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Report to the Chairman, Committee on Labor and Human Resources, and the Honorable Hank Brown, U.S. Senate

January 1995

RYAN WHITE CARE ACT

Access to Services by Minorities, Women, and Substance Abusers

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Human Services Division

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January 13, 1995

The Honorable Nancy Kassebaum
Chairman
Committee on Labor and Human Resources
United States Senate

The Honorable Hank Brown
United States Senate

The acquired immunodeficiency syndrome (AIDS) epidemic, in its second decade, continues to escalate at an alarming rate. AIDS is the second leading cause of death for men between ages 25 and 44 and the fourth leading cause of death for women in that age group. Since the first cases were identified in 1981, more than 400,000 people in the United States have been diagnosed with AIDS. Furthermore, as many as 1 million people in the nation may be infected with the human immunodeficiency virus (HIV), which causes AIDS.

AIDS is affecting minorities, women, and injection drug users (IDU) at an increasing rate. As of September 1989, African-Americans and Hispanics accounted for 43 percent of cumulative AIDS cases, women for 10 percent, and IDUs for 21 percent. From July 1993 through June 1994, the distribution of newly reported AIDS cases was 56 percent African-American and Hispanic, 17 percent women, and 28 percent IDUs.

The African-American and Hispanic communities have been particularly hard hit. These communities are disproportionately affected by the AIDS epidemic. African-Americans represent 12 percent of the nation's population but account for 32 percent of the cumulative AIDS cases as of June 1994. Similarly, while Hispanics account for 9 percent of the population, 17 percent of the cumulative AIDS cases affect Hispanics. Concerns have been raised whether all these affected populations have been receiving needed HIV services.

This report responds to your request that we determine the extent to which HIV-infected populations, such as African-Americans, Hispanics, women, and IDUs, receive medical and support services funded by the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990.[1] Because there are no national data to address this issue, we visited five

[1]Support services include but are not limited to case management, counseling, financial assistance, and transportation.

locations—Baltimore, Denver, Los Angeles, Sacramento, and the Maryland suburbs of Washington, D.C. We chose sites on the basis of varying size and demographics of their HIV-infected populations, how long they have been receiving Ryan White CARE Act funding, and the amount of funding. At these locations, we interviewed program administrators and reviewed incidence and utilization data provided by them. We also interviewed Ryan White CARE Act-funded service providers and advocates for HIV-infected people. Additionally, we discussed this issue with national HIV/AIDS organizations and officials of the Department of Health and Human Services' Health Resources and Services Administration (HRSA). (See app. I for our objective, scope, and methodology.)

Results in Brief

We found that minorities, women, and IDUs generally use services at a rate that reflect their representation in the HIV-infected population in the five locations. Medical and support services providers and advocates of HIV-infected people told us that this corresponds to their experience of the usage of Ryan White CARE Act-funded services. These providers and advocates also said, however, that barriers exist that may limit access to services to certain groups.

Background

The Ryan White CARE Act of 1990 (P.L. 101-381) was enacted to improve the quality and availability of medical and support services for individuals and families with HIV disease. For fiscal year 1994, 34 eligible metropolitan areas (EMA)[2] received $320 million under title I of the act; the 54 states and territories received $162.7 million under title II of the act.

EMAs award Ryan White CARE Act title I funds to providers of medical and support services. These providers include hospitals, ambulatory care facilities, community health centers, community-based organizations, and hospices, among others. Ryan White CARE Act funds cannot be used for in-patient care but can be used for in-patient case management services that expedite hospital discharge.

States and territories use title II funds to establish and operate HIV care consortia that provide services to HIV-infected individuals and their families. A consortium is an association of one or more public and nonprofit service providers operating in areas determined by the state to be most affected by HIV disease. The consortium uses the funds to plan,

[2]To be eligible for funding, metropolitan areas must have a total of more than 2,000 AIDS cases or a per capita incidence of 25 cumulative AIDS cases for every 100,000 people in the population.

develop, and deliver medical and support services. In addition to funding consortia, states use title II funds to provide HIV-infected people with home and community-based care services, continuity of health insurance coverage, and prescription drugs such as antiviral medications.

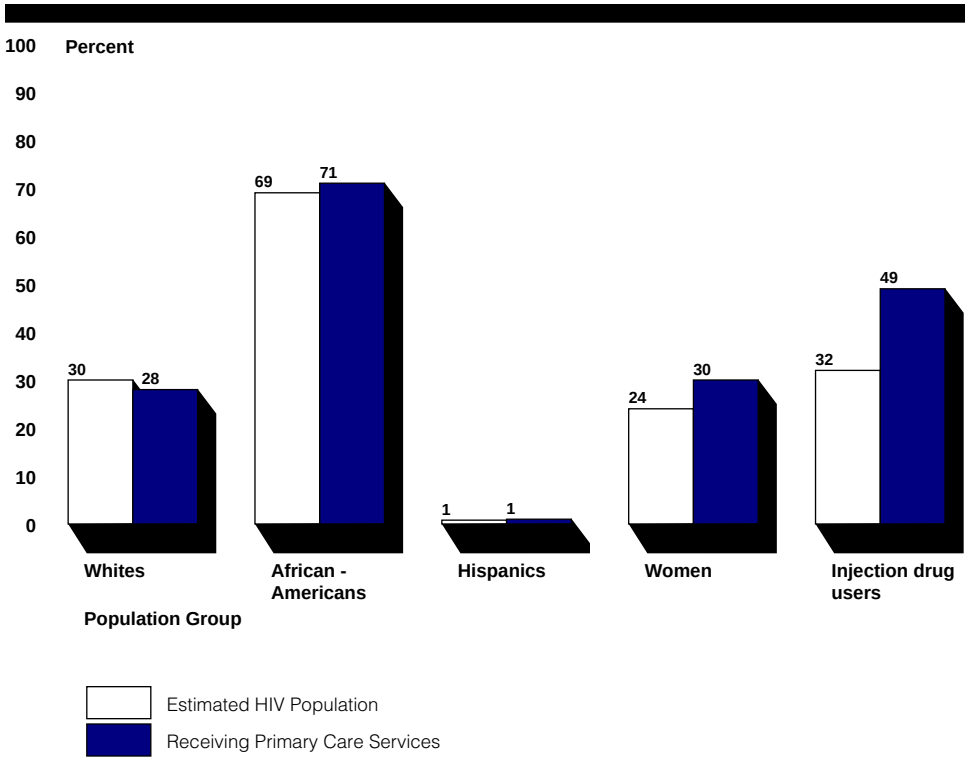
HRSA's Division of HIV Services is responsible for awarding and monitoring title I and II grants. One-half of title I funds and all of title II funds are awarded on the basis of legislated formulas. EMAs apply to HRSA for additional or supplemental funding. HRSA requires that EMAs, in their applications, describe activities directed toward community-based and minority service providers that would improve access to care for low-income and underserved populations. Project officers monitor grantees' compliance with requirements and progress in serving affected groups. HRSA also offers technical assistance, such as organizational development and capacity building in underserved communities, to the grantees through the project officers and a contractor.

Minorities, Women, and IDUs Are Receiving Ryan White Services

At the five locations we visited, minorities, women, and IDUs appear to access Ryan White CARE Act-funded medical and support services generally in similar or somewhat greater proportion than their representation in the HIV-infected population.[3] In a few instances, some subpopulations used fewer services. For example, in Los Angeles, Hispanics accounted for 23 percent of the estimated HIV-infected population but used 13 percent of drug abuse treatment services during the 3-month period we analyzed. To illustrate the use of services, figure 1 shows that the use of primary care services in Baltimore is generally in proportion to or slightly higher than the estimated HIV-infected population. (See app. II for the distribution of other services we analyzed in the five locations.)

[3]At some locations, some service providers did not report one or more client characteristic, such as gender or risk group. In those locations, we could not compare all population and client characteristics.

Figure 1: Distribution of CARE Act-Funded Primary Care Services in the Baltimore EMA
(January-March 1994)



Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, primary care services providers received 40.6 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 839 primary care visits were conducted.

We also sought views on access from advocates for HIV-infected people and medical and support service providers located in the five areas we studied. We selected advocates and providers representing and serving various populations, including minorities, women, and IDUs. The advocates and providers affirmed that affected groups generally accessed services in proportion to their representation in the HIV-infected population.

Several Barriers May Limit Access to Services

Use rates of CARE Act-funded services may not fully explain access to services. Providers and advocates told us about many barriers to access that in their view are particularly difficult to overcome. HIV-infected people often have other priorities and pressing needs that may affect the extent to which they seek HIV- related care. Substance abuse and homelessness, among other barriers, were mentioned as affecting the extent to which HIV/AIDS- infected people seek services.

In some instances, lack of knowledge about and lack of motivation to seek services affect the extent to which some people use services. Additionally, the advocates and providers told us of other barriers, including a lack of trust of the medical community, denial of the disease by some HIV-infected people, and a reluctance to obtain care from a provider of a certain racial or ethnic group or who primarily serves a different racial or ethnic group than that of the person seeking services. As agreed, we did not try to determine the extent to which these barriers limit access to services.

We discussed our findings with officials of HRSA's AIDS Program Office, the Division of HIV Services, and the Office of Science and Epidemiology. They generally agreed with our findings, and we incorporated their suggestions where appropriate.

We are sending copies of this report to the Secretary of Health and Human Services; the Assistant Secretary for Health; the Administrator, Health Resources and Services Administration; and other interested parties. We will make copies available to others on request.

If you or your staff have any questions about this report, please call me at (202) 512-7119 or Bruce D. Layton, Assistant Director, at (202) 512-6837. Other contributors to this report include Roy Hogberg, Howard Cott, Marie DeCocker, and Mark Vinkenes.

Mark V. Nadel
Associate Director
National and Public Health Issues

Contents

Abbreviations

AIDS	acquired immunodeficiency syndrome
CARE	Comprehensive AIDS Resources Emergency
EMA	eligible metropolitan area
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
IDU	injection drug user

Objective, Scope, and Methodology

Our objective was to determine the extent to which selected human immunodeficiency virus- (HIV) infected subpopulations, that is, African-Americans, Hispanics, women, and injection drug users (IDU) were receiving services in proportion to their representation in their areas' HIV-infected populations. To conduct our study, we visited five locations: Baltimore, Denver, and Los Angeles eligible metropolitan areas (EMA); the Sacramento, California, Consortium; and the Suburban Maryland HIV Consortium (serving the Maryland suburbs of Washington, D.C.). We chose sites on the basis of varying size and demographics of HIV-infected population, how long they have been receiving Ryan White CARE Act funding, and the amount of funding. We cannot generalize the results of our work to all Ryan White CARE Act-funded EMAs and consortia.

To determine the extent to which HIV-infected populations were being served, we compared the estimated HIV-infected population at each site with service provider reports of clients served. The estimates and reports identified such characteristics as race/ethnicity, gender, and mode of HIV transmission. Each EMA estimated its own HIV-infected population. The consortia did not have the estimated HIV-infected population for their areas so we used reported AIDS cases for our analysis.

At each location, we reviewed one or more medical or support service funded by the Ryan White CARE Act. For each EMA and consortium, we selected the top priority services they identified. We did this by choosing those services that cumulatively accounted for about half of the funds as estimated by the EMAs and consortia. The percent of funding accounted for ranged from 41.3 percent in Denver to 69.9 percent in Baltimore. Using this method for selecting services, the number of services we used for analysis varied from one service in Sacramento to seven services in Baltimore. For Denver and Los Angeles, we identified three services and, for Suburban Maryland, we identified two.[4]

For the identified services, we obtained data on the characteristics of clients served by Ryan White CARE Act-funded providers. We obtained the data from provider-generated reports to the EMA or consortia. The data were generally for a 3-month period but, since reporting requirements varied at the EMAs and consortia, reporting periods were not consistent across locations. Table I.1 shows the services and reporting periods for each location.

[4]In Denver, we identified three services—primary care, case management, and dental care—that comprised about 50 percent of projected 1994 title I funds. However, because Denver's dental care program was in a developmental stage, the small number of clients did not allow us to analyze client characteristics.

Table I.1: Services and Reporting Period Used in Analysis of Clients Served

Location	Services	Reporting periods
Baltimore	Primary care	January - March 1994
	Financial vouchers Mental health Housing services Counseling Case management Transportation	April - June 1994
Denver	Primary care Case management	July - September 1994 June - August 1994
Los Angeles	Primary care	July 1993 - June 1994
	Substance abuse treatment Case management	January - March 1994
Sacramento	Case management	July - September 1992
Suburban Maryland	Primary care Case management Mental health	May - August 1994

Using the estimated HIV-infected populations or reported AIDS cases and the client demographics, we compared the population and client characteristics to determine the extent to which the HIV-infected populations were receiving medical and support services.

At each location, we also interviewed service providers who received Ryan White CARE Act funds for 1994 or advocacy groups. We discussed their views on our interpretation of the data, comparing HIV-infected populations with clients served as well as barriers that may limit access to HIV-related medical and support services. Table I.2 shows the providers and advocates we interviewed at each location.

Table I.2: Providers and Advocates Interviewed

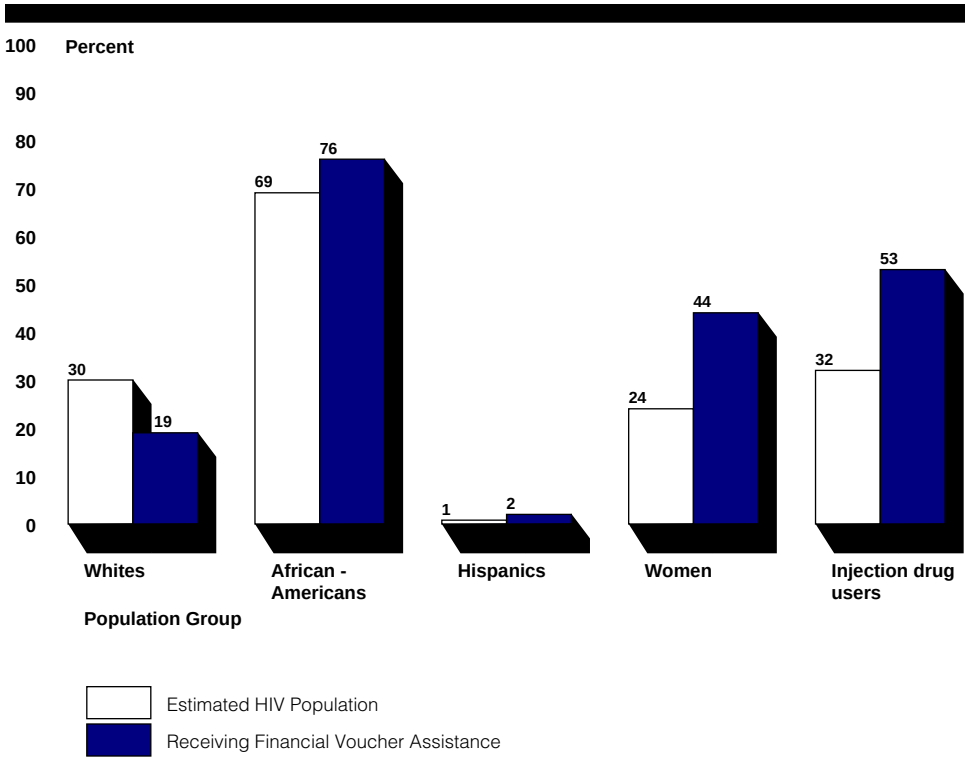
Location	Provider or advocate
Baltimore	Chase Brexton Clinic AIDS Action Baltimore HERO (Health Education Resource Organization)
Denver	Colorado AIDS Project Empowerment Program People of Color Consortium Against AIDS Denver Indian Health and Family Services Urban League of Metro Denver Denver Department of Health and Hospitals Children's Hospital Dental Clinic
Los Angeles	AIDS Health Care Foundation Drew University of Medicine and Science - HIV Cochair of Women's Caucus of Los Angeles AIDS Regional Board
Sacramento	Women's Civic Improvement Club Sacramento AIDS Foundation
Suburban Maryland	Black Women's Health Council Greater Baden Health Clinic

To get a broader perspective about access to services, we discussed access to services with two organizations—the National Minority AIDS Council and AIDS Action Council. We also discussed our analysis with officials of Health Resources and Services Administration's Division of HIV Services.

We conducted our work from June through December 1994 in accordance with generally accepted government auditing standards.

Use of Certain Ryan White CARE Act-Funded Services in Five Locations

Figure II.1: Distribution of CARE Act-Funded Financial Voucher Services in the Baltimore EMA
(April-June 1994)



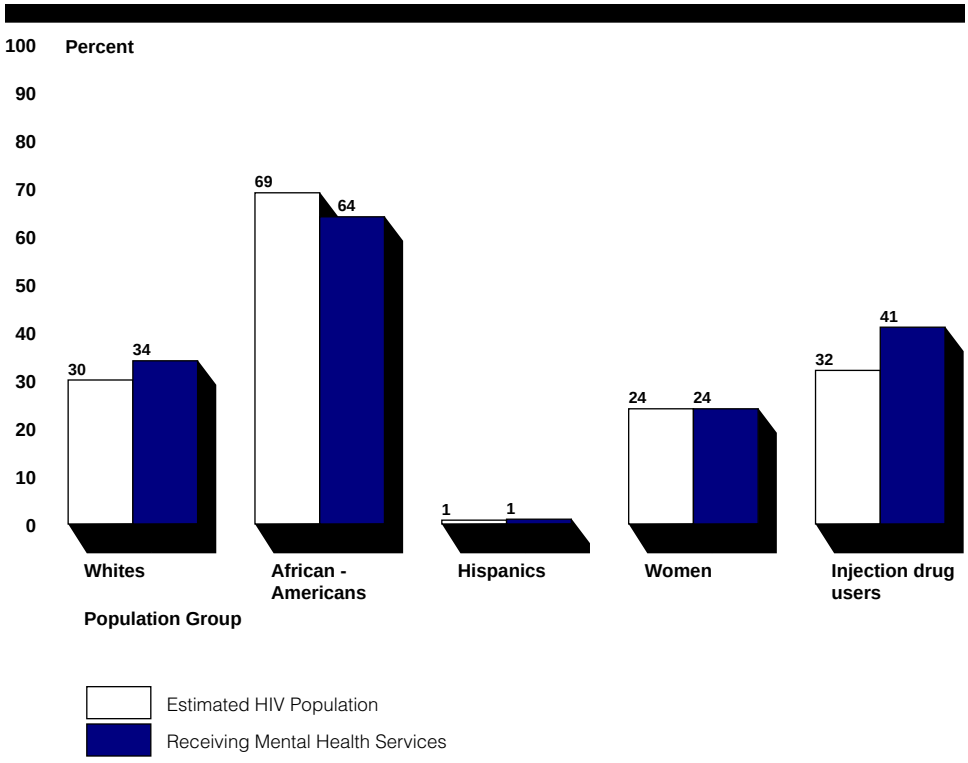
Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, financial voucher services providers received 10.2 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 937 financial vouchers were provided.

Figure II.2: Distribution of CARE Act-Funded Mental Health Services in the Baltimore EMA (April-June 1994)



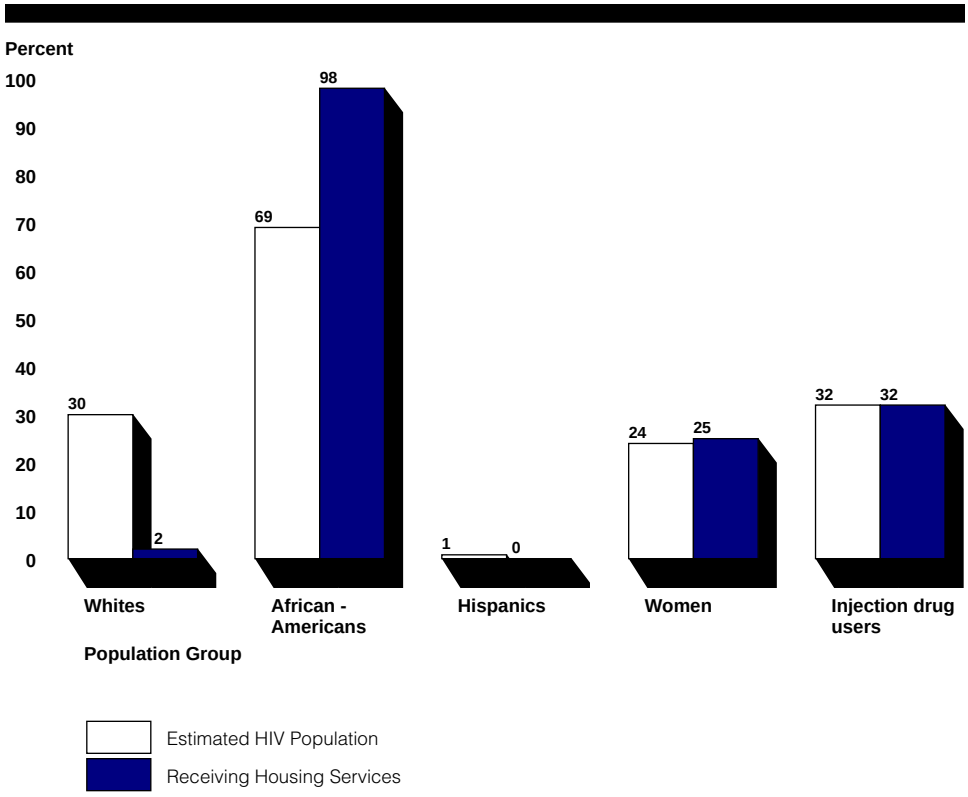
Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, mental health services providers received 6.8 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 1,301 mental health visits were conducted.

Figure II.3: Distribution of CARE Act-Funded Housing Services in the Baltimore EMA (April-June 1994)



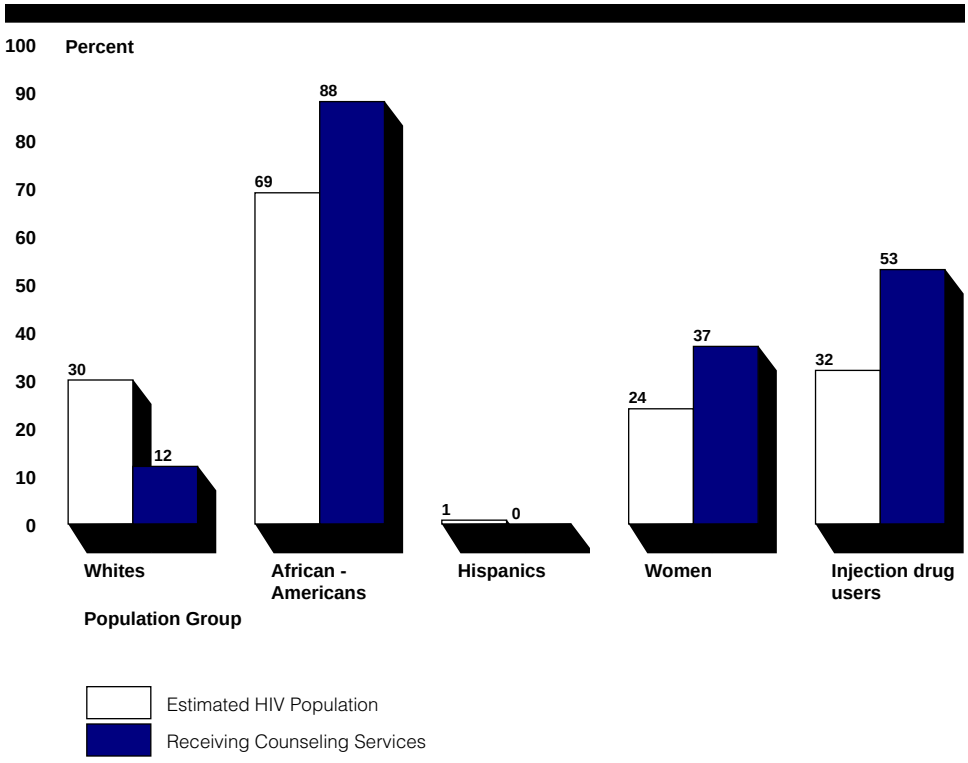
Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, housing services providers received 3.5 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 59 encounters occurred to assist in providing housing.

Figure II.4: Distribution of CARE Act-Funded Counseling Services in the Baltimore EMA (April-June 1994)



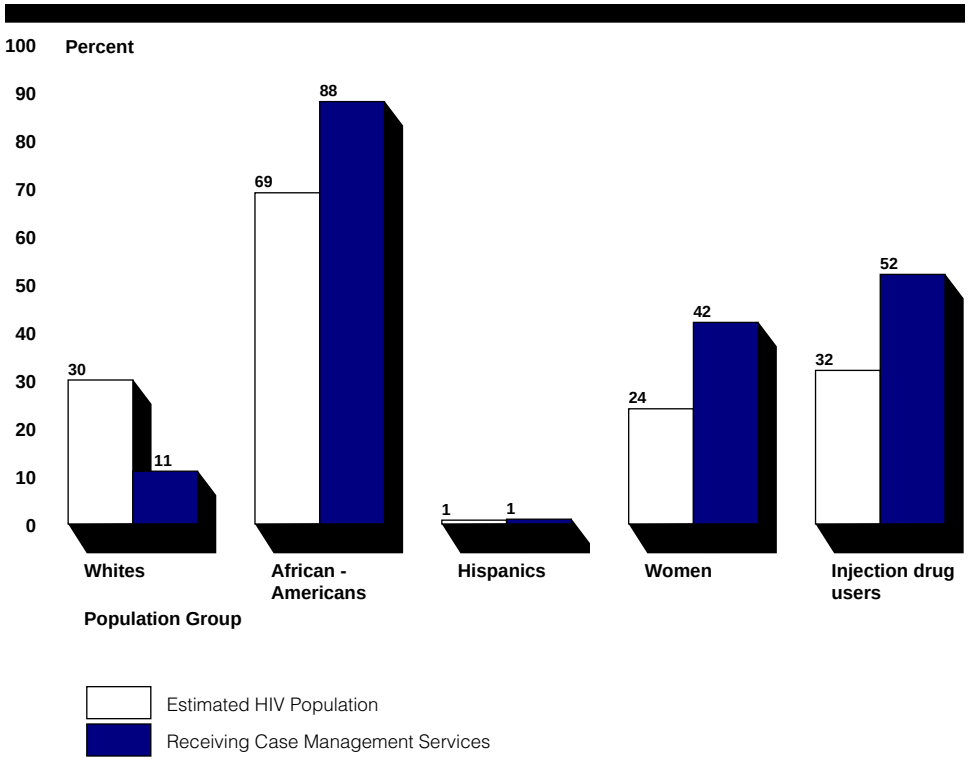
Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, counseling services providers received 3.4 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 133 counseling visits were provided.

Figure II.5: Distribution of CARE Act-Funded Case Management Services in the Baltimore EMA
(April-June 1994)



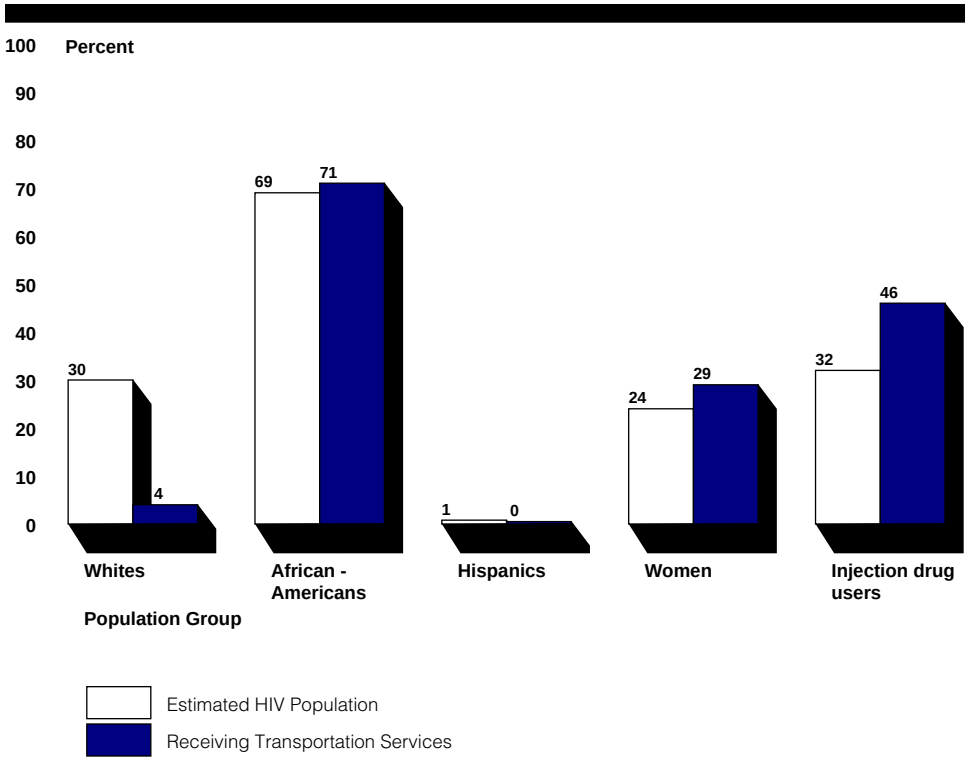
Notes:

1. Of the $4.6 million title I and II funds awarded in 1994, case management services providers received 3 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, 383 case management visits were conducted.

Figure II.6: Distribution of CARE Act-Funded Transportation Services in the Baltimore EMA (April-June 1994)



Notes:

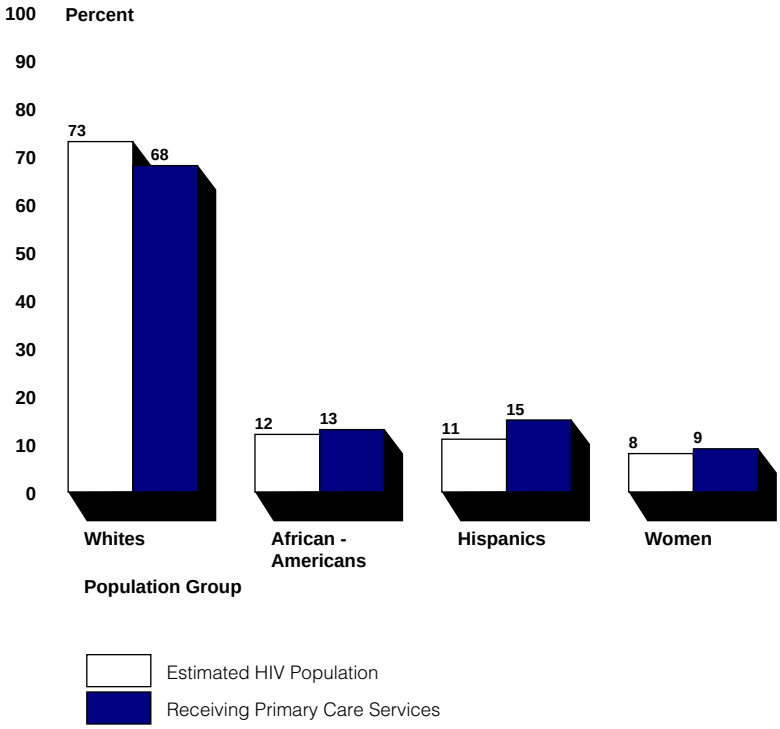
1. Of the $4.6 million title I and II funds awarded in 1994, transportation services providers received 2.4 percent.

2. The Baltimore EMA estimates its HIV-infected population to be about 16,500 persons.

3. During the 3-month period, transportation to, for example, medical appointments and support groups was provided 214 times.

4. The race/ethnicity and gender were unknown for about 25 percent of the clients, and, for about 41 percent of the clients, transmission mode was unknown.

Figure II.7: Distribution of CARE Act-Funded Primary Care Services in the Denver EMA (July-September 1994)



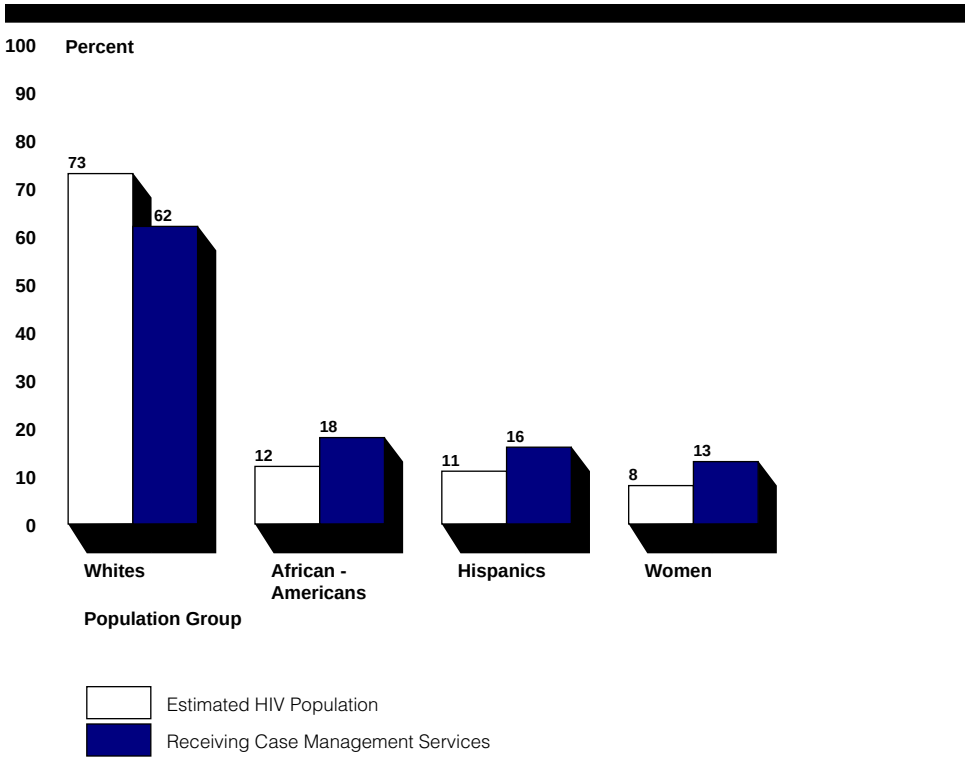
Notes:

1. Of the $4.4 million title I and II funds awarded in 1994, primary care services providers received 22.7 percent.

2. The Denver EMA estimates its HIV-infected population to be about 7,076 persons.

3. During the 3-month period, about 1,240 clients received primary care services.

Figure II.8: Distribution of CARE Act-Funded Case Management Services in the Denver EMA
(June-August 1994)



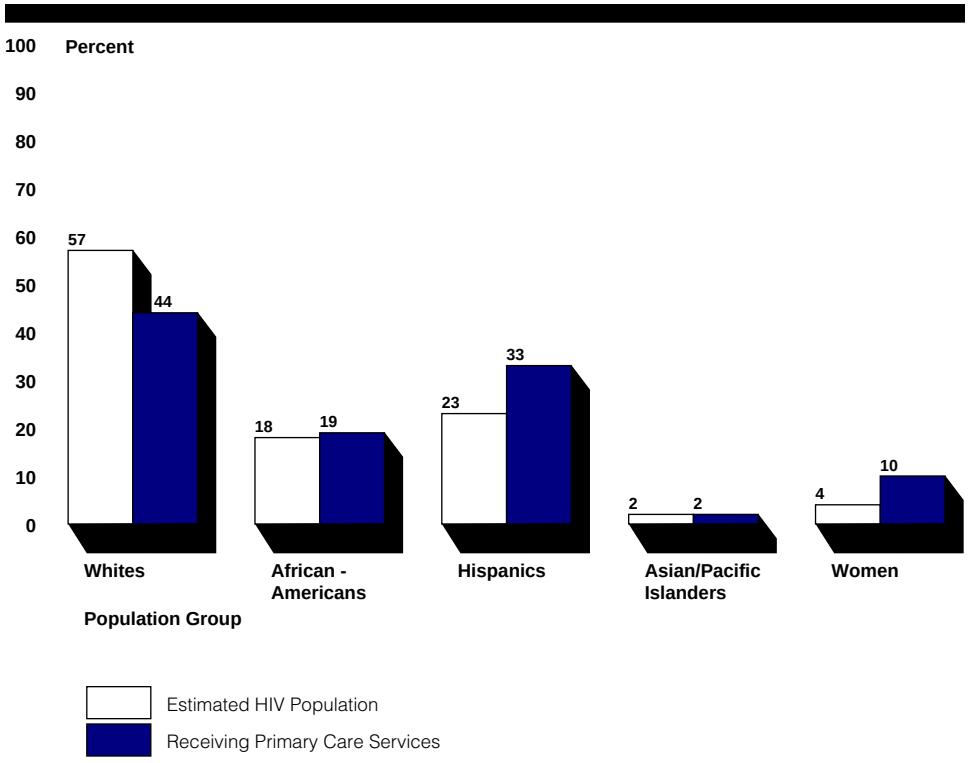
Notes:

1. Of the $4.4 million title I and II funds awarded in 1994, case management services providers received 18.6 percent.

2. The Denver EMA estimates its HIV-infected population to be about 7,076 persons.

3. During the 3-month period, about 938 clients received case management services.

Figure II.9: Distribution of CARE Act-Funded Primary Care Services in the Los Angeles EMA (July 1993-June 1994)



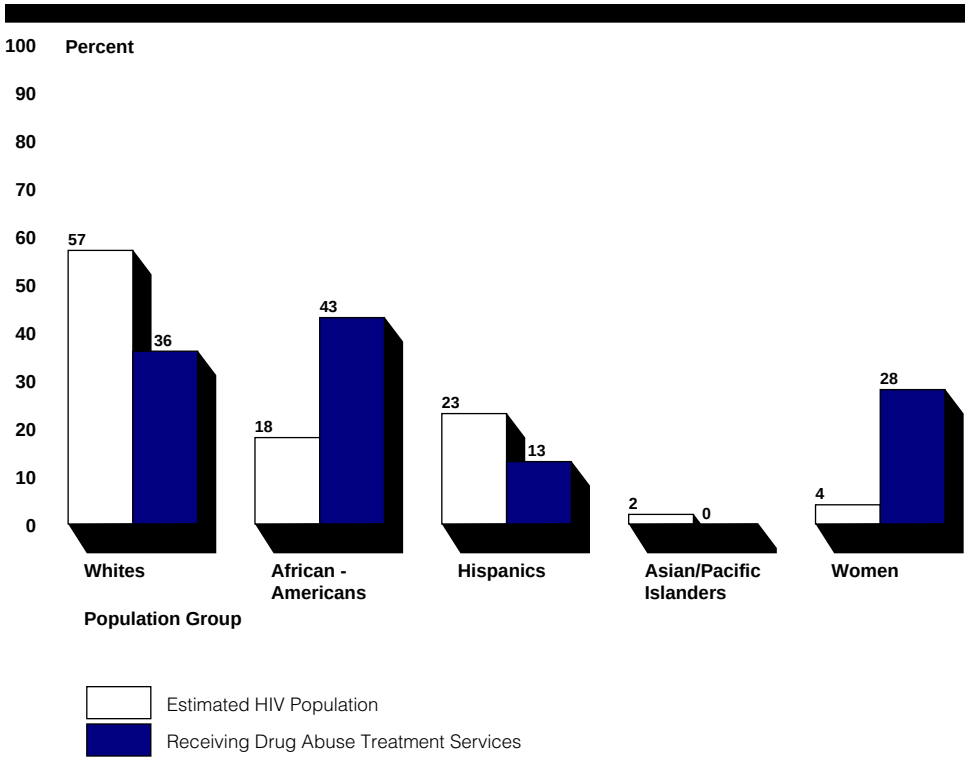
Notes:

1. Of the $27.6 million title I and II funds awarded in 1994, primary care services providers received 37.2 percent.

2. The Los Angeles EMA estimates its HIV-infected population to be about 52,000 persons.

3. During the 12-month period, about 5,830 clients received primary care services.

Figure II.10: Distribution of CARE Act-Funded Drug Abuse Treatment Services in the Los Angeles EMA
(January-March 1994)



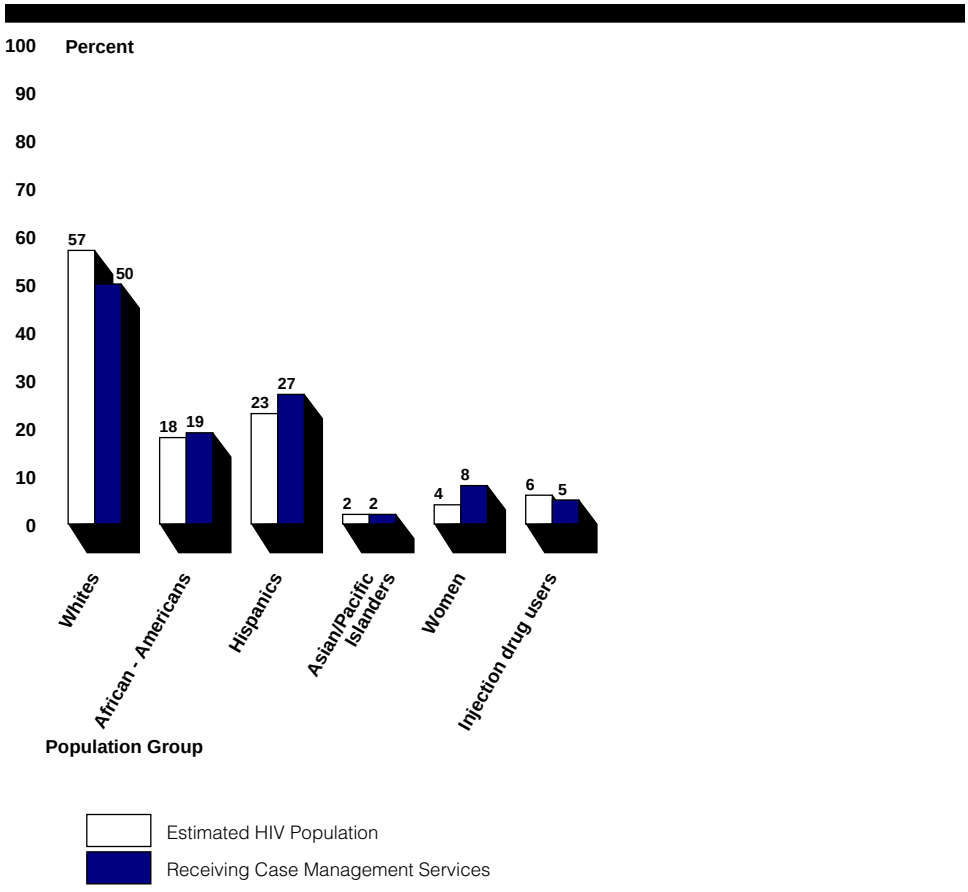
Notes:

1. Of the $27.6 million title I and II funds awarded in 1994, drug abuse treatment services providers received 9.1 percent.

2. The Los Angeles EMA estimates its HIV-infected population to be about 52,000 persons.

3. During the 3-month period, about 91 clients received drug abuse treatment services.

Figure II.11: Distribution of CARE Act-Funded Case Management Services in the Los Angeles EMA
(January-March 1994)



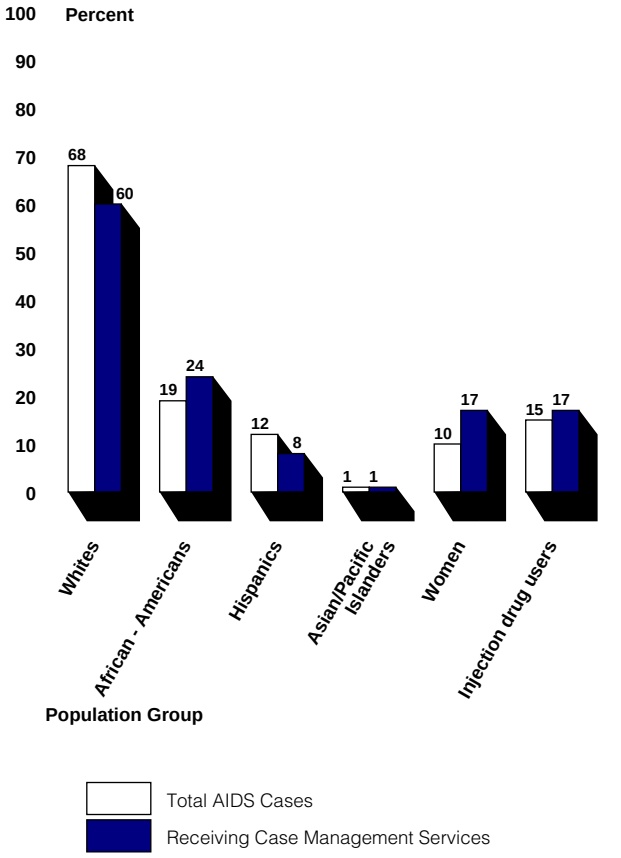
Notes:

1. Of the $27.6 million title I and II funds awarded in 1994, case management services providers received 8.3 percent.

2. The Los Angeles EMA estimates its HIV-infected population to be about 52,000 persons.

3. During the 3-month period, about 91 clients received drug abuse treatment services.

Figure II.12: Distribution of CARE Act-Funded Case Management Services in the Sacramento Title II Consortium (July-September 1992)



Notes:

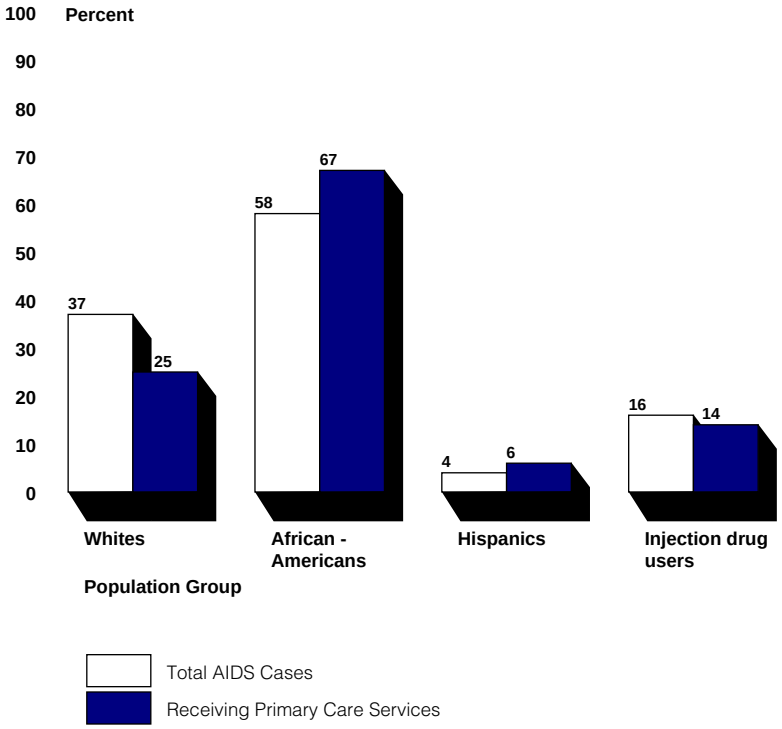
1. Of the $861,899 title II funds awarded in 1994, case management services providers received 45.2% of the funds.

2. The Sacramento Title II Consortium did not have estiamtes of its HIV population. The consortium has about 630 AIDS cases.

3. During the 3-month period, about 375 clients received case management services.

4. Client data more recent than 1992 were not available.

Figure II.13: Distribution of CARE Act-Funded Primary Care Services in the Suburban Maryland HIV Alliance
(May-August 1994)



Notes:

1. Of the $1.9 million title I and II funds awarded in 1994, primary care services providers received 24.2 percent.

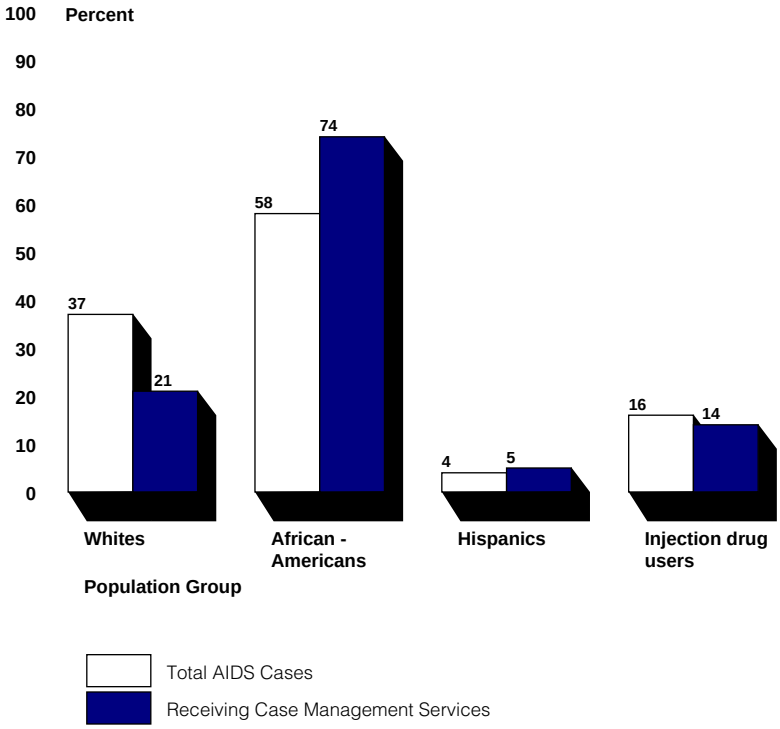
2. The Suburban Maryland HIV Alliance did not have estimates of its HIV population. The consortium has about 1,200 AIDS cases.

3. During the 4-month period, 612 primary medical care visits were conducted.

4. Data were not available to compare share of AIDS cases by gender.

5. Injection drug users comprise 10% of the AIDS cases in one county and 21% in another county. We estimate that about 16% of the AIDS cases in the consortium are injection drug users.

Figure II.14: Distribution of CARE Act-Funded Case Management Services in the Suburban Maryland HIV Alliance (May-August 1994)



Notes:

1. Of the $1.9 million title I and II funds awarded in 1994, case management services providers received 17.2 percent.

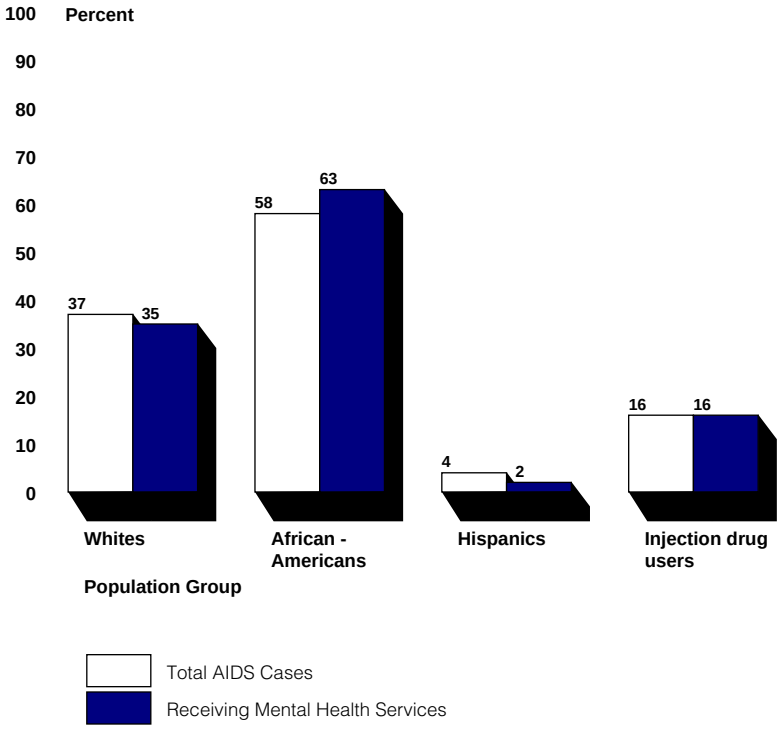
2. The Suburban Maryland HIV Alliance did not have estimates of its HIV population. The consortium has about 1,200 AIDS cases.

3. During the 4-month period, 673 case management visits were conducted.

4. Data were not available to compare share of AIDS cases by gender.

5. Injection drug users comprise 10% of the AIDS cases in one county and 21% in another county. We estimate that about 16% of the AIDS cases in the consortium are injection drug users.

Figure II.15: Distribution of CARE Act-Funded Mental Health Services in the Suburban Maryland HIV Alliance
(May-August 1994)



Notes:

1. Of the $1.9 million title I and II funds awarded in 1994, mental health services providers received 7.2 percent.

2. The Suburban Maryland HIV Alliance did not have estimates of its HIV population. The consortium has about 1,200 AIDS cases.

3. During the 4-month period, 154 mental health visits were conducted.

4. Data were not available to compare share of AIDS cases by gender.

5. Injection drug users comprise 10% of the AIDS cases in one county and 21% in another county. We estimate that about 16% of the AIDS cases in the consortium are injection drug users.

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