



NEW HOPE, NEW CHALLENGES
A PROFILE OF THE HIV/AIDS EPIDEMIC IN CALIFORNIA

SEPTEMBER

2000

NORTHERN CALIFORNIA GRANTMAKERS
AIDS TASK FORCE
AIDS PARTNERSHIP CALIFORNIA

EXECUTIVE SUMMARY

The new and enhanced drug therapies now available to treat HIV and AIDS continue to lead to widespread improvements in the quality and length of life of persons living with HIV and AIDS. This welcome development has given a renewed sense of hope and purpose to our efforts to combat the disease through treatment and research. At the same time, the very success of these medications has led to a decrease in our sense of urgency about the epidemic, reflected by a decrease in attention on the part of the public, the media, policymakers, and funders.

The HIV/AIDS epidemic in California, however, is far from over. Although the number of deaths from AIDS and the rate of new AIDS diagnosis has declined each year since 1995, the number of people living with AIDS in California has continued to increase steadily. Today, approximately **1 in every 7** Americans living with AIDS resides in California, and at least **44,900** Californians are living with AIDS. Researchers also believe that as many as **85,600** additional Californians may now be living with HIV.

Despite changes in the characteristics of groups affected by AIDS, the AIDS epidemic in California continues to have a disproportionate impact on **men who have sex with men**. Nearly **80%** of all adult California AIDS cases occur among men who have sex with men, including men who have sex with men and inject drugs, versus **53%** of all national cases. At the same time, **women** are being increasingly impacted by HIV and AIDS in California. While women made up just under **9%** of all persons diagnosed with AIDS in 1994, they made up **12%** of all Californians diagnosed with AIDS in 1999.

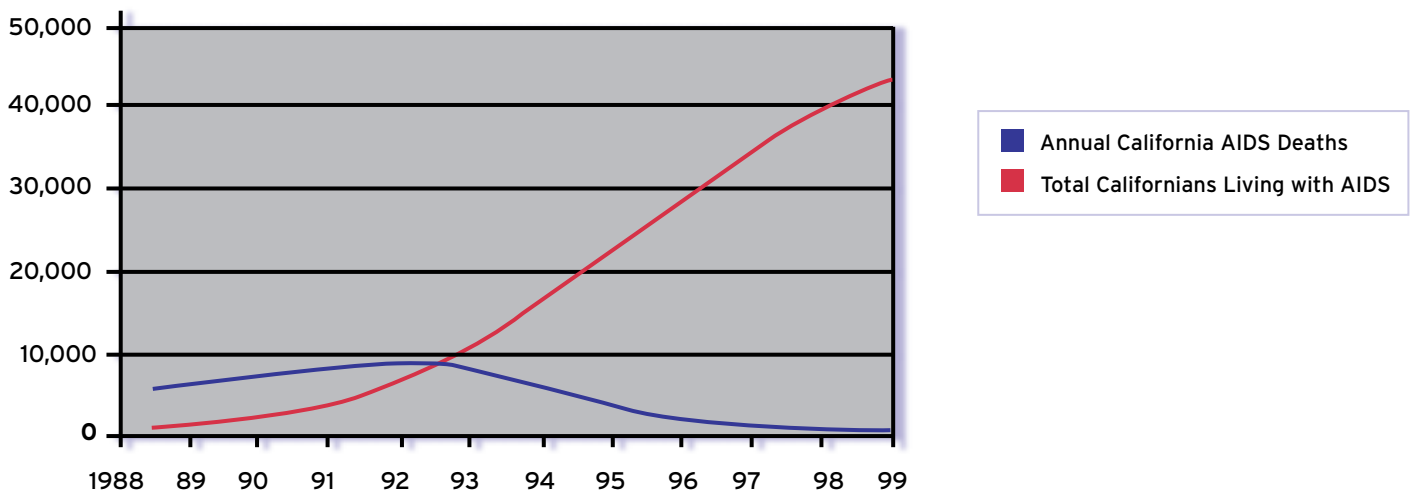
People of color in California are heavily impacted by the HIV/AIDS epidemic, and their proportion within the overall AIDS caseload is increasing. In 1988, people of color made up slightly less than **30%** of all new AIDS cases reported in California. But by 1999, the percentage had grown to **55%** of all new AIDS cases. Today, almost **20%** of all persons living with AIDS in California are African Americans, and **25%** are Latinos and Latinas. **African Americans** continue to be over-represented among persons living with AIDS compared to their numbers in the general population.

Even with the discouraging news regarding AIDS, there are still important opportunities to significantly reduce new cases of HIV infection. Today, it is being recognized that it is time for a dramatic change in our attitudes toward **primary prevention for persons living with HIV**. Growing numbers of men and women are living with HIV for a much longer timespan than previously, and are living healthier, more sexual lives in the process. Many need support and advice on how to discuss and maintain safe behavior with their partners. Previously, many prevention efforts have been either undifferentiated or focused on HIV-negative persons, and have not been directed specifically to prevention for persons living with HIV. It is of critical importance to support the development of prevention efforts that help meet the unique prevention needs of persons living with HIV, and that offer, sensitive, compassionate, and respectful interventions that give HIV-positive individuals the skills and support they need to enact and maintain the safest possible lifestyles for themselves and others.

THE CRISIS OF HIV/AIDS IN CALIFORNIA IS FAR FROM OVER

Although the number of deaths from AIDS and the rate of new AIDS diagnoses have declined each year since 1995, the number of people living with AIDS in California has continued to increase steadily. This is the case because people with AIDS are living much longer following their diagnosis, while thousands of additional new cases of AIDS continue to be diagnosed in California each year. (Fig. 1).

FIGURE I. Annual AIDS Deaths and Total Californians Living with AIDS, 1988 - 1999¹



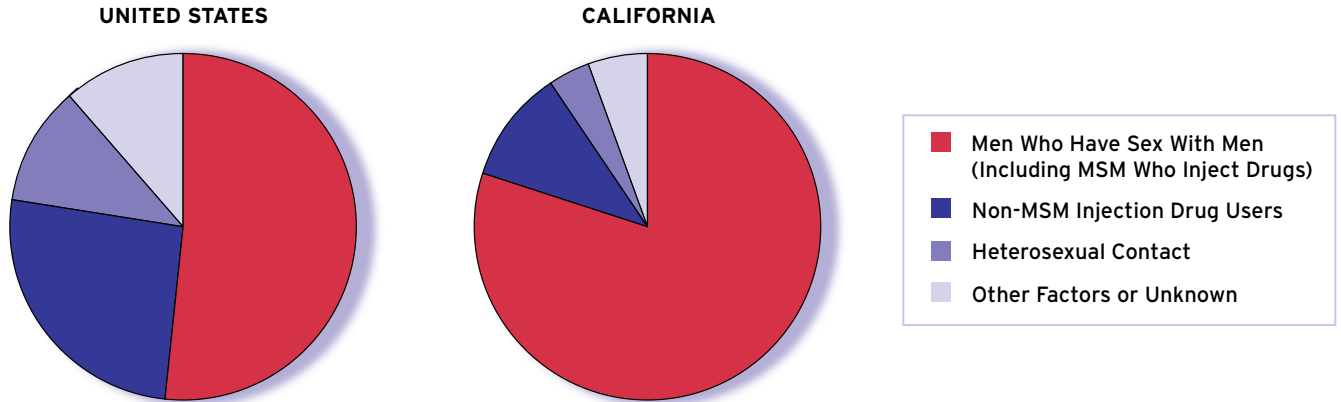
Approximately 1 in every 7 Americans living with AIDS resides in California. As of December 31, 1999, an estimated 44,900 Californians were living with AIDS, a number that represents just under 15% of the 299,994 Americans reported to be living with AIDS at the end of 1999. In 1999 alone, a total of 3,986 new AIDS cases were diagnosed in California.

The AIDS cases cited above do not include persons who have been infected with HIV, but have not been diagnosed with AIDS. A report issued by the State of California in late 1997 projected that as many as 130,500 Californians could already be living with HIV or AIDS. If this number were applied to California's current estimated population of 34.3 million, it would mean that approximately 1 in every 263 Californians is now living with HIV or AIDS.

Despite changes in the characteristics of groups affected by AIDS, the AIDS epidemic in California continues to have a disproportionate impact on men who have sex with men (MSM). As of December 31, 1999, nearly 80% of all adult California AIDS cases had occurred among men who have sex with men, including those who inject drugs. By contrast, these same groups made up only 53% of the cumulative national AIDS caseload by the end of 1999 (See Fig. 2 on following page).

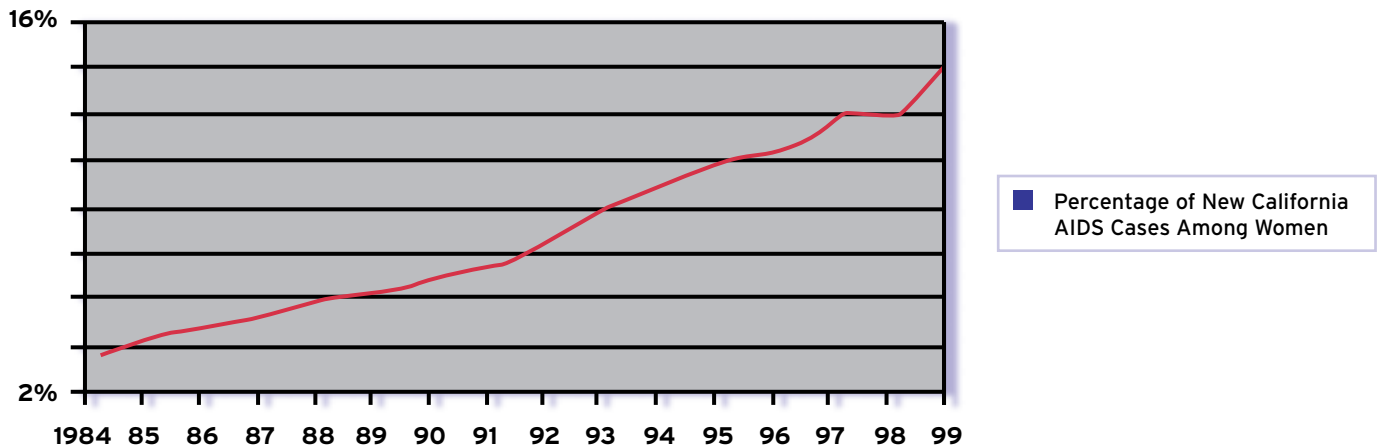
¹Source for all figures in this report: Office of AIDS, California Department of Health Services.

FIGURE 2. Comparison of Cumulative AIDS Cases in the U.S. and California by Transmission Category as of December 31, 1999



Women and young gay men in California are being increasingly impacted by HIV and AIDS. While women made up just under 9% of all persons diagnosed with AIDS in 1994, they made up 12% of all Californians diagnosed with AIDS in 1999 (Fig. 3). Meanwhile, a recent study of 425 gay men aged 18-29 in San Francisco found that 18% were already infected with HIV. In a survey of gay men aged 18-25 in three medium-sized West Coast communities, 43% of the sample reported having engaged in unprotected intercourse during the previous six months.

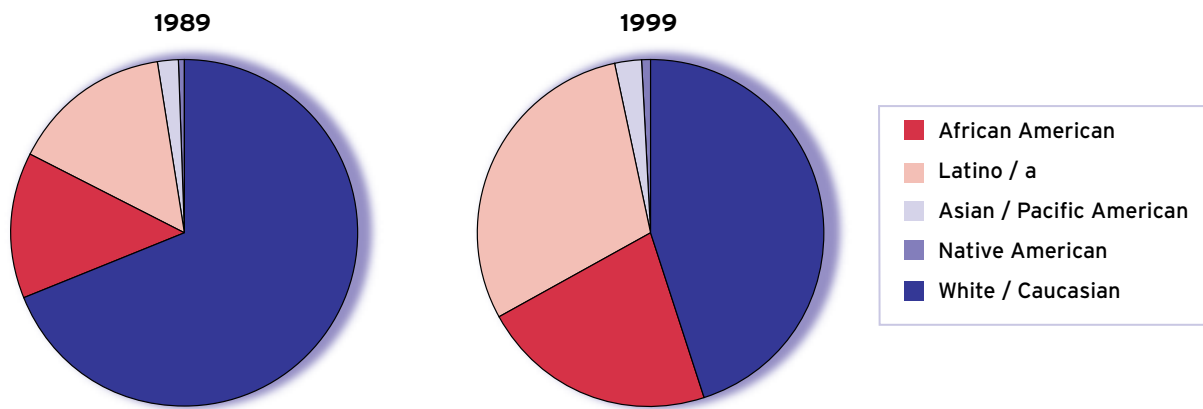
FIGURE 3. AIDS Cases Among Women as a Proportion of All Californians Diagnosed With AIDS, 1984 - 1999



HIV/AIDS IN CALIFORNIA: A GROWING CRISIS AMONG COMMUNITIES OF COLOR

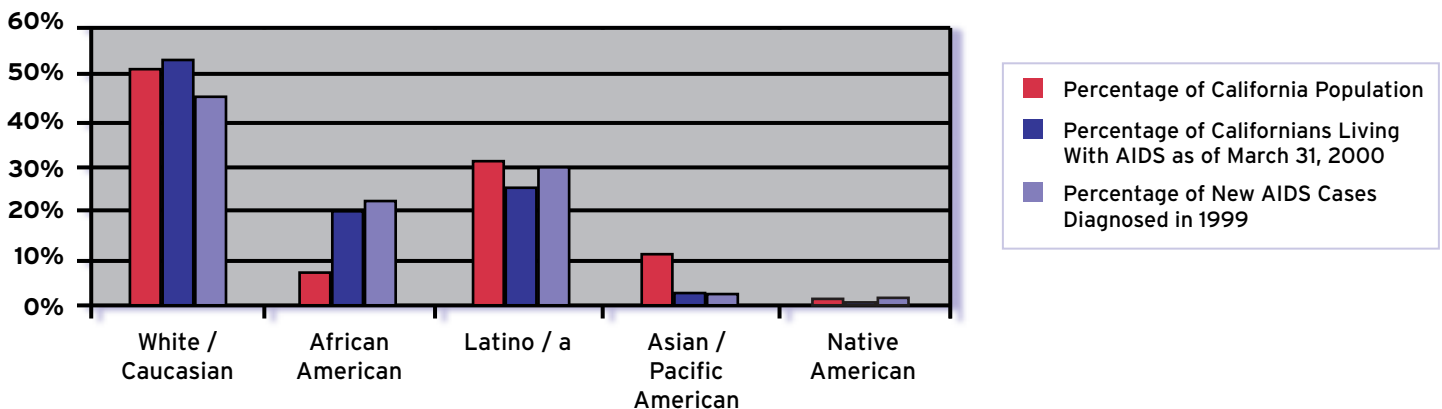
People of color in California continue to be heavily impacted by the HIV/AIDS epidemic, and their proportion within the overall AIDS caseload is increasing. In 1988, people of color made up less than 30% of all new AIDS cases reported that year. By 1999, the percentage had grown to 55% of all new AIDS cases (Fig. 4).

FIGURE 4. Comparison of New California AIDS Cases by Ethnicity, 1989 & 1999



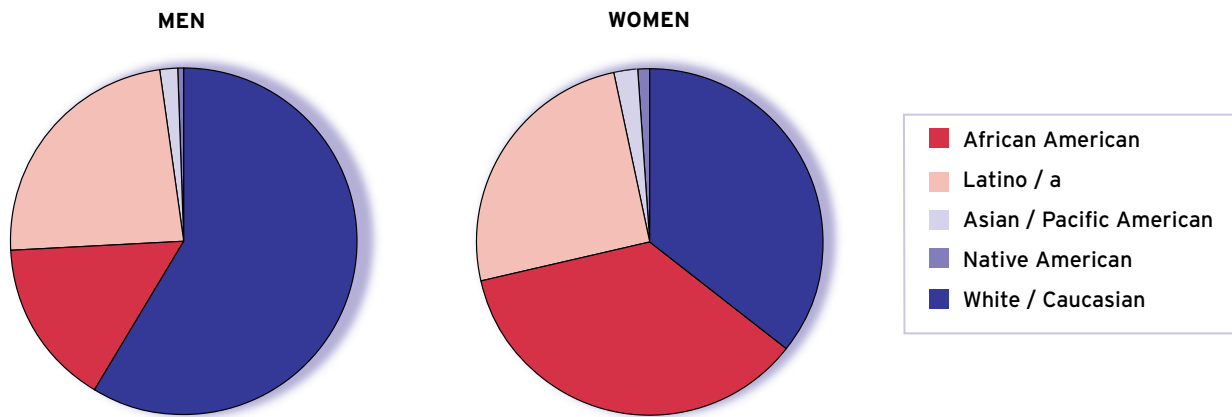
HIV/AIDS in California continues to have an expanding impact on African-American and Latino/Latina communities. Just under 20% of all persons living with AIDS in California as of March 31, 2000 were African Americans, while 25% were Latinos/Latinas. While most ethnic groups, including Latinos/Latinas, Asian/Pacific Americans, and Native Americans continue to be under-represented in relation to their numbers within the overall California population, African Americans are significantly over-represented in relation to the general population. At the same time, among those diagnosed with AIDS in 1999, the percentage of new Latino/a AIDS cases increased significantly, and became nearly equal to this group's proportion within the overall California population (Fig. 5).

FIGURE 5. Ethnic Distribution of Californians Living with AIDS as of December 31, 1999



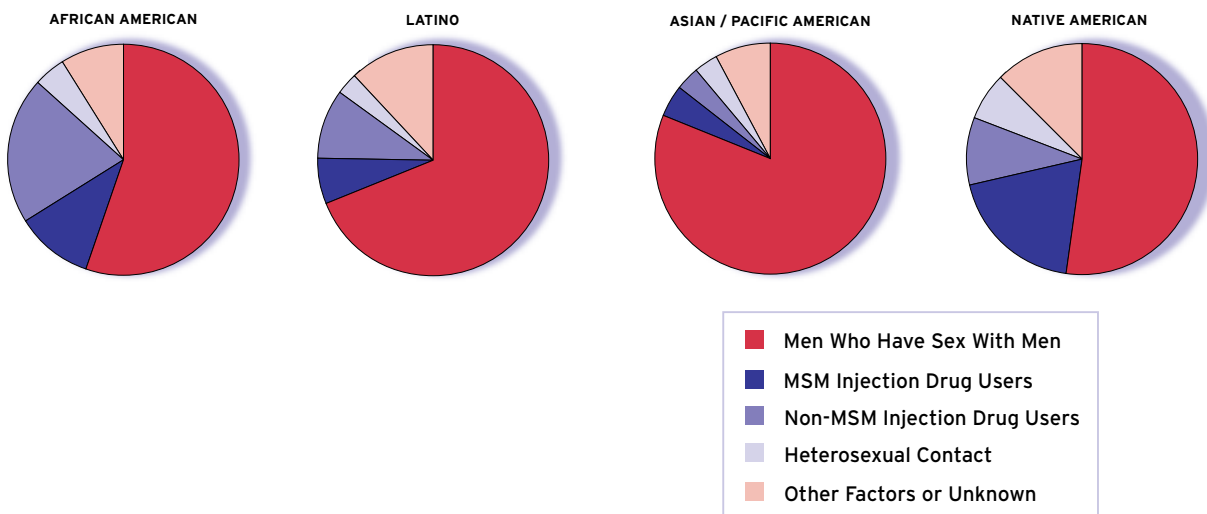
Women comprise a much greater percentage of people living with AIDS among African Americans compared to women in other ethnic groups. Fully 38% of all women living with AIDS in California are African Americans, versus only 17% of men (Fig. 6).

FIGURE 6. Ethnicity of Men and Women Living with AIDS in California as of March 31, 2000



It is vital to note that among all major ethnic minority groups in California—including African Americans, Latinos/Latinas, Asian/Pacific Americans, and Native Americans—men who have sex with men (MSM) continue to constitute the majority of males living with AIDS in each ethnic group. Among all Latino men living with AIDS as of March 31, 2000, for example, nearly 70% were infected with HIV through sex with another man, while nearly 80% of Asian/Pacific Americans had been infected through sex with another man (Fig. 7).

FIGURE 7. HIV Transmission Categories for Men of Color Living with AIDS in California as of March 31, 2000

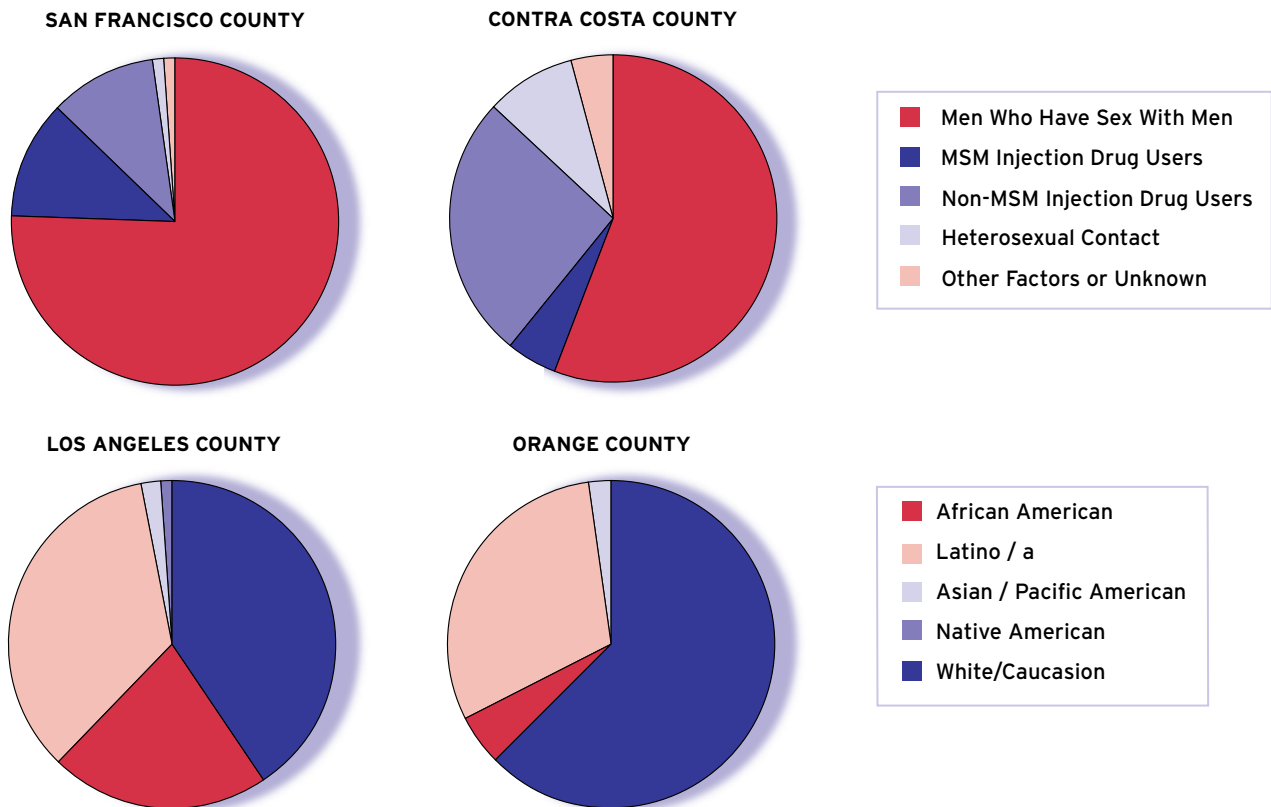


HIV/AIDS IN CALIFORNIA'S 58 COUNTIES: ONE STATE, MANY EPIDEMICS

Due to California's immense size and diversity, the incidence and demographics of HIV/AIDS can vary dramatically from county to county. This means that no one approach or system can apply to the entire state, and that each region or jurisdiction has distinct HIV service and prevention needs.

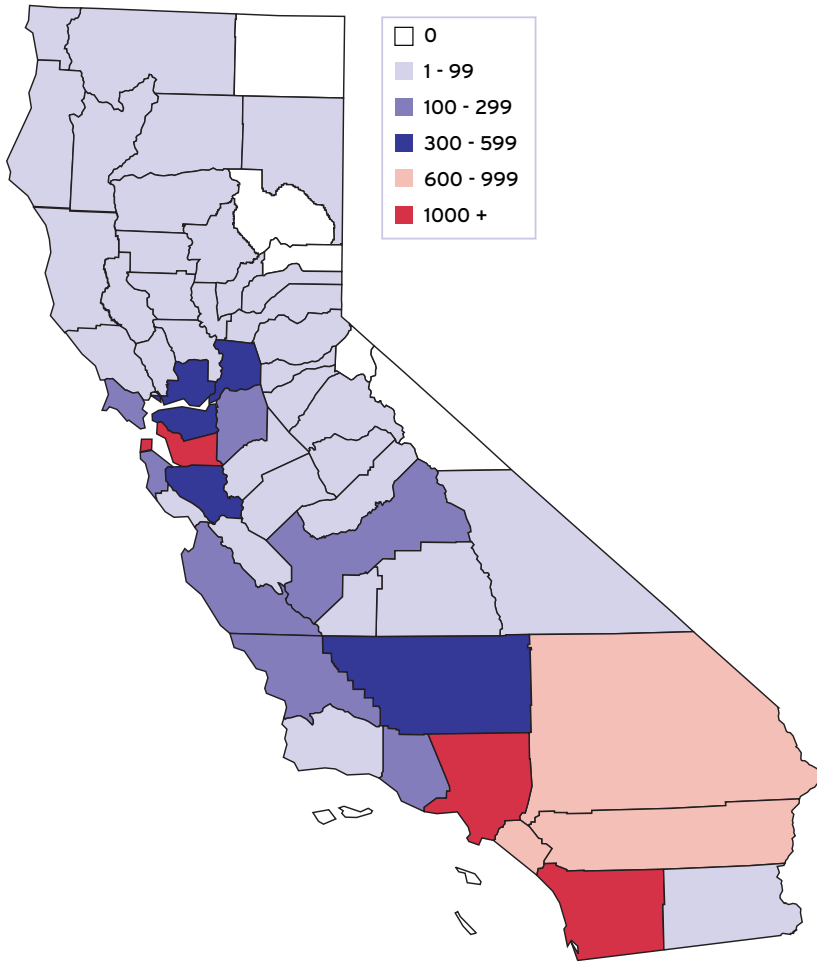
In San Francisco County, for example, approximately 80% of all adults living with AIDS as of March 31, 2000 were men who have sex with men—including those who inject drugs—while only 12% were persons who had become infected through injection drug use alone. Yet in Contra Costa County, located just across San Francisco Bay, only 61% of cases occurred among men who have sex with men - including those who inject drugs—while 26% of cases resulted from injection drug use alone, more than double the percentage in San Francisco. Meanwhile, in Los Angeles County, only 41% of persons living with AIDS as of March 31, 2000 were white, while in adjacent Orange County to the south, fully 61% of persons living with AIDS were white (Fig. 8).

FIGURE 8. Comparisons by County of Persons Living with AIDS by Transmission Category and Ethnicity as of March 31, 2000



The number and percentage of persons living with AIDS who are members of ethnic minority communities can also vary greatly from county to county throughout the state. The map on the following page shows the distribution of people of color living with AIDS in California's 58 counties (Fig. 9).

FIGURE 9. Number and Percentage of Persons of Color Living with AIDS in California's Counties as of Dec. 31, 1999



Of the 15 California counties in which more than 50% of their residents living with AIDS are persons of color, only five include more than 300 persons of color living with AIDS. These counties are listed below (Table 1).

TABLE I. AIDS Among Persons of Color in Five California Counties

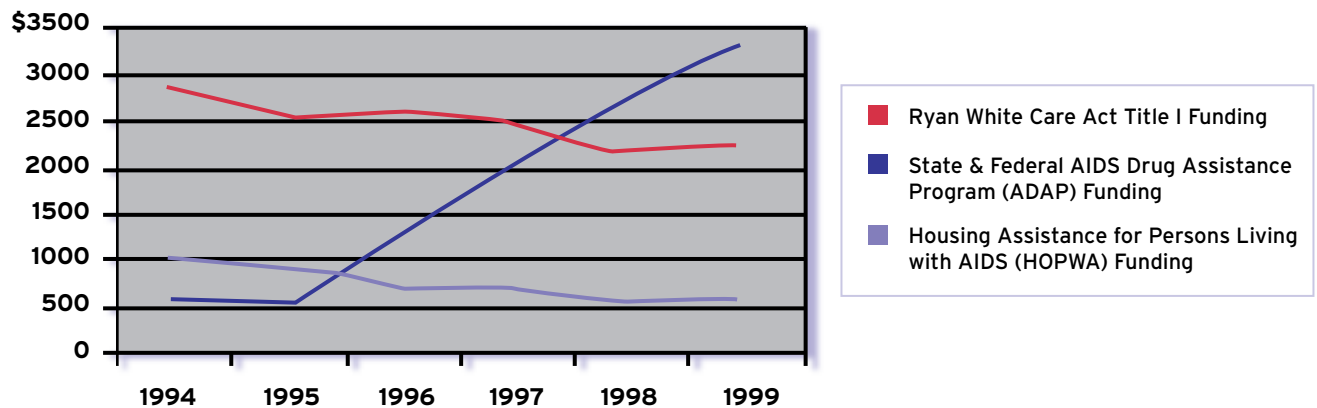
	Total Number of Persons of Color Living with AIDS as of December 31, 1999	Percentage of Persons Living with AIDS Who Are Persons of Color
Alameda County	1,220	61.4%
Kern County	302	59.6%
Los Angeles County	8,212	60.2%
San Bernardino County	673	56.9%
Solano County	348	63.9%

THE COST OF CARE: FINANCING HIV/AIDS IN CALIFORNIA

Federal and state dollars continue to constitute the primary source of support for HIV/AIDS care and treatment in California. Funds made available in the state through the Ryan White CARE Act totalled over **\$200 million** last year, with care allocations through the critical Title I program equaling just under **\$102 million** in 1999. Meanwhile, federal housing funds through the Housing Opportunities for Persons Living with AIDS program (HOPWA) provided almost **\$30 million** in support for Californians living with HIV and AIDS in 1999. Overall, these funding programs have been providing a gradually diminishing per capita allocation for persons living with AIDS over the last five years (Fig. 10).

Conversely, continuous growth in spending has occurred within the AIDS Drug Assistance Program (ADAP), a joint state and federal program that represents the primary source of funding for the expensive combination drug therapies that help low-income Californians with HIV and AIDS live longer and healthier lives. California ADAP funding grew by **over 700 percent** between 1994 and 1999, from a total of **\$17.5 million** in 1994—before the advanced combination therapies appeared—to **\$143.6 million** in 1999.

FIGURE 10. Comparison of Per Capita Title I, ADAP, and HOPWA Funding, 1994 - 1999



Even with new breakthroughs in HIV-related drug therapies, it is important to note that the overall **costs** of providing medical care and social services to persons living with AIDS **may not be decreasing as a result of these developments**. Combination therapies have led to heartening increases in both length and quality of life for persons living with HIV and AIDS. However, this means that there is an increasingly larger number of persons with HIV/AIDS in the state, many of whom require both medical and social services throughout their lives.

PRIMARY PREVENTION FOR PEOPLE LIVING WITH HIV: A MISSING LINK IN THE HIV PREVENTION SYSTEM

"Primary prevention for people living with HIV must become a priority on the prevention agenda. One positive person is involved in each case of HIV transmission, yet for far too long prevention providers and researchers have shied away from a focus on "prevention for positives". There is an urgent need - and sufficient expertise - to move forward with prevention campaigns focused on helping people living with HIV and AIDS avoid passing their infection along to others."

—From *"Designing Primary Prevention for People Living with HIV,"* AIDS Research Institute, University of California San Francisco and the National Association of People With AIDS.

From the earliest years of the HIV/AIDS epidemic, **two** parallel systems for confronting the epidemic emerged. The **HIV/AIDS care and service system** focused its attention on supporting and treating those persons living with HIV infection and AIDS, while the **HIV prevention system** focused its efforts mainly on those who were not yet infected with HIV.

This 'two-track' approach reflected the fact that for the first decade of the AIDS epidemic, HIV-related illness was extremely difficult to control. People living with AIDS frequently suffered through severe bouts of infection, and were assumed to need all their strength merely to focus on maintaining their health status. Meanwhile, the stigma and fear associated with HIV in the early years of the epidemic led to an environment in which the focus was placed on those who were not infected with HIV, rather than those who were already living with the virus.

But the two-track model of HIV prevention and care missed one critical point: namely, that every incident of new HIV infection involves one person who is already HIV-positive. In focusing our attention on preventing infection either among those who are HIV-negative or among the general public as a whole, our state and nation failed to develop effective programs and strategies to help encourage and promote safer behaviors among those already living with the AIDS virus.

Current funding for prevention for HIV-positive persons continues to reflect this persistent blind spot. Of the \$48 million in state and federal funds allocated for HIV prevention in California, only 9%—or about \$4.4 million - is specifically targeted to people living with HIV.

Today, however, it is recognized that it is time for a dramatic change in attitudes toward primary prevention for persons living with HIV. Growing numbers of men and women are living with HIV for a much longer timespan, and are living healthier, more sexual lives in the process. Many are beginning to consider and explore the possibility of new intimate relationships for the first time in many years, and need support and advice on how to discuss and maintain safe behavior with their partners. New evidence is also beginning to point to an increase in sexual risk-taking among both HIV-positive and HIV-negative persons.

As noted in a recent report published by the Mission Neighborhood Health Center in San Francisco, "a fulfilling, active sex life is as important to HIV-positive persons as it is to HIV-negative persons." **It is critically important to support the development of prevention efforts that help meet the unique prevention needs of persons living with HIV, and that offer, sensitive, compassionate, and respectful interventions that give HIV-positive individuals the skills and support they need to enact and maintain the safest possible lifestyles for themselves and others.**

RESOURCES FOR HIV/AIDS FUNDERS AND PROVIDERS

AIDS Partnership California at Northern California Grantmakers

AIDS Partnership California is a statewide public/private collaboration supporting grantmaking, organizational capacity-building for persons of color agencies, and private funder education. (877) 624-2755, (510) 272-9448 or apc@ncg.org.

California AIDS Hotline

The hotline provides general HIV/AIDS information and referrals to services. English/Spanish/Filipino: (800) 367-2437 or TDD: (888) 225-2437

California Department of Health Services Office of AIDS

The Office provides both in-person and web-based support, resources, and information for public and private organizations involved or interested in HIV/AIDS prevention and care issues. (916) 445-0553 or www.dhs.ca.gov/aids

Funders Concerned About AIDS (FCAA)

FCAA is a philanthropic affinity group of the Council on Foundations whose mission is to mobilize organized philanthropic resources and leadership, domestically and internationally, to eradicate the HIV/AIDS pandemic and address its social and economic consequences. (212) 573-5533.

HIV InSite Website

Sponsored by the AIDS Research Institute at the University of California at San Francisco. The website's areas include medical information, prevention and education, social issues, community and research resources, and international issues. www.hivinsite.ucsf.edu

Kaiser Daily HIV/AIDS Report

A web-based information service of the Kaiser Health Information Network, sponsored by the Henry J. Kaiser Family Foundation. The Daily Report and its related updates provide a summary of both domestic and international HIV/AIDS prevention and care issues. Subscribe at <http://report.kff.org/hivaids/>

Workplace Resource Center Website

Sponsored by the National AIDS Fund. This website provides practical tools for both employers and employees who are dealing with HIV in the workplace. www.aidsfund.org



AIDS PARTNERSHIP CALIFORNIA: A NEW APPROACH TO PREVENTION FUNDING AND CAPACITY- BUILDING FOR COMMUNITIES OF COLOR ORGANIZATIONS

In order to create a viable new option for addressing the continuing crisis of HIV infection among HIV-infected communities of color in California, Northern California Grantmakers launched an innovative new program in July 2000 called AIDS Partnership California. **AIDS Partnership California** is a statewide initiative funded jointly by the Northern California Grantmakers AIDS Task Force, the California State Office of AIDS, and a variety of California foundation and corporate funders.

One of the central purposes of AIDS Partnership California is to award a series of innovative grants to community-based ethnic minority organizations to support HIV prevention services for HIV-positive persons of color. While these grants are important because they support innovative new prevention interventions, what is more unique is that grants are awarded through a private/public partnership that incorporates the State Office of AIDS and a variety of California foundation and corporate funders. AIDS Partnership California tests a groundbreaking model of public/private cooperation that helps sustain and foster expanded HIV/AIDS grantmaking statewide.

A further important function of AIDS Partnership California is its emphasis on building the capacity of community-based people of color organizations to seek private funding for HIV/AIDS. The Partnership sponsors a series of workshops through which ethnic minority agencies receive training in areas such as funder relations, program planning, and evaluation. Capacity-building grants are awarded to the program's grantee agencies. In addition, the program works to increase the effectiveness of HIV grantmaking by providing information and technical assistance that enhances the quality of HIV prevention grantmaking by California's private foundation and corporate funders.

If you are interested in additional information regarding AIDS Partnership California or in exploring the possibility of participation in the program, please feel free to contact AIDS Partnership California.

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NORTHERN CALIFORNIA GRANTMAKERS AIDS TASK FORCE

The Northern California Grantmakers AIDS Task Force (ATF) is a unique coalition of concerned foundation and corporate funders formed in 1988 to address the crisis of HIV/AIDS in the San Francisco Bay Area through focused grantmaking. Since its founding, the ATF has awarded over 270 grants totaling \$7.8 million, benefiting the lives of many thousands of Bay Area residents at risk for HIV infection, as well as those living with HIV.

Grantmaking by the ATF has spanned a wide range of areas: prevention, prevention research, care and treatment, public policy, training, strategic restructuring, and an African American Communities Initiative. These grants have improved care, treatment, and the quality of life for persons with HIV; prevented countless new HIV infections; fought AIDS discrimination; and helped to encourage state and federal government to increase AIDS expenditures by billions of dollars. The ATF has achieved these outcomes by successfully pooling creative and flexible dollars to meet the needs that the public sector has been unable—or unwilling—to meet

Current Members of the AIDS Task Force:

Academy of Friends	Walter and Elise Haas Fund
Atkinson Foundation	The Luke B. Hancock Foundation
The California Endowment	The William and Flora Hewlett Foundation
The California HealthCare Foundation	The Henry J. Kaiser Family Foundation
The California Wellness Foundation	Kaiser Permanente
Columbia Foundation	Marin Community Foundation
Community Foundation Silicon Valley	The National AIDS Fund
Compton Foundation, Inc.	The Bernard Osher Foundation
East Bay Community Foundation	Peninsula Community Foundation
Elton John AIDS Foundation	The San Francisco Foundation
The Gap Foundation	Charles & Helen Schwab Family Foundation
The Fred Gellert Family Foundation	Levi Strauss Foundation
The Wallace Alexander Gerbode Foundation	Wayne and Gladys Valley Foundation
Richard and Rhoda Goldman Fund	Wallis Foundation
Evelyn and Walter Haas, Jr. Fund	van Loben Sels Foundation
Miriam and Peter Haas Fund	

The HIV/AIDS Epidemic in California

