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RYAN WHITE CARE ACT

Access to Services by
Minorities, Women, and
Substance Abusers

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Mr. Chairman and Members of the Subcommittee:

I appreciate the opportunity to be here today to discuss our report on access to federally funded services by women, minorities, and substance abusers with the acquired immuno-deficiency syndrome (AIDS). The AIDS epidemic is in its second decade and, continues to escalate at an alarming rate. AIDS is the leading cause of death for men between 25 and 44 years old and the fourth leading cause of death for women in that age group. Recently the African-American and Hispanic communities have been particularly hard hit. And AIDS is affecting more women and injection drug users.

In the early 1980s, communities began to address the need to provide services to populations infected with the human immuno-deficiency virus (HIV). Many community-based and AIDS service organizations were established to assist primarily gay, white men. In 1990, the Ryan White CARE Act (P.L. 101-381) was enacted to improve the quality and availability of medical and support services for individuals and families with HIV. But with changes in the makeup of the HIV-infected population and the increased availability of medical and social services through the CARE Act, concerns have been raised about whether the service delivery system has been able to accommodate the needs of increasing numbers of minorities and women infected with HIV. Therefore, we were asked last year to assess whether CARE Act funding was reaching these groups.

Today I would like to focus my comments on (1) who is getting services and (2) the barriers to care. My comments are based on our January 1995 report.¹ Because national data do not exist on populations served, we supplemented our information by visiting five areas--Baltimore; Denver; Los Angeles; Sacramento, California; and the Maryland suburbs of Washington, D.C.

In brief, we found that minorities, women, and injection drug users generally use services at a rate that reflect their representation in the HIV-infected population in the five areas we visited. Service providers and advocates of HIV-infected people in these communities agreed with this assessment of the patient population receiving Ryan White CARE Act-funded services. Nonetheless, these HIV-infected groups may have to rely on Ryan White CARE Act-funded services more so than other subpopulations. Therefore, there may still be unmet needs for care. Providers and advocates described barriers to care that are particularly difficult to overcome, such as homelessness, substance abuse, and language and cultural differences. Providers mentioned the importance of outreach to help overcome these barriers.

¹Ryan White CARE Act: Access to Services by Minorities, Women, and Substance Abusers (GAO-HEHS-95-49, Jan. 13, 1995).

BACKGROUND: RYAN WHITE CARE ACT

The Ryan White CARE Act provides federal funds to state and local areas for medical and support services for HIV-infected individuals and their families. For fiscal year 1995, 42 eligible metropolitan areas (EMA)² received \$349.4 million under title I of the act; the 54 states and territories received \$174.8 million under title II of the act.³

Under title I of the act, EMAs are required to establish planning councils that are made up of service providers and representatives of affected communities, among others. The councils develop a plan for service delivery and set priorities for allocating funds. The councils also provide input on which service providers receive funding. EMAs award CARE Act funds to providers of medical and support services. These providers include hospital outpatient clinics⁴, community health centers, community-based organizations, and hospices, among others.

States and territories use title II funds in one or more ways. About one-half of title II funds are used to establish and operate HIV care consortia in areas most affected by HIV. These consortia--consisting of public and nonprofit private organizations that provide services to HIV-infected individuals and their families--assist in the planning, development, and delivery of medical and social 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. The Division of HIV Services within the Department of Health and Human Services' Health Resources and Services Administration (HRSA) is responsible for awarding and monitoring title I and II grants.

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

³In addition to titles I and II, title IIIb supports outpatient early intervention HIV services for people with AIDS and HIV. For fiscal year 1994, \$21.4 million was awarded to public and nonprofit private entities. Title IV provides for clinical research on therapies for pediatric patients and pregnant women with HIV and provides for health care to pediatric patients and their families. In fiscal year 1994, \$46.5 million was awarded.

⁴Ryan 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.

MINORITIES, WOMEN, AND INJECTION DRUG USERS
ARE RECEIVING RYAN WHITE SERVICES

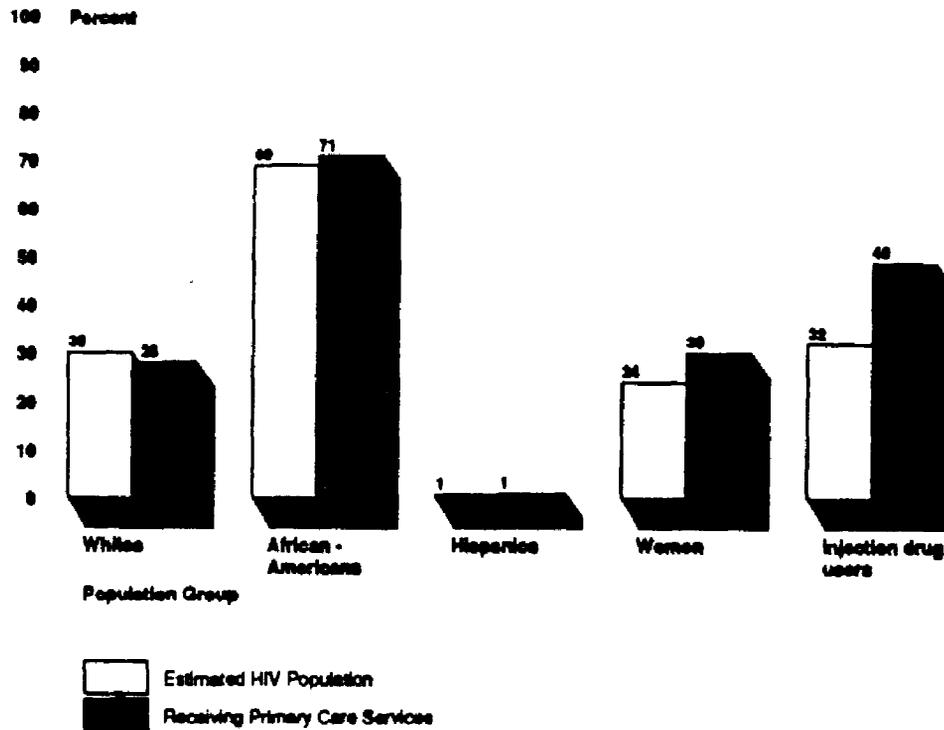
Even as the profile of the AIDS epidemic is changing, local service delivery systems appear to be reaching increasing numbers of HIV-infected minorities, women, and injection drug users. This is especially important because minorities are becoming infected at a greater rate than whites. For example, African-Americans represent 12 percent of the nation's population but accounted for 33 percent of the cumulative AIDS cases as of December 1994. Similarly, while Hispanics represent 9 percent of the population, they accounted for 17 percent of the cumulative AIDS cases. Another indicator of the changing profile of the epidemic is that as of September 1989, African-Americans and Hispanics accounted for 43 percent of cumulative AIDS cases, women for 10 percent, and injection drug users for 21 percent. By 1994, the distribution of newly reported AIDS cases was 58 percent African-American and Hispanic, 17 percent women, and 32 percent injection drug users.

Access to Ryan White CARE Act-funded medical and support services for minorities, women, and drug users appears to be in proportion to their representation in the HIV-infected population. In our visits to the five areas⁵ we compared the HIV-infected populations, which were estimated by the EMAs and consortia, with the number of clients served for certain periods in 1994 as reported by service providers. These estimates and reports identified such characteristics as race/ethnicity, gender, and mode of transmission.⁶ To illustrate the use of services in one city, Baltimore, figure 1 shows that the use of primary care services is generally in proportion to or slightly higher than the estimated HIV-infected population. (See our Jan. 1995 report for further examples of the distribution of services among affected populations in the five areas.)

⁵We chose these areas 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.

⁶At some areas, some service providers did not report one or more client characteristic, such as gender or risk group. In those areas, we could not compare all population and client characteristics.

Figure 1: Distribution of CARE Act-Funded Primary Care Services in the Baltimore EMA (Jan.-Mar. 1994)



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

The Baltimore EMA estimates its HIV-infected population at 16,500 persons.

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

Advocates and providers we talked to affirmed that affected groups generally accessed services in proportion to their representation in the HIV-infected population. We obtained views on access from advocates and providers representing and serving various populations, including minorities, women, and injection drug users.

Use rates of CARE Act-funded services, however, may not fully explain access to or the need for services. Although minorities, women, and substance abusers appear to receive services in proportion to their representation in the population, these HIV-infected groups may have to rely on Ryan White CARE Act-funded services more so than other subpopulations. Minorities generally

have lower incomes than whites and are much more likely to be without health insurance. Therefore, minorities are more likely to depend upon publicly funded services such as those funded by the Ryan White CARE Act.

BARRIERS MAY LIMIT ACCESS

Providers and advocates told us about many barriers to access for HIV-infected individuals that are particularly difficult to overcome. HIV-infected people who are substance abusers and homeless have difficulty in seeking services because of the dysfunctional nature of their lives. For women, lack of child care limits the ability to make and keep appointments for HIV-related services. Another problem in seeking services is the lack of transportation. One provider said that transportation subsidies, usually for bus fare, are provided to clients. However, some clients, such as women with small children or persons with disabilities, need other forms of transportation.

In some instances, the lack of knowledge about and lack of motivation to seek services affect the extent to which people use services. Providers said that some clients are seeking services during the later stages of infection. HIV-infected people in some cases do not seek services because of denial or ignorance of the disease and a lack of trust of the medical community. Also mentioned were cultural differences and language barriers that limit access.

Several providers told us of individuals' 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. Some minorities and women are reluctant to obtain assistance from an organization that serves a predominately white male clientele or that is perceived as a gay white male organization.

Providers, advocates, and HIV-infected persons whom we contacted acknowledge the benefits that the Ryan White CARE Act has made in providing needed services to minorities, women, and substance abusers. However, to help in overcoming barriers to care, they also recognize the need for local outreach services to make HIV-infected people aware of prevention, the availability of services, and the need to seek medical attention early on. Such outreach services can increase the likelihood that HIV-infected persons receive needed services.

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This concludes my prepared remarks. I would be pleased to respond to any questions you might have.

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