **37,302** to **39,286** over the same period, an increase of 5.4%. New data analyses conducted in

## ESTIMATING THE SIZE OF CALIFORNIA'S IN-CARE HIV-POSITIVE POPULATION

Our project used a number of approaches to estimate the total number of persons with HIV in California who are aware of their HIV status and receiving care but are not included in the names-based system. This included applying estimates of the percentage of persons with HIV who are unaware of their HIV status; the percentage of persons with HIV who are not in care; and estimated numbers of backlogged cases which had been reported to county health departments but had not yet been followed-up and reported to the State Office of AIDS.

*The most problematic aspect of our task involved estimating the total number of persons living with HIV in California whose infection had not yet progressed to AIDS.* While case data on persons living with AIDS are relatively complete, it is difficult to estimate the number of persons living with non-AIDS HIV because we simply do not know how many of these individuals there are in the state. At least 20% of persons with HIV—and possibly many more—are unaware they have HIV, either because they have never undergone testing or because have not been tested since becoming HIV-infected. Other persons tested positive for HIV before the implementation of names-based reporting but have not accessed care since, which means that they are also not included in the names-based system, although this number is continually shrinking as people re-enter care due to illness.

Our task was complicated by the fact that the Los Angeles and San Francisco regions, which together include roughly half of all persons living with HIV and AIDS in the state, estimate a near-equal ratio of persons living with AIDS (PLWA) to persons living with non-AIDS HIV (PLWH). Nationwide, CDC data imply a ratio of roughly 1:1.6 PLWA to PLWH. However, because of the age of the epidemic in LA and San Francisco, many persons with HIV progressed to AIDS before anti-retroviral drugs became available in 1996. Thus, these two regions estimate a ratio of PLWA to PLWH at 1:1.1 in Los Angeles and 1:1.06 in San Francisco. This means that California's statewide ratio of persons PLWA to PLWH cannot be as high as 1:1.6, but must be somewhere between 1:1 and 1:1.6.

early 2011 by the State Office of AIDS comparing persons in the ADAP and ARIES databases to the statewide registry also found dramatic reductions in the number of individuals who are receiving state-funded care but might not be included in the statewide database.

**These factors all began to point to a robust HIV names-based registry system in which a relatively small number of persons with HIV in care are not included in the system in comparison to the total number of persons aware of their diagnosis and living with HIV in the state.** At the time of this writing, we estimate this total to be

significantly **less than 10,000 cases**, although difficulties in knowing the total number of persons with HIV and the total number of persons in care make it impossible to create a definitive estimate. This outcome speaks to our state's success in utilizing limited resources to ensure that California will be able to claim its fair share of federal dollars. It also speaks to the importance of continuing efforts to build the names-based registry by bringing persons with HIV who are out of care into the system and by identifying and linking to care HIV-infected persons who are currently unaware of their serostatus.

### 4 ISSUES AND RECOMMENDATIONS FOR THE HIV NAMES-BASED REPORTING SYSTEM

**The findings of our research do not mean that the system is without problems or barriers, or that there is not room for improvement.** Because of the scope and complexity of the reporting system, there are several key issues that have the potential to limit the quality and completeness of data or to result in unnecessary or duplicative efforts. Several federal policies also have the potential to reduce or diminish California's share of federal funding based on the population of persons with HIV and AIDS it is currently serving. The following section presents a summary of some of the most important of these issues, followed by proposed recommendations on possible ways to address them. It is important to note that any potential legislative, regulatory, or policy changes would need to be carefully evaluated to determine potential negative repercussions and to ensure that funding reallocations do not damage essential programs and services.

#### ISSUE #1: ELIMINATING DISTINCTIONS BETWEEN HIV AND AIDS IN SURVEILLANCE REPORTING

In the early years of the HIV epidemic, the distinction between an HIV diagnosis and an AIDS diagnosis was significant. In those years, before the development of advanced HIV treatment therapies, a person receiving a diagnosis of AIDS had little chance of ever returning to their pre-AIDS health status, or of having viral load or t-cell counts modified to pre-diagnosis levels. Maintaining separate reporting status for HIV and AIDS was a way of tracking the progression of the epidemic by drawing a distinction between persons with AIDS who were usually in advanced stages of HIV infection, versus persons with HIV in earlier stages of infection. This could also be helpful in planning and allocating resources because health care costs could be expected to be significantly higher for persons diagnosed with AIDS than for persons with HIV only.

*In the early years of the HIV epidemic, the distinction between an HIV diagnosis and an AIDS diagnosis was significant. However, because of changes in treatment, existing distinctions between HIV and AIDS in surveillance reports may no longer be meaningful enough to justify maintaining a separate reporting status.*

Over the past two decades, however, advances in HIV treatment therapies have dramatically altered and in many cases completely reversed that earlier paradigm. Today, antiretroviral medications can delay an AIDS diagnosis for decades. The cost of these medications has also narrowed the cost distinction between caring for persons with AIDS and caring for persons with non-AIDS HIV. An individual who has advanced far enough in their HIV infection to receive a formal diagnosis of AIDS can often have a very real expectation of returning to the health status they enjoyed in an earlier stage of HIV infection, possibly for many years or decades, and potentially with the chance of living a normal lifespan. In fact, a person living with AIDS can be as healthy as a person with non-AIDS HIV when they are receiving regular medications to help them maintain their health status. Often, receipt of an AIDS diagnosis reflects the fact that an individual has not been receiving regular HIV treatment, either because they have been unaware of their HIV status or because they have not sought recent care for their illness.

**For these reasons, existing prior distinctions between HIV and AIDS in HIV-related surveillance reports may no longer be meaningful enough to justify maintaining separate reporting status.** Statistics on the number of persons with AIDS versus HIV no longer tell us anything truly significant about these populations from a planning or cost perspective, since an AIDS diagnosis is no longer a reliable predictor of an individual's potential quality or length of life or treatment cost following a diagnosis. The distinction also does not provide a reliable barometer of the how the epidemic is progressing, since many persons living with AIDS would no longer meet the AIDS diagnosis criteria if entering care today, and because persons with HIV live for increasingly longer periods of time without progressing to AIDS.

Equally important in the context of this report is the fact that significant resources are continually being spent to reclassify persons with non-AIDS HIV when they receive an AIDS diagnosis. These resources might be better spent in conducting outreach, testing, and case follow-up to ensure

that the HIV case registry is as complete as possible, and that the registry reflects up-to-date data regarding the characteristics and health status of the HIV-infected population.

Instead of applying outmoded criteria for reporting disease status, we propose that surveillance specialists, planners, and policymakers work to develop new ways of reporting HIV infection that provide more meaningful and relevant information in helping plan and allocate resources and services. Surveillance reporting could be expanded to include already-accessible information such as total number of years since HIV diagnosis or HIV infection status of persons at the time they received their original HIV diagnosis. Reporting could also include information on cities or counties in which persons with HIV are receiving care, and how long they have been getting care there. Reporting could also track the course of HIV infection within specific sub-populations in order to track inequities in disease progression and to target resources to rectify these gaps.

*Instead of applying outmoded criteria for reporting disease status, we propose that surveillance specialists, planners, and policymakers work to develop new ways of reporting HIV infection that provide more meaningful and relevant information in helping plan and allocate resources and services.*

## RECOMMENDATIONS

- On a national basis, consider eliminating the outdated distinction between HIV and AIDS statuses in HIV-related surveillance reporting, both to reflect new medical realities and to better apply resources that are currently used for case reclassification.
- Create new and more relevant approaches to tracking the impact and progression of HIV in relation to specific populations, regions, and groups, such as information on length of time since original HIV diagnosis, status at time of diagnosis, and regions in which persons are receiving care and for how long.

## ISSUE #2: NEED FOR EXPANDED FUNDING FOR CASE FOLLOW-UP AT THE COUNTY LEVEL

When the HIV names-based reporting system was introduced in 2006, it created a significant mandate for expanded surveillance follow-up at the county level. However, the mandate was not accompanied by new long-term resources that would help counties carry out these tasks, forcing counties to use already-stretched resources to follow-up on newly

*A new infusion of resources would help counties follow up new HIV case reports and develop more effective systems for information and data sharing among local entities. Expending additional funds to support case follow-up at the county level would easily pay for itself in terms of new support for HIV care services.*

reported HIV cases. This situation has become more strained with continuing cuts to county surveillance systems, with some counties coping with backlogs of hundreds or even thousands of cases. A new infusion of resources would help counties follow up new HIV case reports and develop more effective systems for information and data sharing among local entities. Counties could use expanded case follow-up funds to hire additional staff, devote existing staff to HIV follow-up, or to utilize the services of a traveling team of specialists based at the State Office of AIDS who could support counties in conducting case follow-up for specific periods of time.

Expending additional funds to support case follow-up at the county level would easily pay for itself in terms of new support for HIV care services. The Los Angeles County Department of Health Services has estimated that the average cost for following up and verifying a new reported HIV case using county resources is approximately **\$992**. The estimated yield for the jurisdiction for that new case is upward of \$1,700 each year per additional case report.

#### **RECOMMENDATION**

- Expand funding for HIV case finding and report follow-up at the county level, and explore alternative methods for supporting and facilitating these services.

#### **ISSUE #3: LACK OF A CENTRALIZED CASE REPORTING SYSTEM IN CALIFORNIA**

Some states such as Oregon utilize a centralized statewide reporting structure in which potential new HIV cases are initially reported to a single statewide hub before being sent to individual counties for verification and follow-up. This system allows the state to eliminate many duplicated cases before they are followed up on by county health departments, thereby reducing the workload for individual counties. The size and scale of California, along with funding restrictions and political realities, make the creation of a single centralized HIV reporting system in our state impractical. However, some approaches could be implemented that might reduce at least some of the burden on individual counties through more cooperative approaches to case reporting and data sharing.

One such approach would involve giving local health jurisdictions limited access to the entire statewide HIV case registry to allow them to identify whether a newly reported local case had already been reported in another county. Such a process has already begun to be implemented for Los Angeles and San Francisco and might be possible for other jurisdictions as well. While case follow-up would still have to take place in most cases, such access would at least allow jurisdictions to prioritize follow-up for cases that appeared to be entirely new, accelerating the rate at which new cases were reported to the system. Appropriate firewalls could also be developed to ensure that local health jurisdictions were able to access only selected client identifier data so that information on other jurisdictions could not be accessed and so individual patient records could not be modified.

#### **RECOMMENDATION**

- Continue the process of giving local health jurisdictions in California limited access to the state HIV case registry for the purpose of examining whether a newly reported HIV case is already in the system.

*The size and scale of California, along with funding restrictions and political realities, make the creation of a single centralized HIV reporting system in our state impractical. However, giving local health jurisdictions limited access to the entire statewide HIV case registry to allow them to identify whether a newly reported local case had already been reported in another county would allow jurisdictions to prioritize case follow-up and accelerate the rate at which new cases were reported to the system.*

#### **ISSUE #4: ADDRESSING THE GAP BETWEEN PRELIMINARY AND CONFIRMATORY RAPID HIV TEST RESULTS**

When a preliminary HIV positive rapid test result is received, it must be confirmed through a more scientifically accurate laboratory test before it can be formally reported to the names-based system. This process normally takes about a week, and clients must return to receive their test result in a one-on-one session.<sup>4</sup> At this session, the client is informed of the test results and an effort is made to link the client to care as rapidly as possible. At the same time, patient data is collected so that the case can be reported to the names-based registry.

Unfortunately, however, many persons who receive a preliminary HIV-positive rapid test result do not return to receive their confirmatory HIV test result. When this occurs, a full names report is not taken and the case is not reported to the local health department or the State Office of AIDS. If the individual does not enter care, the person may not be entered into the names-based system for many years. Additionally, it is not possible to confirm whether individuals who do not return for a confirmatory test have been linked to care. Non-linkage to care can lead to serious health complications and a greater chance of passing HIV on to others. Developing approaches to help address this gap could expand the comprehensiveness of the names-based reporting system while having important impacts on public health.

A new set of guidelines issued by the California Office of AIDS on October 13, 2010 attempted to bridge the gap between a confirmatory test result and linkage to care by recommending that patients could in some cases **be referred directly to a medical care and treatment site to receive their confirmatory HIV test.**<sup>5</sup> This would eliminate the step of obtaining a confirmatory test result before linking clients to care and could result in more rapid and reliable service connections. It could also reduce the costs associated with conducting confirmatory HIV tests at traditional testing venues, potentially freeing up funds for expanded testing and testing outreach. However, the approach could also open up a new gap in the HIV case registry, since some individuals might never report to the primary care site to receive their confirmatory test. Rigorous procedures will need to be in place to ensure that individuals are directly linked to clinics that can provide the confirmatory HIV test upon receipt of a preliminary positive HIV test result.

Another potential approach to addressing the gap between preliminary and confirmatory rapid test results would involve the creation of a **voluntary, confidential case registry for persons who receive a preliminary positive HIV rapid test, with information collected at the time of the preliminary test result.** Under state law, an individual with a preliminary HIV-positive test result cannot currently be reported to the local health officer or the Office of AIDS for the purposes of HIV surveillance. This means that providers now collect only a limited amount of client contact information at the time a preliminary positive test result is received—information such as address and phone number that is intended mainly to help providers locate clients if they do not return for their confirmatory test. The lack of more extensive client data limits agencies' ability to track or obtain information on persons who do not return for a confirmatory test. Creation of a voluntary, preliminary case reporting

system for persons who receive a preliminary positive test result could help address this problem. Through such a system, providers could seek consent from clients to collect and report a pre-determined set of client data at the time of the initial preliminary positive HIV result. This data would not have the same level of detail as the names-based report but would have more detail than is currently collected at the time of the preliminary result. If a client returned for a confirmatory test, this report would be discarded, since a full names-based form would be then completed. However, if a client did not return to receive a confirmatory HIV-positive test result, the preliminary result could be forwarded to the local health

*Creating a voluntary, confidential case registry for persons who receive a preliminary positive HIV rapid test, with information collected at the time of the preliminary test result, could help jurisdictions prioritize case follow up, improve care linkage, and help target resources more effectively.*

officer and the Office of AIDS to be entered into a new database separate from the names-based registry. Comparisons could be run to see if the person might already be included in the names-based registry. The system would also provide useful demographic data on persons who do not return for confirmatory tests, allowing resources to be targeted more effectively. The preliminary registry system could also give providers additional contact information to assist with case follow-up and tracking in an attempt to link the individual to care, including following-up with clients who are referred to primary care sites for their confirmatory HIV test.

An additional approach could involve rewarding HIV testing sites for increasing their return rate on confirmatory test results and/or for linking confirmed HIV-positive clients to care. Such rewards could take the form of discounted rates on HIV testing materials, or an added incentive payment. This approach is already being used in Los Angeles County to reward agencies for successfully linking a newly identified HIV positive client to care. Of course, in a time of diminished resources, any such expenses would need to be carefully evaluated and weighed against other needed programs or services.

## RECOMMENDATIONS

- Explore creating a new voluntary, confidential case registry containing detailed information on individuals at the time they receive a preliminary positive rapid HIV test result so that more extensive information is available on per-



sons who do not return to receive their confirmatory HIV test result.

- Consider developing new incentives to reward agencies that have high rates of return for confirmatory HIV test results or that document successful linkages to HIV care for HIV-positive individuals.

<sup>4</sup> In the case of a conventional, non-rapid test, no initial confirmatory result is given and the patient must return to receive their HIV test results approximately two weeks later.

<sup>5</sup> State of California Department of Public Health, Office of AIDS, *Guidance for HIV Confirmation Testing in HIV Testing Venues*, Memo by Michelle Roland, MD, Office of AIDS Director, Sacramento, CA, October 13, 2010.

### **ISSUE # 5: ADDRESSING FEDERAL AND STATE ISSUES IN HIV REPORTING AND ALLOCATIONS**

It has long been believed that many persons with HIV migrate to other states following receipt of an HIV diagnosis. Persons with HIV may migrate to receive better or more affordable HIV care, to be near family and friends, to live in a more supportive region, or for reasons totally unrelated to their HIV diagnosis, such as moving to a new location to take advantage of a job opportunity. Under current CDC policy, for purposes of HIV reporting, a confirmed diagnosis of HIV becomes **permanently assigned** to the specific jurisdiction in which the HIV diagnosis was first made. This means, for example, that if an individual first received a confirmatory HIV test result in a specific county in Nevada and then immediately moved to California to receive HIV care, that in-

*Under current CDC policy, for purposes of HIV reporting, a confirmed diagnosis of HIV becomes permanently assigned to the specific jurisdiction in which the HIV diagnosis was first made. According to the California Office of AIDS, many new HIV and AIDS cases reported to the CDC by California are not added to the statewide registry because they have already been previously diagnosed in another state.*

dividual would be perpetually listed in surveillance data as a Nevada HIV case, and the state and county would always continue to receive Ryan White formula funding for that case. The same applies to persons who receive an HIV diagnosis in one state and then later receive an AIDS diagnosis in another. In this case, the Ryan White funding associated with the case continues to reside in the state in which the original HIV diagnosis was first made, even though a more intensive level of care may be being provided in another

state. According to the California Office of AIDS, many new HIV and AIDS cases reported by California to the CDC are not added to the statewide registry because they have already been previously diagnosed in another state. The time and energy involved in tracing and reporting this high volume of cases represents a significant use of valuable time and resources at both the state and local level, while suggesting a potentially high degree of interstate migration by persons with HIV into California.

At the present time, no data are currently published at the national level that would allow us to estimate net interstate migration patterns of persons with HIV. While policymakers frequently assume that interstate migration balances itself out over time, there is no way to know if this is actually the case. It may be possible that some states receive a significantly higher number of persons with HIV migrating into their state to receive care than others. Such information would be useful in identifying service utilization trends among persons living with HIV and AIDS nationally.

At least **three** potential approaches could help address this issue at the federal level. The first involves CDC reporting. Because it already has the information, it would be extremely useful if the CDC published regular data on the **number of HIV cases that are not able to be included in each state's HIV database each year because they have already been previously diagnosed in another state.** This would help provide a clearer national picture of the interstate migration patterns of persons living with HIV. Inclusion of demographic data on factors such as ethnicity, gender, age, and transmission category related to these populations would give an even clearer picture of who is moving from state to state and why. Interpreting migration rates on a per capita basis for each state would help ascertain which states are absorbing a higher burden of care than the Ryan White Program is compensating them for. While the data would not be conclusive – since individuals could quickly move to other states – it would provide a useful snapshot of potential migration patterns in a given year. It could also help HIV service planners and providers anticipate new populations who may need care in their states over the coming months or years. Additionally, if it were found that state-to-state migration patterns roughly balanced themselves out on a per capita basis, then it would confirm that the current system of listing a case by original HIV diagnosis is indeed a good surrogate marker for current residence.

Another approach relates to access to the **CDC's national HIV case registry.** If it were possible for states or localities to have limited access to the national database in order to ascertain whether a new case identified in their state has

*It would be extremely useful if the CDC published regular data on the number of HIV cases that are not able to be included in each state's HIV database each year because they have already been previously diagnosed in another state. This would help provide a clearer national picture of the interstate migration patterns of persons living with HIV.*

already been diagnosed elsewhere, it could save a substantial amount of time and resources related to validating and reporting new HIV cases. While not all duplication could definitively be eliminated through this process, a significant percentage potentially could lead to significant cost savings for both states and local health jurisdictions.

Finally, it may be time to re-examine our longstanding policies related to the city and state of origin of HIV/AIDS cases. Because an HIV case stays in the original state in which the case was identified on a permanent basis—regardless of where a person receives care or receives an AIDS diagnosis—current CDC reporting does not give an accurate picture of the burden of HIV/AIDS care in each state, and does not tell us where persons are actually receiving care. This in turn creates inequities in formula-based federal HIV care funding because funding does not always go to the jurisdiction in which the individual is receiving care. Furthermore, the current system provides an unreliable model for predicting HIV infection risk in a given state or community, since assessing risk could be more accurately based on the number of persons presently living with HIV in a region who are capable of transmitting the virus to others, rather than on the region in which HIV was first diagnosed, which may or may not be the region in which the virus was initially contracted.

Ideally, the solution to this problem would be to create a system in which the CDC tracks and reports exactly where each individual is receiving care at a given point in time each year, in order to base prevention and care planning and funding on these realities. However, such a system would be highly burdensome and would require significant new resources along with continual cross-checking that could result in unreliable data. Basing federal funding on such a system could also result in dramatic resource fluctuations from year to year, which would put untenable burdens on local systems of care. A more practical approach at the CDC level might be to create a new **stratified reporting system** in which one set of data lists the state in which an individual first received an HIV diagnosis while another set of data lists the state in which an individual first received a diagnosis of AIDS. This would at least reflect some of the migration patterns of per-

sons with HIV without necessarily taking funding away from the original state in which an HIV case originated.

Similarly, at the level of the Ryan White Program, the policy of linking Part A and Part B formula funding to the original city and state in which an HIV and/or AIDS diagnosis was first made should also be reexamined. There is a significant question of fairness in relation to the policy of basing funding not on where individuals are currently receiving HIV care, but instead on the city and state of first HIV diagnosis. During the next reauthorization process—if such a reauthorization takes place—it may be useful to explore methods for awarding a **partial case credit** for persons diagnosed in another state or region who have been receiving care for a minimum number of years in a different location, without taking credit away from the original state or region in which the case was first diagnosed. Such an approach could help ensure a more equitable and effective use of resources to address the needs of persons currently in care. At the same time, the approach would recognize the difficulties that would be involved in following persons with HIV/AIDS on a short-term basis as they moved from state to state or region to region to receive care.

Meanwhile, at the state level, it would be extremely useful for the California Office of AIDS to regularly report statistical and demographic data on the population of persons with HIV who are reported to the CDC but are not entered into the registry because they have already been diagnosed in another state. According to the California Office of AIDS, these cases

*It may be time to re-examine our longstanding policies related to the city and state of origin of HIV/AIDS cases. Because an HIV case stays in the original state in which the case was identified on a permanent basis—regardless of where a person receives care or receives an AIDS diagnosis—current CDC reporting does not give an accurate picture of the burden of HIV/AIDS care in each state and does not tell us where persons are actually receiving care. This in turn creates inequities in formula-based federal HIV care funding because funding does not always go to the jurisdiction in which the individual is receiving care.*

are currently maintained in the statewide registry, where they are classified as “secondary ownership” cases. However, information about these secondary ownership cases is not currently included in statewide epidemiology reports. Providing regular reports on the scope and nature of this popula-

tion would allow providers and planners to track information on how many persons diagnosed with HIV elsewhere are entering California to receive care each year, and where they are going to receive care. The information would also reveal what these populations look like in terms of demographics such as age, gender, ethnicity, and transmission category, again in order to better allocate limited resources and plan for emerging populations. While not impacting Ryan White allocations to the state under current guidelines, this information would provide a clearer and more detailed picture of the total population of persons with HIV being served in California.

### RECOMMENDATIONS

- Request that the US Centers for Disease Control and Prevention—which maintains national HIV case data—publish annual data showing the number of reported HIV cases in each state that have been previously reported in another state, along with demographic data on these populations and per capita calculations to assess relative impact.
- Allow limited access by states to the national CDC database in order to ascertain whether a new case has already been reported in another state, in turn reducing time and energy spent validating and reporting new HIV cases.
- If the current distinction between AIDS and HIV is maintained, consider modifying CDC reporting to separately list state of origin for HIV cases and state of origin for diagnosed AIDS cases, and consider providing updates to states when an individual shifts from being an HIV to an AIDS case.
- Propose introducing a new tiered provision in formula-based federal HIV funding which would to some degree take into consideration the current state in which an individual is receiving long-term HIV care.
- Expand surveillance reporting by the California Office of AIDS to include separate data on people who have received an HIV or AIDS diagnosis in California and are currently receiving care in the state but who are classified as secondary cases and not currently included in statewide surveillance reports because they had previously been diagnosed with HIV in another state.

### ACKNOWLEDGMENTS

This report was conceived by Phil Curtis, Director of the Government Affairs Division at AIDS Project Los Angeles (APLA), who served as director of the project team; and by Dr. Arleen Leibowitz and Kevin Farrell, LCSW, of the UCLA Center for HIV Identification, Prevention, and Treatment Services (CHIPTS), who provided invaluable research, support, and review services related to the project. The report was researched and written by Robert Whirry, Program Development Consultant. The report was funded through generous support from the California HIV/AIDS Research Program (CHRP), Grant # RP08-LA-604.

Generous assistance was given during the report research and development process by the California Office of AIDS, whose staff provided continual feedback and support, and conducted essential research and information-gathering. Our special thanks go to Dr. Michelle Roland, Director of the California Office of AIDS; Dr. Karen Mark, Chief of the Office's HIV Surveillance, Research, and Evaluation Branch; and Steven Starr, Chief of the Office's Surveillance Section.

Key support in preparing this report was provided by Lisa Murawski of the California Legislative Analyst's Office, who prepared the original 2010 report which prompted our research. Douglas Frye, MD, MPH, Director of the Los Angeles County HIV Epidemiology Program, provided indispensable information in regard to the dynamics of the HIV reporting system and the issues facing local jurisdictions. Aaron Fox at AIDS Project Los Angeles provided additional project support and information. Nettie DeAugustine, Manager of the Preventive Health Bureau of the City of Long Beach Department of Health and Human Services helped give credibility to our initial research efforts by publicizing the project to the California Coalition of Local AIDS Directors (CCLAD).

Gabriel McGowan, Director of Communications at AIDS Project Los Angeles, coordinated design, printing and production of the report.

Our thanks also go to the many individuals who participated in project-related interviews and who responded to inquiries during the report development process.

# **APLA**

---

**AIDS Project  
Los Angeles**



**Funded through Generous Support from the California HIV/AIDS  
Research Program (CHRP), Grant #RP08-LA-604**