

**2002**

CALENDAR YEAR

# RYAN WHITE CARE ACT ANNUAL DATA SUMMARY

## Introduction

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The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act provides funding to States, cities, and public or private nonprofit entities to improve the quality and availability of care for medically underserved individuals and families affected by HIV/AIDS. Reflecting the diversity of communities across the country, CARE Act funds may be used to develop, organize and deliver an array of medical, health, and social support services to people living with HIV/AIDS. Within this range of services, the CARE Act provides financial assistance for services that, otherwise, would not be available to these vulnerable populations.

Every year, recipients of CARE Act funds are required to report to the Health Resources and Services Administration's HIV/AIDS Bureau (HRSA/HAB) how those funds have been used to provide services to low-income and underserved individuals and families living with HIV/AIDS. The Ryan White CARE Act Data Report (CADR) is the annual reporting instrument that must be completed by agencies and organizations receiving funds to describe: 1) characteristics of their organization; 2) the number and characteristics of clients they served; 3) the types of services provided; and 4) the

number of clients receiving these services and the number of client visits by type of service. Agencies/organizations that provide counseling and testing services report on the number of individuals receiving these services. In addition, providers of ambulatory/outpatient medical care provide some information on the outcomes of their services.

This annual summary contains five sections describing how CARE Act funds have been used in communities around the Nation. The document includes data from 2,696 provider agencies/organizations receiving CARE Act funds that reported CADR data in 2002. These providers received funding from one or more of the following CARE Act programs: Title I, Title II (with ADAP reported separately), Title III-EIS, Title IV, and/or Title IV-Youth.

Given the nature of the CADR, the specific CARE Act Program (Title I, II, III, IV or IV-Youth) that funded particular client services can not be determined. Although service organizations may be funded by multiple CARE Act programs, these providers are required to complete only one CADR that includes information on all services provided regardless

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An annual report of the Health Resources and Services Administration's HIV/AIDS Bureau, U.S. Department of Health and Human Services

# HIV/AIDS: A BRIEF OVERVIEW

## HISTORY

AIDS (acquired immunodeficiency syndrome) was first reported in the United States in 1981 and has since become a major worldwide epidemic. AIDS is caused by the human immunodeficiency virus (HIV). By killing or damaging cells of the body's immune system, HIV progressively destroys the body's ability to fight infections and certain cancers. People living with AIDS may get life-threatening diseases called opportunistic infections, which are caused by microbes such as viruses or bacteria that usually do not make healthy people sick.

## DEFINITION

The term AIDS applies to the most advanced stages of HIV infection. The Centers of Disease Control and Prevention (CDC) developed official criteria for the definition of AIDS and is responsible for tracking the spread of AIDS in the United States.

CDC's definition of AIDS includes all HIV-infected

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of the funding source. Please remember that CADR Sections 1 and 2 report the characteristics of providers and clients, respectively. By contrast, CADR Sections 3, 4, 5, 7, and 8 describe the types of services provided by CARE Act funded service organizations and the number of clients receiving these services regardless of the Ryan White CARE Act funding stream.

The utility of CADR data is limited by duplicated client counts. CADR data as collected and reported by individual providers are generally unduplicated. However, since an individual client may receive services from more than one provider, there is no way of knowing that the counts of individuals served by one provider are not also included in the counts of another service provider. Thus, aggregating provider data to the national level results in duplicate client counts. ■

## Provider Information

Using data from Section 1 of the CADR, this section of the report describes the characteristics of the CARE Act providers (n=2,696) that reported data between January 2002 and December 2002. The provider information narrative is based on the data tables presented in this section.

## REPORTING SCOPE

CARE Act providers have the option of reporting on eligible or funded services. When they report on eligible services, providers are reporting on any service permitted under any title of the CARE Act, regardless of whether or not the providers use a specific title to pay for these services. Reporting eligible services pro-

vides a comprehensive picture of the services being delivered to HIV-positive clients. More than three-quarters of the 2,696 CARE Act providers (87 percent) reported on all eligible services in 2002.

Conversely, if providers report on funded services, the data reported by providers includes those services that were actually paid for by a specific Title of the CARE Act. This latter reporting category requires prior approval from HRSA project officers. Thirteen percent of providers (n=357) reported only those services funded by the CARE Act.

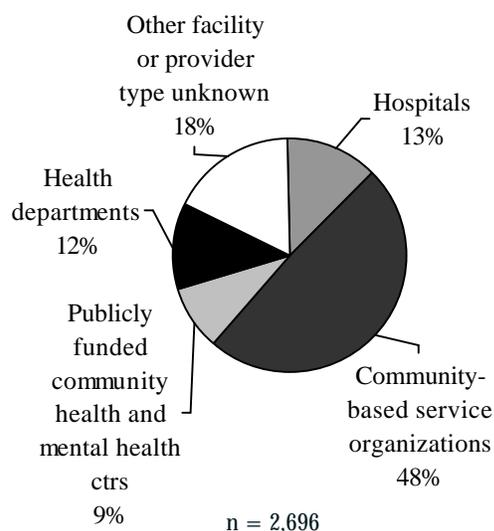
## PROVIDER TYPE

A variety of different types of organizations provide CARE Act services. Almost half of all CARE Act providers (48 percent) were identified as community-based service organizations (CBOs). Hospitals comprised 13 percent of all CARE Act providers in 2002 and 12 percent were health departments. Collectively, publicly-funded community health and community mental health centers represented 9 percent (n=245) of providers. CARE Act providers identifying as substance abuse treatment centers, solo/group private medical practices, multiple fee-for-service providers, people living with HIV/AIDS (PLWHA) coalitions, or VA facilities comprised 6 percent (n=156) of providers. Other provider types comprised 12 percent of all CARE Act service organizations (Figure 1 and Table 1, page 4).

Seven percent of all CARE Act provider organizations (n=181) received Public Health Service (PHS) Section 330 fund-

ing. Community health centers and community mental health centers comprised 77 percent of the organizations receiving these 330 funds. Other types of organizations receiving PHS Section 330 funding included other community-based organizations, health departments and hospitals (data not shown).

Figure 1. CARE Act Provider Types, 2002<sup>1,21</sup>



## OWNERSHIP STATUS

In 2002, CARE Act providers reported various types of ownership status. Of the 2,696 CARE Act providers reporting data in 2002, 64 percent were private, nonprofit (not faith-based) organizations. About six percent of CARE Act providers in 2002 (n=151) were faith-based organizations. Twenty-three percent of providers reported their ownership status as publicly owned (local, State, or Federal) (n=599).

people who have fewer than 200 CD4 positive T cells per cubic millimeter of blood or a CD4+ percentage of less than 14 (Healthy adults usually have CD4 positive T-cell counts of 1,000 or more). In addition, the definition includes 26 clinical conditions that affect people with advanced HIV disease. Most of these conditions are opportunistic infections that generally do not affect healthy people. In people with AIDS, these infections are often severe and sometimes fatal because the immune system is so ravaged by HIV that the body cannot fight off certain bacteria, viruses, fungi, parasites, and other microbes.

(source: National Institute of Allergy and Infectious Disease, National Institutes of Health. *Fact Sheet—HIV Infection and AIDS: An Overview*. October, 2003.)

## SUMMARY OF THE HIV/AIDS EPIDEMIC

It is estimated that almost 1.5 million people in the United States have been infected with HIV since the start of the HIV/AIDS epidemic.<sup>1</sup> More than 500,000 people have already died and another 850,000-950,000 are estimated to be living with HIV/AIDS.<sup>2,3</sup>

The number of people living with HIV and AIDS in the United States continues to increase.<sup>4</sup> The increase is in part the result of treatment advances that have significantly reduced AIDS mortality. Concurrently, the number of new infections has not decreased and there are indications that HIV infections may be on the rise among some populations.

AIDS cases have been reported in all 50 States, the District of Columbia, and the United States territories. In the United States, by region, the Northeast had the highest AIDS case rate in 2002, followed by the South, West and Midwest.<sup>5</sup> In 2002, the South had the greatest number of people living with AIDS and AIDS cases diagnosed, followed by the

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Table 1. Provider Type and Ownership Status of CARE Act Providers, 2002<sup>1</sup>

| Provider type (n=2,696)                          | Total | Percent |
|--|-------|---------|
| Hospital   | 355   | 13%     |
| Publicly funded community health ctr             | 214   | 8%      |
| Publicly funded community mental health ctr      | 31    | 1%      |
| Community-base service organization              | 1284  | 48%     |
| Health department                                | 330   | 12%     |
| Substance abuse treatment ctr                    | 55    | 2%      |
| Solo/group private medical practice              | 50    | 2%      |
| Reporting for multiple fee-for-service providers | 32    | 1%      |
| PLWHA coalition                                  | 16    | 1%      |
| VA facility                                      | 3     | *       |
| Other facility                                   | 321   | 12%     |
| Missing  | 5     | *       |
| Ownership status (n=2,696)                       | Total | Percent |
| Public/local                                     | 344   | 13%     |
| Public/state                                     | 248   | 9%      |
| Public/Federal                                   | 17    | 1%      |
| Private, nonprofit (not faith-based)             | 1736  | 64%     |
| Private, for profit                              | 156   | 6%      |
| Unincorporated                                   | 4     | *       |
| Faith-based organization                         | 151   | 6%      |
| Other  | 36    | 1%      |
| Missing  | 4     | *       |

\* Less than 0.1 percent.

## SOURCE OF CARE ACT FUNDING

Organizations completing a 2002 CADR were asked to indicate which CARE Act programs provided funding for services delivery. These providers received funding from one or more CARE Act programs. Organizations may have received funding directly from the Federal government as a Ryan White CARE Act grantee, through a subcontract with a CARE Act grantee and/or through Title II funding from a consortia agency. Of the 2,696 providers submitting data in 2002, 1,554 providers received Title I funds; 1,422 providers received Title II funds; 442 providers received Title III-EIS funds; and 265

providers received Title IV funds. Thirty-six providers received Title IV-Youth funds (Table 2).

Table 2. Source of CARE Act Funding, 2002

| Source of CARE Act funding (n=2,696) | Total | Percent |
|--------------------------------------|-------|---------|
| Title I                              | 1,554 | 58%     |
| Title II                             | 1,422 | 53%     |
| Title III                            | 442   | 16%     |
| Title IV                             | 265   | 10%     |
| Title IV, youth                      | 36    | 1%      |

As previously mentioned, CARE Act providers frequently receive funds from more than one Title of the CARE Act. Many of these same providers also may have received funds from additional, non-Ryan White CARE Act sources. In 2002, 20 percent or 545 providers received funds from two CARE Act sources;

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Table 3. Distribution of CARE Act Funding Sources Among Providers, 2002<sup>1</sup>

| Number of Sources | Source of Funding               | Number      | Percent       | Total Number | Total Percent |
|-------------------|---------------------------------|-------------|---------------|--------------|---------------|
| 1                 | Title I                         | 966         | 35.8%         | 1933         | 71.7%         |
|                   | Title II                        | 825         | 30.6%         |              |               |
|                   | Title III (EIS)                 | 86          | 3.2%          |              |               |
|                   | Title IV                        | 48          | 1.8%          |              |               |
|                   | Title IV-Youth                  | 8           | 0.3%          |              |               |
| 2                 | Titles I, II                    | 298         | 11.1%         | 545          | 20.3%         |
|                   | Titles II, III                  | 99          | 3.7%          |              |               |
|                   | Titles I, III                   | 76          | 2.8%          |              |               |
|                   | Titles I, IV                    | 29          | 1.1%          |              |               |
|                   | Titles II, IV                   | 20          | 0.7%          |              |               |
|                   | Titles III, IV                  | 15          | 0.6%          |              |               |
|                   | Titles IV, IV-Youth             | 5           | 0.2%          |              |               |
|                   | Titles I, IV-Youth              | 2           | 0.1%          |              |               |
|                   | Titles II, IV-Youth             | 1           | *             |              |               |
| 3                 | Titles I, II, III               | 66          | 2.5%          | 179          | 6.8%          |
|                   | Titles I, II, IV                | 41          | 1.5%          |              |               |
|                   | Titles I, III, IV               | 34          | 1.3%          |              |               |
|                   | Titles II, III, IV              | 29          | 1.1%          |              |               |
|                   | Titles I, IV, IV-Youth          | 3           | 0.1%          |              |               |
|                   | Titles II, IV, IV-Youth         | 2           | 0.1%          |              |               |
|                   | Titles II, III, IV-Youth        | 2           | 0.1%          |              |               |
|                   | Titles I, II, IV-Youth          | 1           | *             |              |               |
|                   | Titles III, IV, IV-Youth        | 1           | *             |              |               |
| 4                 | Titles I, II, III, IV           | 28          | 1.0%          | 36           | 1.3%          |
|                   | Titles I, II, IV, IV-Youth      | 5           | 0.2%          |              |               |
|                   | Titles I, II, III, IV-Youth     | 1           | *             |              |               |
|                   | Titles II, III, IV, IV-Youth    | 1           | *             |              |               |
|                   | Titles I, III, IV, IV-Youth     | 1           | *             |              |               |
| 5                 | Titles I, II, III, IV, IV-Youth | 3           | 0.1%          | 3            | 0.1%          |
| <b>Total</b>      |                                 | <b>2696</b> | <b>100.0%</b> | <b>2696</b>  | <b>100.0%</b> |

\*Less than 0.1 percent

approximately 7 percent of providers (n=179) received funds from three CARE Act sources; and 1 percent of providers (n=36) received funds from four CARE Act sources (Table 3). Three providers received funds from all five CARE Act sources. The providers receiving funds from one CARE Act source numbered 1,933 providers (or 72 percent).

## GRANTEE SUPPORT

Organizations may receive CARE Act funding to provide supportive services to grantees. In some cases, organizations only provide grantees with these supportive services. In others, organizations provide both grantee supportive services and direct client services. In the 2002 CADR, providers reported if they provided any of the following services to their grantee of record: planning or evaluation, ad-

Northeast, West and Midwest.<sup>6</sup>

Thirty percent of the estimated new AIDS diagnoses among adults/adolescents are attributed to heterosexual sex, 40 percent to sex between men, and 24 percent directly to injection drug use.<sup>7</sup> AIDS among women continues to grow. In 2002, women comprised 26 percent of the new AIDS cases reported. In comparison, seven percent of the new AIDS cases in 1986 were among women.<sup>8</sup> The perinatal transmission rate in the United States has significantly declined.<sup>9</sup> In 2002, perinatal transmission accounted for approximately 0.2 percent of all new AIDS cases.<sup>10</sup>

Since the beginning of the epidemic HIV and AIDS has disproportionately affected racial and ethnic minorities. This trend continues; minority Americans now represent the majority of new HIV and AIDS cases, Americans living with AIDS, and deaths among persons with AIDS in the United States.<sup>11</sup> In 1990, 30 percent of those diagnosed with AIDS were African American. In 1998, African Americans

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accounted for 48 percent of new AIDS cases and 60 percent of cases among women. In comparison, African Americans accounted for 50 percent of new AIDS cases and 67 percent of cases among women in 2002.<sup>12</sup>

## FOOTNOTES

<sup>1</sup> Fleming, P., et al. HIV prevalence in the United States, [Abstract]. In: Program and abstracts of the 9<sup>th</sup> Conference on Retrovirus and Opportunistic Infections; Seattle, Washington; February 24-28, 2002.

<sup>2</sup> CDC, HIV/AIDS Surveillance Report, Vol. 14, 2002. (Hereafter "CDC Report 2002.")

<sup>3</sup> Fleming, P., et al. 2002, supra n 1.

<sup>4</sup> CDC, HIV/AIDS Surveillance Report, Vol. 13, No. 2, 2001.

<sup>5</sup> CDC, HIV/AIDS Surveillance Report, Vol. 14, 2002, cited in Kaiser Family

ministrative or technical support, fiscal intermediary services, technical assistance, capacity development, and/or quality management. Three of these six services were most frequently provided to the grantee of record by a provider agency: planning or evaluation support (539 providers), quality management support (437 providers), and administrative or technical support (406 providers). These categories of support are not mutually exclusive, i.e., an organization may have provided more than one of these support services to the grantee.

## TARGET POPULATIONS OF INTEREST

Providers were asked to indicate if one or more specific population groups were targeted for special emphasis, outreach efforts or service delivery during the 2002

reporting period. Among the populations of special interest for the CARE Act grantees, the four most frequently targeted populations included communities of color (61 percent of providers), women (58 percent of providers), injection drug users (46 percent), and homeless persons (41 percent). The remaining targeted population are shown in Table 4.

## RACIAL/ETHNIC GROUP REPRESENTATION GREATER THAN 50%

Thirty-five percent or 945 of all CARE Act provider organizations reported that members of racial/ethnic minority groups comprised more than 50 percent of the organization's professional staff providing direct HIV services. Among CARE Act providers, 25 percent of the organi-

Table 4. Characteristics of CARE Act Providers, 2002<sup>2</sup>

| <b>Target populations of interest (n=2,696)</b>                    | <b>Total</b> | <b>Percent</b> |
|--|--------------|----------------|
| Migrant/farm workers   | 219          | 8%             |
| Rural population other than migrant workers                        | 509          | 19%            |
| Women  | 1553         | 58%            |
| Children/child   | 771          | 29%            |
| Communities of color   | 1649         | 61%            |
| Homeless   | 1113         | 41%            |
| Gay, lesbian, bisexual youth                                       | 632          | 23%            |
| Gay, lesbian, bisexual adults                                      | 1208         | 45%            |
| Incarcerated persons   | 588          | 22%            |
| All adolescents  | 569          | 21%            |
| Runaway or street youth  | 292          | 11%            |
| Injection drug users   | 1245         | 46%            |
| Non-injection drug users   | 971          | 36%            |
| Parolees   | 626          | 23%            |
| Other  | 325          | 12%            |
| Missing  | 1            | <1%            |
| <b>Racial/ethnic group representation greater the 50% (n=2696)</b> | <b>Total</b> | <b>Percent</b> |
| Board members  | 673          | 25%            |
| Professional staff members   | 945          | 35%            |
| Solo/group private health practice                                 | 65           | 2%             |
| "Traditional" provider serving people of color                     | 911          | 34%            |
| Other agency type  | 463          | 17%            |
| Missing  | 1            | <1%            |

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zations reported that racial/ethnic minorities comprised more than 50 percent of their Board of Directors. Thirty-five percent of all providers (n=515) reported that their professional staff consisted of more than 50 percent racial/ethnic minority group members. A small number (2 percent; n=65) were solo or group health practices. Thirty-four percent of providers reported that although their board and staff were not composed of a majority of racial/ethnic minority group members, they historically serve racial/ethnic minorities in communities of color (Table 4).

## STAFFING

CARE Act providers report the number of paid, full-time equivalent staff (FTEs) that were funded by the CARE Act along with the number of volunteer, full-time equivalent positions dedicated to HIV care during the 2002 reporting period. Of the CARE Act providers reporting paid staff members (n=2,339), the mean number of paid FTEs was 8.42 persons (Table 5). Among CARE Act providers reporting volunteer staff FTEs (n=746), the mean number of volunteer staff FTEs was 11.82.

Table 5. CARE Act Provider Organization Staffing, 2002

| Staff     | No. of providers | Mean staff per provider | (Min-Max values) |
|-----------|------------------|-------------------------|------------------|
| Paid      | 2339             | 8.42                    | (.01-780)        |
| Volunteer | 746              | 11.82                   | (.02-750)        |

Table 6. CARE Act Funding Amounts, 2002

| CARE Act Program            | Total (dollars) | Mean      | (Min-Max values)      |
|-----------------------------|-----------------|-----------|-----------------------|
| Title I (n=1438)            | \$610,095,979   | \$424,267 | (\$19-\$29,479,811)   |
| Title II (n=1277)           | \$502,396,509   | \$393,419 | (\$50-\$133,000,000)  |
| Title III (n=397)           | \$174,570,230   | \$439,723 | (\$450-\$1,142,974)   |
| Title IV (n=247)            | \$68,943,223    | \$279,122 | (\$1,765-\$2,274,327) |
| Dental expenditures (n=544) | \$39,906,041    | \$73,356  | (\$8-\$2,461,363)     |

## CARE ACT FUNDING AMOUNTS

The amount of CARE Act funds that providers report receiving is presented in Table 6. It must be noted that the following funding amounts are as reported by CARE Act providers and may not match fiscal year awards. Differences between actual fiscal year funding and provider reported funding are due to carry-over from the previous funding period and supplemental funding. A total of \$610,095,979 was distributed to 1,438 providers through Title I of the CARE Act. The mean amount awarded to these providers was \$424,267 (with some providers being awarded as much as \$29,479,811) to deliver CARE Act services. In 2002, 1,277 Title II providers reported receiving a total of \$502,396,509. The mean amount awarded to these Title II providers was \$393,419. Providers in Title III-EIS (n=397) reported receiving a total of \$174,570,230, with a mean award of \$439,723. Providers in Title IV (n=247) reported receiving a total of \$68,943,223 with a mean award of \$279,122.

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Foundation, HIV/AIDS in the United States, Fact Sheet, March 2004.

<sup>6</sup> Id.

<sup>7</sup> CDC Report 2002

<sup>8</sup> CDC, HIV/AIDS Surveillance Reports, 1986-2002, cited in Kaiser Family Foundation, HIV/AIDS in the United States, Fact Sheet, March 2004.

<sup>9</sup> Id.

<sup>10</sup> CDC Report 2002.

<sup>11</sup> Id.

<sup>12</sup> Id.

## THE RYAN WHITE CARE ACT

The AIDS epidemic has taken an unspeakable toll since its onset in the early 1980s. The epidemic has hit hardest among populations at risk for poverty, lack of health insurance, and disenfranchisement from the health care system.

Congress enacted the Ryan White Comprehensive AIDS Resources Emergency Act (CARE Act) in August 1990 to improve the quality and availability of care and treatment for low-income, uninsured, and underinsured individuals and families affected by HIV disease. The CARE Act, which is administered by the HIV/AIDS Bureau of the Health Resources and Services Administration, was reauthorized in May 1996 and, again, in October 2000. Biomedical research into HIV/AIDS is carried out by the National Institutes of Health. The collection of surveillance data and the development of prevention programs are handled by the Centers for Disease Control and Prevention.

The Ryan White CARE Act programs work with cities,

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The information for dental expenditures (excluding funds from the Dental Reimbursement Program and the Community Based Dental Partnership Program) requires additional explanation. This line item includes all CARE Act funds from all Titles that were used to pay for dental expenses incurred by CARE Act providers. A total of 544 CARE Act providers reported \$39,906,041 in dental expenditures for CARE Act clients in 2002. The mean amount of dental expenditures reported by dental providers was \$73,356 (with some providers reporting as much as \$2,461,363 in dental expenditures) ■



## Client Information

Using data from Section 2 of the CADR, this section of the report describes the characteristics of CARE Act clients as reported by CARE Act providers (n=2,696) that reported data between January 2002 and December 2002. The client information narrative is based on the data tables presented in this section.

### CLIENTS SERVED

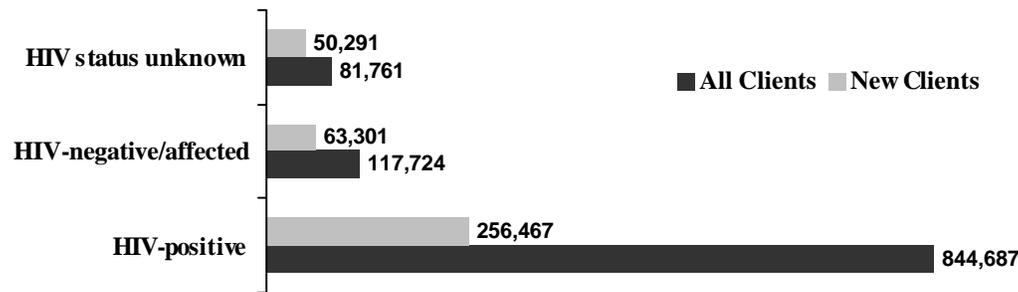
In 2002, CARE Act providers served 1,044,172 duplicated clients. Service organizations reported a total of 370,059 duplicated, new clients. Of the total clients served, 844,687 (81 percent) were HIV-positive while 199,485 duplicated clients (19 percent) were HIV-affected<sup>3</sup>. Among new clients, 256,467 duplicated

clients (69 percent) were HIV-positive, and 113,592 (or 31 percent) of duplicated clients were HIV-affected (Figure 2).

### GENDER

Overall, 64 percent of clients were male while 33 percent were female. One percent of the clients served in 2002 were transgender. Interestingly, the gender distribution varies by HIV status (positive or affected). Among HIV-positive duplicated clients receiving services by a CARE Act provider, a majority (68 percent) were male and a smaller proportion of clients (31 percent) were female. This is in contrast to the clients that were HIV-affected: 48 percent were male and 42 percent were female (Table 7, page 0).

Figure 2. Total Duplicated Clients Served, Ryan White CARE Act, 2002<sup>3,4,5</sup>



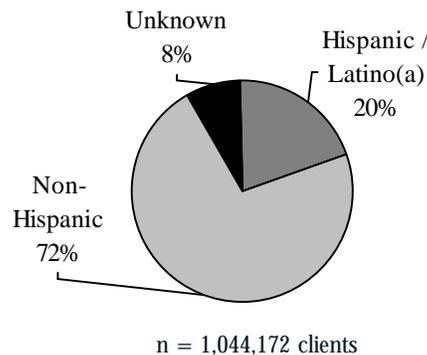
## AGE

Overall, 55 percent of the clients served in 2002 were in the age group 25 to 44 years while 29 percent were in the age group 45 to 64 years. Findings were similar for HIV-positive clients: 60 percent were in the age group 25 to 44 years while 32 percent of the clients were in the age group 45 to 64 years. The situation was different for HIV-affected clients: 35 percent were in the age group 25 to 44, 18 percent were in age group 45 to 64, and about the same percentage were in the unreported group (17 percent) and in the 13 to 24 age group (16 percent).

## ETHNICITY

Twenty percent of all clients served were Hispanic/Latino(a) and 72 percent were non-Hispanic/Latino(a) (Figure 3). Similarly, 20 percent of all HIV-positive clients served were Hispanic/Latino(a) and 75 percent were non-Hispanic/Latino(a). Among HIV-affected clients, 23 percent were Hispanic/Latino(a) and 59 percent were non-Hispanic/Latino(a). Ethnic identity was unknown for a large percentage (19 percent) of HIV-affected clients.

Figure 3. Total Ethnicity, 2002



## RACE

For clients overall and among those who were HIV-positive, over 50 percent of the clients served by CARE Act providers were members of racial minority groups<sup>6</sup> (Figure 4, page 11). Race was unknown or unreported for a sizeable percentage of clients (Table 7, page 10). Whites comprised approximately 34 percent and 35 percent, respectively, of clients served both overall and among those who were HIV-positive. For clients who were HIV-affected, race was unknown or unreported for a large percentage of clients (26 percent).

States, and local community-based organizations to provide services to approximately 533,000 individuals each year who do not have sufficient health care coverage or financial resources for coping with HIV disease. This estimate of 533,000 individuals served by the CARE Act is derived through statistical modeling to estimate the extent of duplication in provider reports of clients served. The majority of CARE Act funds support primary medical care and essential support services. A smaller, but equally critical portion is used to fund technical assistance, clinical training and research on innovative models of care. The CARE Act, first authorized in 1990, is currently funded at \$1.9 billion.

# THE PROGRAMS THAT MAKE UP THE CARE ACT

## TITLE I

Title I provides grants to 51 Eligible Metropolitan Areas (EMAs) disproportionately affected by HIV/ AIDS. These areas must have at least 500,000 residents and have reported at least 2,000 AIDS cases in the previous 5 years. Title I funds may be used to provide a continuum of care for persons living with HIV disease. Services include:

- Outpatient and ambulatory health services including substance abuse and mental health treatment.

- Early intervention services that include outreach, counseling and testing, and referral services designed to identify HIV-positive individuals who know their HIV status.

- Outpatient and ambulatory support services including case management to the extent that these support services facilitate, enhance, support or sustain delivery, continuity or benefits of health services.

- Inpatient case management services that expedite discharge and prevent unneces-

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Table 7: Gender, Age, Ethnicity, and Race of Clients Who Received CARE Act Services, 2002<sup>1, 3, 5, 6, 7, 8, 9</sup>.

|                                   | HIV-positive   |             | HIV-affected   |             | Total            |             |
|-----------------------------------|----------------|-------------|----------------|-------------|------------------|-------------|
|                                   | Number         | Percent     | Number         | Percent     | Number           | Percent     |
| <b>Gender</b>                     |                |             |                |             |                  |             |
| Male                              | 571,378        | 68%         | 95,928         | 48%         | 667,306          | 64%         |
| Female                            | 264,562        | 31%         | 84,225         | 42%         | 348,787          | 33%         |
| Transgender                       | 4,085          | 1%          | 3,781          | 2%          | 7,866            | 1%          |
| Unknown/unreported                | 4,662          | 1%          | 15,551         | 8%          | 20,213           | 2%          |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Age</b>                        |                |             |                |             |                  |             |
| Less than 2 years                 | 3,230          | <1%         | 7,581          | 4%          | 10,811           | 1%          |
| 2 - 12 years                      | 13,105         | 2%          | 17,005         | 9%          | 30,110           | 3%          |
| 13 - 24 years                     | 34,529         | 4%          | 32,630         | 16%         | 67,159           | 6%          |
| 25 - 44 years                     | 504,665        | 60%         | 70,437         | 35%         | 575,102          | 55%         |
| 45 - 64 years                     | 267,270        | 32%         | 34,934         | 18%         | 302,204          | 29%         |
| 65+ years                         | 11,260         | 1%          | 2,752          | 1%          | 14,012           | 1%          |
| Unknown/unreported                | 10,628         | 1%          | 34,146         | 17%         | 44,774           | 4%          |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Ethnicity</b>                  |                |             |                |             |                  |             |
| Hispanic/Latino(a)                | 167,439        | 20%         | 45,090         | 23%         | 212,529          | 20%         |
| Non-Hispanic                      | 631,102        | 75%         | 117,252        | 59%         | 748,354          | 72%         |
| Unknown/unreported                | 46,146         | 6%          | 37,143         | 19%         | 83,289           | 8%          |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Race</b>                       |                |             |                |             |                  |             |
| White                             | 299,123        | 35%         | 57,076         | 29%         | 356,199          | 34%         |
| Black or African American         | 388,835        | 46%         | 82,336         | 41%         | 471,171          | 45%         |
| Asian                             | 7,988          | 1%          | 1,688          | 1%          | 9,676            | 1%          |
| Pacific Islander                  | 1,204          | <1%         | 108            | <1%         | 1,312            | <1%         |
| Native American/<br>Alaska Native | 5,500          | 1%          | 702            | <1%         | 6,202            | 1%          |
| More than one race                | 30,365         | 4%          | 6,698          | 3%          | 37,063           | 3%          |
| Unknown/unreported                | 111,672        | 13%         | 50,877         | 26%         | 162,549          | 16%         |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |

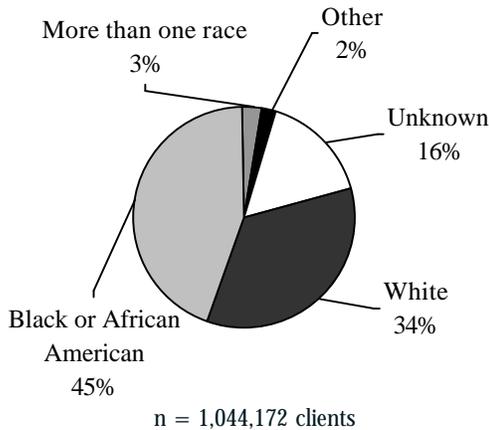
## HOUSEHOLD INCOME

Overall, the percentage of clients with incomes equal to or below the Federal Poverty Level (FPL) was 44 percent (Table 8). Household income status was unknown or unreported for a third of clients. In examining household income by HIV status, 65

percent of HIV-positive clients had household incomes equal to or below FPL or between 101 to 200 percent of the FPL. By contrast, only 22 percent of clients who were HIV-affected had household incomes in the same category. CARE Act providers did not report the household income status for most HIV-affected clients (sixty-seven percent).

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Figure 4. Total Race, 2002<sup>1, 9</sup>



## HOUSING ARRANGEMENTS

Permanent housing arrangements were reported for 49 percent of clients overall and 55 percent among clients who were HIV-positive. Among those who were HIV-positive, 11 percent of the clients receiving services from CARE Act providers in 2002 were living in non-permanent housing. Eight percent of the HIV-affected clients served were non-permanently

housed. The housing status was unknown for 57 percent of HIV-affected clients.

## HIV/AIDS STATUS

Overall, most clients receiving CARE Act services were recorded in one of three categories: 1) HIV-positive, not AIDS (34 percent); 2) AIDS as defined by CDC (28 percent); or 3) HIV-positive, AIDS unknown (19 percent) (Table 9).

## ENROLLMENT STATUS

Among the HIV-positive clients who received CARE Act services in 2002, 59 percent were active and had a history of receiving CARE Act care and treatment services with the CARE Act providers while 24 percent were active and new to the CARE Act provider (Table 9). By contrast, 19 percent of HIV-affected clients were active and continuing in the providers' programs, 28 percent were active and new to the programs, and 43 percent

## TITLE II

Title II provides grants to States and Territories to improve the quality, availability, and organization of HIV/AIDS health care and support services. Services include:

- :: Ambulatory health care.
- :: Home-based health care.
- :: Insurance coverage.
- :: Medications.
- :: Support services.
- :: Outreach to HIV-positive individuals who know their HIV status.
- :: Early intervention services.
- :: HIV Care Consortia, which assess needs and contracts for services.

Title II also provides access to medications through the AIDS Drug Assistance Program (ADAP).

## AIDS DRUG ASSISTANCE PROGRAM (ADAP)

ADAP provides medications for the treatment of HIV disease. Program funds may also be

Table 8: Household Income and Housing Arrangements for Clients Who Received CARE Act Services, 2002<sup>1, 3, 5, 10, 11, 12, 13, 14</sup>

|                             | HIV-positive   |             | HIV-affected   |             | Total            |             |
|-----------------------------|----------------|-------------|----------------|-------------|------------------|-------------|
|                             | Number         | Percent     | Number         | Percent     | Number           | Percent     |
| <b>Household Income</b>     |                |             |                |             |                  |             |
| Equal to or below FPL       | 424430         | 50%         | 38094          | 19%         | 462524           | 44%         |
| 101-200% FPL                | 125608         | 15%         | 6444           | 3%          | 132052           | 13%         |
| 201-300% FPL                | 42051          | 5%          | 2159           | 1%          | 44210            | 4%          |
| Greater than 300% FPL       | 31409          | 4%          | 19133          | 10%         | 50542            | 5%          |
| Unknown/unreported          | 221189         | 26%         | 133655         | 67%         | 354844           | 34%         |
| <b>Total</b>                | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Housing Arrangements</b> |                |             |                |             |                  |             |
| Permanently housed          | 463,992        | 55%         | 50,870         | 26%         | 514,862          | 49%         |
| Non-permanently housed      | 90,712         | 11%         | 16,484         | 8%          | 107,196          | 10%         |
| Institution                 | 24,902         | 3%          | 2,610          | 1%          | 27,512           | 3%          |
| Other                       | 14,183         | 2%          | 16,168         | 8%          | 30,351           | 3%          |
| Unknown/unreported          | 250,898        | 30%         | 113,353        | 57%         | 364,251          | 35%         |
| <b>Total</b>                | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |

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used to purchase health insurance for eligible clients. Amendments to the Ryan White CARE Act in October 2000 added additional language allowing ADAP funds to be used to pay for services that enhance access, adherence, and monitoring of drug treatments. The program is funded through Title II of the CARE Act, which provides grants to States and Territories.

### TITLE III EARLY INTERVENTION SERVICES (EIS)

Title III EIS supports outpatient HIV early intervention services and ambulatory care. Title III grants, in contrast to grants under the previous Titles, are awarded directly to providers. Services include:

- :: Risk-reduction counseling on prevention, antibody testing, medical evaluation, and clinical care.

- :: Antiretroviral therapies; protection against opportunistic infections; and ongoing medical, oral health, nutritional, psychosocial, and other care services for HIV-infected clients.

- :: Case management to

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HIV-affected clients had an unreported or unknown enrollment status.

### MEDICAL INSURANCE

Overall, 38 percent of clients receiving services from CARE Act providers were covered by publicly-funded medical insurance, 21 percent of clients had no medical insurance, and 8 percent had private insurance. HIV-positive clients were more likely to be Medicaid recipients (28 percent) or to have no medical

insurance (25 percent). Insurance status was unknown or unreported for 30 percent of all clients. A majority of the clients with unknown or unreported medical insurance were HIV-affected (Table 9).

Table 9: Disease Status, Enrollment Status, and Medical Insurance Status for Clients Who Received CARE Act Services, 2002<sup>1, 3, 5, 15, 16</sup>

|                                   | HIV-positive   |             | HIV-affected   |             | Total            |             |
|-----------------------------------|----------------|-------------|----------------|-------------|------------------|-------------|
|                                   | Number         | Percent     | Number         | Percent     | Number           | Percent     |
| <b>HIV/AIDS Status</b>            |                |             |                |             |                  |             |
| HIV positive, not AIDS            | 359,773        | 43%         | -              | -           | 359,773          | 34%         |
| HIV positive, AIDS unknown        | 195,398        | 23%         | -              | -           | 195,398          | 19%         |
| CDC-defined AIDS                  | 289,516        | 34%         | -              | -           | 289,516          | 28%         |
| HIV-negative                      | -              | -           | 90,992         | 46%         | 90,992           | 9%          |
| Unknown/unreported                | -              | -           | 108,493        | 54%         | 108,493          | 10%         |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Clients' Enrollment Status</b> |                |             |                |             |                  |             |
| Active, new to program            | 204,740        | 24%         | 55,110         | 28%         | 259,850          | 25%         |
| Active, continuing in program     | 500,564        | 59%         | 37,279         | 19%         | 537,843          | 52%         |
| Deceased                          | 13,858         | 2%          | 344            | 0%          | 14,202           | 1%          |
| Inactive                          | 70,707         | 8%          | 21,132         | 11%         | 91,839           | 9%          |
| Unknown/unreported                | 54,818         | 7%          | 85,620         | 43%         | 140,438          | 13%         |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |
| <b>Medical Insurance</b>          |                |             |                |             |                  |             |
| Private                           | 72,026         | 9%          | 6,535          | 3%          | 78,561           | 8%          |
| Medicare                          | 69,911         | 8%          | 2,056          | 1%          | 71,967           | 7%          |
| Medicaid                          | 236,001        | 28%         | 28,119         | 14%         | 264,120          | 25%         |
| Other public                      | 56,568         | 7%          | 6,273          | 3%          | 62,841           | 6%          |
| No insurance                      | 207,151        | 25%         | 11,676         | 6%          | 218,827          | 21%         |
| Other                             | 15,335         | 2%          | 16,989         | 9%          | 32,324           | 3%          |
| Unknown/unreported                | 187,695        | 22%         | 127,837        | 64%         | 315,532          | 30%         |
| <b>Total</b>                      | <b>844,687</b> | <b>100%</b> | <b>199,485</b> | <b>100%</b> | <b>1,044,172</b> | <b>100%</b> |

# Service Utilization

Using data from Section 3 of the CADR, this section of the report describes provider services utilized by clients through the CARE Act between January 2002 and December 2002. The service utilization narrative is based on the data tables presented in this section.

## SERVICE UTILIZATION FOR HEALTH CARE SERVICES

Organizations providing one or more health care and/or case management service report the number of clients receiving each service as well as the total number of visits per service. Table 10 presents the total number duplicated clients served and the number of visits reported by CARE Act providers during 2002 for each health care service and case management. Case management services and

outpatient/ambulatory medical care services were the most frequently utilized CARE Act services in 2002. CARE Act case management providers reported serving 332,377 HIV-positive clients. More than 3.6 million client visits were recorded by the CARE Act providers delivering case management services to HIV-positive clients. Case management services include activities such as initial assessment of service needs; development of a comprehensive, individualized service plan; coordination of client services; and periodic re-evaluation and adaptation of the individualized service plan over the life of the client.

Next, CARE Act providers reported that outpatient/ambulatory medical care services were used by 319,295 clients in a little more than 2 million client visits. In

Table 10. Health Care and Case Management Services, Ryan White CARE Act, 2002

| Health Care Services                  | Number of Duplicated Clients Served | Total Visits |
|---------------------------------------|-------------------------------------|--------------|
| Ambulatory/Outpatient Medical Care    | 319,295                             | 2,099,774    |
| Mental Health Care                    | 81,437                              | 609,314      |
| Oral Health Care                      | 71,504                              | 219,045      |
| Substance Abuse Services, outpatient  | 36,084                              | 630,175      |
| Substance Abuse Services, residential | 3,292                               | 153,250      |
| Rehabilitation Services               | 1,300                               | 14,530       |
| Home health: paraprofessional care    | 3,865                               | 171,991      |
| Home health: professional care        | 2,998                               | 55,226       |
| Home health: specialized care         | 858                                 | 10,448       |
| Case management services              |                                     |              |
| HIV-positive clients                  | 332,377                             | 3,689,838    |
| HIV-affected clients                  | 23,854                              | 124,254      |

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ensure access to services and continuity of care for HIV-infected clients.

:: Attention to other health problems that occur frequently with HIV infection, including tuberculosis and substance abuse.

## TITLE III PLANNING GRANT PROGRAM

Title III Planning Grant Program funds eligible entities in their efforts to plan for the provision of high quality comprehensive HIV primary health care services in rural or urban underserved areas and communities of color. Activities can include but are not limited to:

:: Identifying key stakeholders and engaging and coordinating potential partners in the planning process.

:: Gathering a formal advisory group to plan for the establishment of services.

:: Conducting an in-depth review of the nature and extent of need for HIV primary care services in the community. This should include a local epidemiological profile, an evaluation of the community's service provider

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capacity, and a profile of the target population(s).

:: Defining the components of care and forming essential programmatic linkages with related providers in the community.

:: Researching funding sources and applying for operational grants.

### TITLE III CAPACITY BUILDING GRANT PROGRAM

Title III Capacity Building Program funds eligible entities in their efforts to strengthen their organizational infrastructure and increase their capacity to develop, enhance or expand high quality HIV primary health care services in rural or urban underserved areas and communities of color. Title III Capacity Grant activities fall into three infrastructure development categories: Management Systems, Service Delivery Systems, and Evaluation Systems. Activities can include but are not limited to:

:: Identifying, establishing and strengthening clinical, administrative, managerial, and management information system (MIS) structures.

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addition to HIV primary care, this category of service utilization includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, and other related activities. Clients frequently used three other health care service categories. First, outpatient substance abuse services are defined as the medical treatment and counseling to address substance abuse problems provided in an outpatient setting rendered by a physician or under the supervision of a physician. Slightly more than 36,000 clients received outpatient substance abuse treatment services from providers in 2002. This service category reported 630,175 client visits during the reporting period. Second, mental health services were utilized by 81,437 clients in 609,314 visits. Finally, a total of 71,504 clients received oral health care services (excluding services funded by the Dental Reimbursement Program and the Community Based

Dental Partnership Program) in 2002. Providers of oral health care reported 219,045 client visits. Service utilization for other health care services in 2002 is presented in Table 10, page 13.

### NUMBER OF VISITS PER CLIENT BY SERVICE CATEGORY

The average number of visits per client by type of service is presented in Table 11. It is important to note that for each service type, the actual number of providers serving clients is higher. However, the average number of visits per client was calculated only for those providers reporting valid data for both the number of clients served and number of visits. Please note that providers may offer multiple services; thus, a provider may be included in more than one service category. In addition, the median number of visits per clients is presented for health care service visits per client.

Table 11. Number of Visits per Client by Service Category, 2002<sup>17, 18, 19, 20</sup>

| Health Care Services                  | Number of Providers* | Average Number of visits/client | Median Number of visits/client | Range    |
|---------------------------------------|----------------------|---------------------------------|--------------------------------|----------|
| Ambulatory/Outpatient Medical Care    | 837                  | 6.96                            | 5.06                           | 1-166.67 |
| Mental Health Care                    | 813                  | 7.97                            | 5.12                           | 1-96.77  |
| Oral Health Care                      | 510                  | 2.79                            | 2.20                           | 1-67.83  |
| Substance Abuse Services, outpatient  | 407                  | 20.42                           | 6.13                           | 1-321.52 |
| Substance Abuse Services, residential | 79                   | 27.41                           | 7.83                           | 1-360.00 |
| Rehabilitation Services               | 55                   | 11.43                           | 2.67                           | 1-160.00 |
| Home health: paraprofessional care    | 137                  | 37.03                           | 12.00                          | 1-320.91 |
| Home health: professional care        | 90                   | 17.73                           | 5.96                           | 1-163.85 |
| Home health: specialized care         | 45                   | 11.92                           | 6.06                           | 1-72.00  |
| Case management services              | 1,235                | 14.63                           | 9.20                           | 1-292.45 |

\*Data reported in this table are based on valid reports only. Valid data are defined as providers reporting complete data for both number of clients served and number of visits.

As previously noted, case management and outpatient/ambulatory medical care services were the most utilized CARE Act services in 2002. For case management services, the average number of visits per client was 14.63 (median=9.20; range=1 - 292.45). Among the outpatient/ambulatory medical services utilized in the previous year, the average number of visits per clients was 6.96 (median=5.06; range=1 - 166.67).

Of the outpatient substance abuse services utilized in 2002, the average number of visits per clients was 20.42 (median=6.13; range=1 - 321.52). For mental health care services utilized, the average number of visits per clients was 7.97 (median=5.12; range=1 - 96.77). Finally, for oral health care services (not including services funded by the Dental

Reimbursement Program and the Community Based Dental Partnership Program), the average number of visits per clients was 2.79 (median=2.20; range=1 - 67.83).

## UTILIZATION OF SUPPORT SERVICES

CARE Act providers also deliver an array of supportive services to HIV-positive and HIV-affected clients (Table 12, page 16). Supportive services are offered by CARE Act programs to promote entry into and retention in HIV primary medical care. CARE Act providers delivered the highest number of support services (duplicated client counts) to HIV-positive clients in the following categories of service: food bank/home-delivered meals (113,673 clients), client advocacy (113,363 clients), health education/risk reduction (111,716 clients), transportation services (100,185 clients), and treatment adherence counseling (91,948 clients). Utilization of support services was somewhat different among HIV-affected clients. The highest number of support services (duplicated client counts) delivered by CARE Act providers to HIV-affected clients included outreach services (86,116 clients) and health education/risk reduction (76,045 clients). Outreach and health education/risk reduction services endeavor to prevent further transmission of HIV among CARE Act clients who are HIV-positive, HIV-affected, and those for whom HIV/AIDS status is unknown. Notice that for all categories of supportive services, CARE Act providers reported serving larger numbers of HIV-positive clients than HIV negative clients. ■

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:: Developing a financial management unit of the organization.

:: Developing and implementing a clinical continuous quality improvement (CQI) program.

:: Purchasing clinical supplies and equipment for the purpose of developing, enhancing, or expanding HIV primary care services.

:: Developing an organizational strategic plan to address managed care changes or changes in the HIV epidemic in the community.

:: A package of activities that includes the development of an organizational strategic plan for HIV care, education of Board members regarding the HIV program, and staff training and development regarding HIV care.

## TITLE IV

Title IV provides family-centered comprehensive care to women, infants, children, youth, and their families, and helps improve access to clinical trials and research. All CARE Act programs are

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required to serve women, infants, children and youth living with HIV disease, but Title IV addresses the needs of these populations specifically. Services include:

:: Primary and specialty medical care.

:: Psychosocial services.

:: Logistical support and coordination.

:: Outreach and case management.

Title IV also provides support services to affected family members of HIV-infected clients.

### SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE (SPNS)

SPNS support the demonstration and evaluation of innovative models of HIV/AIDS care delivery for hard-to-reach populations. The SPNS Program is considered the research and development arm of the Ryan White CARE Act and provides the mechanisms to 1) assess the effectiveness of particular models of care, 2) support innovative program design, and 3) promote replication of effective model.

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Table 12. Number of Duplicate Clients Receiving Support Services From the CARE Act, 2002

| Support Services                          | Total Duplicated HIV-positive Clients | Total Duplicated HIV-affected Clients |
|---|---------------------------------------|---------------------------------------|
| Buddy/companion services                  | 8,729                                 | 494                                   |
| Child care services                       | 3,230                                 | 2,932                                 |
| Child welfare services                    | 939                                   | 565                                   |
| Client advocacy                           | 113,363                               | 9,382                                 |
| Day/respice care for adults               | 5,049                                 | 493                                   |
| Developmental assessment                  | 2,856                                 | 1,277                                 |
| Early intervention services/Titles I & II | 9,638                                 | 2,641                                 |
| Emergency financial assistance            | 74,965                                | 5,290                                 |
| Food bank/home-delivered meals            | 113,673                               | 6,758                                 |
| Health education/risk reduction           | 111,716                               | 76,045                                |
| Housing services                          | 46,037                                | 1,698                                 |
| Legal services                            | 21,679                                | 934                                   |
| Nutritional counseling                    | 73,089                                | 2,649                                 |
| Outreach services                         | 49,247                                | 86,116                                |
| Permanency planning                       | 5,596                                 | 1,593                                 |
| Psychosocial support services             | 87,414                                | 12,792                                |
| Referral: health care/support services    | 86,690                                | 36,291                                |
| Referral: clinical research               | 20,745                                | 1,245                                 |
| Hospice care: residential/in-home         | 1,245                                 | 119                                   |
| Transportation services                   | 100,185                               | 5,486                                 |
| Treatment adherence counseling            | 91,948                                | 2,676                                 |
| Other services                            | 84,707                                | 13,069                                |

## HIV Counseling and Testing

Using data from Section 4 of the CADR, this section of the report describes HIV counseling and testing services utilized by clients through the CARE Act between January 2002 and December 2002. The HIV counseling and testing narrative is based on the data tables presented in this section.

### PROVIDER-RELATED DATA

In 2002, 28 percent of all CARE Act funded organization reporting CADR data (n=753) provided HIV counseling and testing services (Table 13). These services include activities such as pretest counseling on the benefits of testing (in-

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cluding the medical benefits of diagnosing HIV disease in the early stages); and providing HIV antibody tests and posttest counseling (including the benefits of receiving early primary care intervention). Of those providers delivering HIV counseling and testing services to clients, 43 percent of providers (n=320) used CARE Act funds to provide these services while 58 percent of providers (n=433) did not use CARE Act funds. In 2002, 38 percent of providers (n=283) offered partner notification services. Certain States and local jurisdictions mandate that only health department personnel perform partner notification activities. The data reported in the CADR may include information from Ryan White CARE Act providers who must refer partner notification activities to health department personnel for action.

## CLIENT-RELATED DATA

CARE Act providers offering HIV counseling and testing reported important utilization data concerning the clients receiving these services in 2002. The number of infants tested during the reporting period was 13,024.

In 2002, HIV pretest counseling was provided to 773,170 persons with 626,739 persons or 81 percent receiving confidential HIV pretest counseling services and 146,431 persons or 19 percent receiving anonymous HIV pretest counseling services. Of the 773,170 persons who received HIV pretest counseling, 92 percent (n=707,812) were tested for the HIV antibody during the reporting period. Ninety-one percent (n=569,646) of the 626,739 individuals who received pretest counseling underwent confidential testing while 94 percent (n=138,166) of the 146,431 individuals who received anonymous pretest counseling were tested for HIV antibodies (Table 14).

## AIDS EDUCATION AND TRAINING CENTERS (AETC)

The AETCs support education and training of health care providers through a network of eleven regional centers and four national resource centers. The program goal is to increase the number of health care providers who are educated and motivated to counsel, diagnose, treat, and medically manage individuals with HIV infection and to help prevent high risk behaviors that lead to HIV transmission.

## HIV/AIDS DENTAL REIMBURSEMENT PROGRAM (DRP)

The DRP provides reimbursements to dental schools, post-doctoral dental education programs, and schools of dental hygiene for uncompensated costs incurred in providing oral health treatment to patients with HIV disease. The Dental Reimbursement Program awards funds to support these institutions in providing comprehensive oral health care to individuals with HIV. This care includes diagnostic, preventive, oral health education and

Table 13. Number of CARE Act Providers Offering HIV Counseling and Testing, 2002

| Provider-related Data   | Number       | Percent     |
|---|--------------|-------------|
| <b>Program provides HIV counseling and testing services</b>   |              |             |
| Yes   | 753          | 28%         |
| No  | 1,942        | 72%         |
| Missing   | 1            | <1%         |
| <b>Total</b>  | <b>2,696</b> | <b>100%</b> |
| <b>CARE Act funds used to support HIV counseling services</b> |              |             |
| Yes   | 320          | 43%         |
| No  | 433          | 57%         |
| <b>Total</b>  | <b>753</b>   | <b>100%</b> |
| <b>Program offered partner notification</b>                   |              |             |
| Yes   | 283          | 38%         |
| No  | 470          | 62%         |
| <b>Total</b>  | <b>753</b>   | <b>100%</b> |
| Client-related Data   | Number       | Percent     |
| Number of infants tested during reporting period              | 13,024       |             |

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health promotion, restorative, periodontal, prosthodontic, endodontic, oral surgery, and oral medicine services.

### COMMUNITY-BASED DENTAL PARTNERSHIP PROGRAM (CBDPP)

The CBDPP funds eligible entities in their efforts to increase access to oral health care for unserved and underserved rural and urban HIV positive populations. Programs funded by the Community-Based Dental Partnership program are to be collaborative efforts between the eligible entity and community-based dental providers that propose to:

- :: Provide oral health services for individuals with HIV.
- :: Establish and manage clinical rotations for students and residents in community-based settings.
- :: Collaborate and coordinate between the dental education programs and the community-based partners in the delivery of oral health services.
- :: Collect, manage, and report data that will assess/describe the service delivery and educational components of the funded programs.
- :: Ensure patient confidentiality and the establishment and review of a system for control of records of HIV-positive patients.

CARE Act providers reported that a total of 15,691 individuals had a positive test result for the HIV antibody among those who received pretest counseling and were tested. This means that among those who received HIV pretest counseling and were tested for the HIV antibody, 2.2 percent of individuals tested positive for HIV antibodies.

CARE Act providers were also concerned with providing prevention and/or treatment services to individuals after testing. Overall, CARE Act providers reported that 436,661 individuals or 62 percent of those who received HIV pretest counseling and were tested for the HIV antibody returned for posttest counseling. Among those returning for posttest counseling, 340,467 individuals or 78 percent received confidential counseling and 96,194 individuals (22 percent) received anonymous counseling services.

Differences were noted in the rate of return for posttest counseling between individuals who received confidential testing and those who underwent anonymous testing. While 60 percent of individuals who received confidential HIV pretest counseling and testing services returned for posttest counseling, a higher percentage of individual receiving anonymous services (70 percent) returned for posttest counseling.

CARE Act providers reported that a total of 2,638 individuals had a positive test result for the HIV antibody and did not return for posttest counseling. This means that among those who received a positive test result for the HIV antibody through a CARE Act provider, 16.8 percent of individuals did not return for testing results and post test counseling services. ■

Table 14. Number of Persons Receiving HIV Counseling and Testing from CARE Act Providers, 2002

|  | Confidential Testing |         | Anonymous Testing |         | Total   |         |
|--|----------------------|---------|-------------------|---------|---------|---------|
|  | Number               | Percent | Number            | Percent | Number  | Percent |
| Number of individuals who received HIV pretest counseling  | 626,739              |         | 146,431           |         | 773,170 |         |
| Of the individuals receiving pretest counseling, number and percent who were tested for HIV antibodies                                     | 569,646              | 90.9%   | 138,166           | 94.3%   | 707,812 | 91.5%   |
| Of the individuals who received pretest counseling and were tested for HIV antibodies, number and percent who had a positive test          |                      |         |                   |         | 15,691  | 2.2%    |
| Of the individuals who received pretest counseling and were tested for HIV antibodies, number and percent who received posttest counseling | 340,467              | 59.8%   | 96,194            | 69.6%   | 436,661 | 61.7%   |
| Number and percent of individuals who tested positive for HIV antibodies but did not return for posttest counseling                        |                      |         |                   |         | 2,638   | 16.8%   |

# AIDS Drug Assistance Program

## CLIENTS SERVED

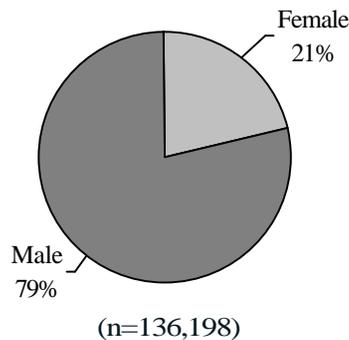
In 2002, 52 State and U.S. Territory AIDS Drug Assistance Programs (ADAPs) served 136,345 enrolled clients. Twenty-four percent of the clients served by ADAP (n=32,221) were newly enrolled during the reporting period. The number of clients served by ADAP in 2002 cannot be compared to previous years because two programs failed to report ADAP data in 2002. However, in the following section on client characteristics, the proportion of clients served by gender, ethnicity, race, and age are compared to previous years.

## CLIENT CHARACTERISTICS

### GENDER

As seen in the Figure 5, the majority of clients served by ADAP were males (79 percent, n=107,185). In comparison, 78 percent of the clients served by ADAP in 2001 were males. In 2002, the 52 programs that reported ADAP data served 29,013 females. Less than one percent of the clients served by ADAP were transgender (Table 15).

Figure 5. Gender of Clients Served by ADAP, 2002



### ETHNICITY

Persons of Hispanic/Latino(a) ethnicity comprised 21 percent of the clients served by ADAP in 2002. Seventy-one percent of ADAP clients were non-Hispanic/Latino(a) and ethnicity was unknown or unreported for eight percent of those served by ADAP (Table 15, page 21).

### RACE

In 2002, African Americans/Blacks comprised 38 percent of the clients served by ADAP. In comparison, 37 percent of ADAP clients were African American/Blacks in 2001. Asian/Native Hawaiian/other Pacific Islander and American Indians/Alaska Natives combined accounted for less than two percent of ADAP clients in 2002, and clients reporting more than one race comprised one percent of ADAP clients served. Forty-three percent of the clients served by ADAP in 2002 were

The CARE Act Data Report (CADR) is an annual data report form used to collect information from grantees and service providers funded under Titles I, II, III and/or IV of the Ryan White CARE Act (CARE Act). The CADR collects general information on provider and program characteristics including the types of organizations providing services (such as ownership status), sources of revenue, expenditures, paid and volunteer staff. Each provider reports information on the demographic, medical and support service utilization, prescription drug use, and health insurance status in total and for different client groups using the CADR.

### WHO COMPLETES THE CADR

The CADR should be completed by all Ryan White CARE Act Title I, II, III, and IV-funded grantees, and provider agencies.

Providers who receive funds under more than one Title should complete this form once and submit copies to all grantees from whom they receive CARE Act funds.

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Each grantee of record should assemble all report forms completed by their providers, then complete one cover page and attach it to the assembled batch of completed forms. The grantee should then submit this entire package to the HRSA data contractor. CAREWare, a free software package assists grantees in collecting client-level data and generating the annual CADR. Download the latest version of CAREWare online at: <http://hab.hrsa.gov/careware/>

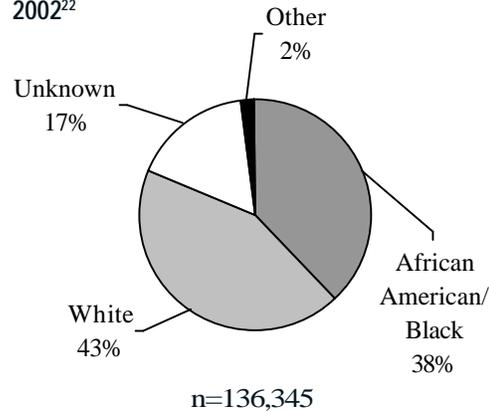
## SUMMARY OF CADR DATA LIMITATIONS

- :: CADR data are descriptive
- :: CADR data may contain duplicate client counts when combined to the grantee or national level
- :: CADR data are aggregate in nature

For more details see "Making the CADR Work for You: A How-to Manual for Using the CARE Act Data Report to Address Your Data Needs" online at <http://hab.hrsa.gov/tools/cadrpublication/toc.htm>

White. Race was unknown or unreported for 17 percent of ADAP clients. (Figure 6).

Figure 6. Race of Clients Served by ADAP, 2002<sup>22</sup>



## AGE

In 2002, 64 percent of the clients served by ADAP were 25 to 44 years of age. Persons age 45 to 64 years comprised 32 percent of the clients served by ADAP and an additional two percent were age 65 years or older. It is interesting to note that the proportion of clients served who were 45 years or older continues to increase. In 2002, 34 percent of ADAP clients were age 45 years or older compared to 29 percent in 2001. Three percent of ADAP clients in 2002 were 13 to 24 years old and less than one percent of clients were age 12 years or younger (Table 15).

## ADAP FUNDING AND EXPENDITURES

ADAPs receive funding from multiple sources. In addition to the Title II ADAP

earmark and ADAP supplemental funding, ADAPs may receive funding from Ryan White CARE Act Title I, Title II base, and other CARE Act funding. Total ADAP funding may include Medicaid; Medicare; other Federal, State and local government funding; other public payments, manufacturer rebates, private contributions, and client payments as well as CARE Act funding. In 2002, the Ryan White CARE Act Title II earmark was the primary source of funding for ADAP.

In FY 2002, a total of \$639,000,000 was awarded to State and territories for AIDS Drug Assistance Programs; an 8.5 percent increase from FY2001. ADAPs reported receiving additional funding of \$287,921,065 from other sources. This included State and local contributions of \$154,265,290 in 2002.

In 2002, the 52 ADAPs submitting CADR data reported drug expenditures totaling \$820,298,784. State ADAPs spent 87 percent or \$710,113,962 of the total drug expenditures on antiretroviral medications (protease inhibitors (PI), nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), and nucleotide reverse transcriptase (NtRT)).

As seen in Figure 7, nucleoside reverse transcriptase inhibitors accounted for 53 percent of all drug expenditures in 2002 followed by protease inhibitors (17 percent) and non-nucleoside reverse tran-

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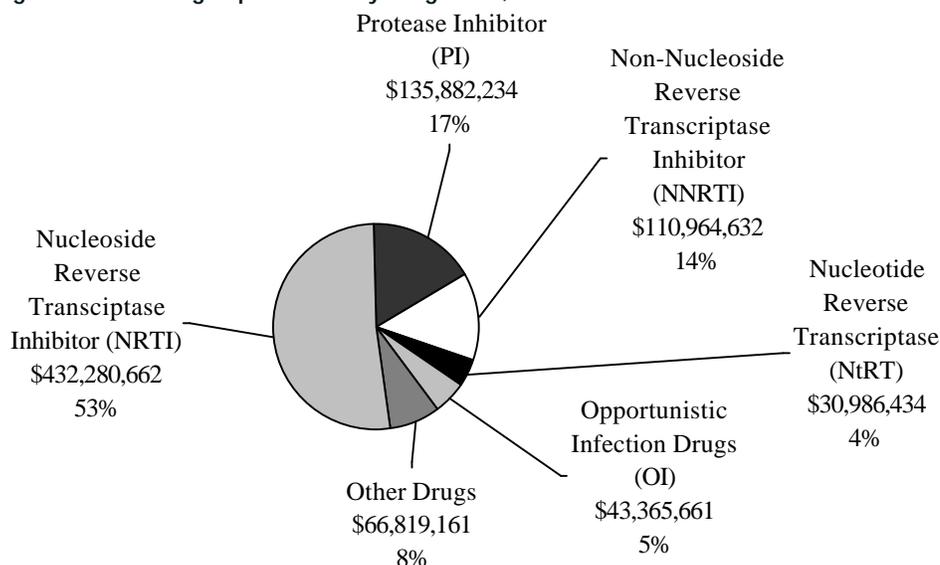
Table 15. Demographic Characteristics of Clients Served by ADAP, 2002

| Demographic Characteristics            | Number         | Percent     |
|--|----------------|-------------|
| <b>Gender</b>                          |                |             |
| Male                                   | 107,185        | 79%         |
| Female                                 | 29,013         | 21%         |
| Transgender                            | 96             | <1%         |
| Unknown/Unreported                     | 51             | <1%         |
| <b>Total</b>                           | <b>136,345</b> | <b>100%</b> |
| <b>Ethnicity</b>                       |                |             |
| Hispanic/Latino(a)                     | 28,470         | 21%         |
| Non-Hispanic                           | 96,403         | 71%         |
| Unknown/Unreported                     | 11,472         | 8%          |
| <b>Total</b>                           | <b>136,345</b> | <b>100%</b> |
| <b>Race</b>                            |                |             |
| White                                  | 58,975         | 43%         |
| African American/Black                 | 51,288         | 38%         |
| Asian/Native Hawaiian/Pacific Islander | 1,292          | 1%          |
| Native American/Alaska Native          | 568            | <1%         |
| More than one race                     | 969            | 1%          |
| Unknown/Unreported                     | 23,065         | 17%         |
| <b>Total</b>                           | <b>136,345</b> | <b>100%</b> |
| <b>Age</b>                             |                |             |
| Less than 2 years                      | 164            | <1%         |
| 2 –12 years                            | 450            | <1%         |
| 13 –24 years                           | 3,468          | 3%          |
| 25 – 44 years                          | 86,888         | 64%         |
| 45 – 64 years                          | 43,119         | 32%         |
| 65+ years                              | 2,167          | 2%          |
| Unknown/Unreported                     | 89             | <1%         |
| <b>Total</b>                           | <b>136,345</b> | <b>100%</b> |

In order to meet funding requirements, CARE Act-funded service providers must complete the CADR to provide detailed information on all clients served during the past calendar year.

The HIV/AIDS Bureau offers Ryan White CAREWare free of charge to grantees and/or service providers seeking a Management Information System (MIS) solution to the collection and reporting of client-level data. The software package provides an easy, user-friendly platform for entering, collecting, and reporting demographic, service encounter, and clinical information for clients receiving services through a Ryan White CARE Act funded- and eligible-program.

Figure 7. Total Drug Expenditures by Drug Class, 2002



### REASONS SERVICE PROVIDERS CHOOSE CAREWARE

:: Affordable. The software and technical assistance is free, so it's accessible to those providers who have limited resources.

:: Reporting simplicity. CAREWare was designed

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specifically to capture/collect all of the data elements required by HAB for the CADR.

:: Tracking capabilities. Enables users to track a range of services (HIV primary care) and aspects of care including medications, lab and screening tests, immunizations, opportunistic infections, and referrals to supportive care.

:: Quality Assurance. Contains edit checks on inputted data for quality assurance.

:: Customizable. It is easily customized so that users can satisfy unique data collection and reporting needs

:: Client monitoring. Produces information that enables individual client monitoring.

Learn more about CAREWare or download the software at [hab.hrsa.gov/CAREWare/](http://hab.hrsa.gov/CAREWare/)



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scriptase inhibitors (14 percent). Nucleotide reverse transcriptase drugs comprised four percent of drug expenditures. Drugs used to prevent or treat opportunistic infections comprised five percent of ADAP drug expenditures in 2002.

Antiretroviral medications (PIs, NRTIs, NNRTIs, and NtRTs) were the most commonly prescribed HIV medications provided by State ADAPs in 2002 (Table 16). It is important to note that these drugs are prescribed in combination; therefore, a single client may have received multiple drugs. Stavudine, combivir, and lamivudine (NRTIs) were the most commonly prescribed drugs in 2002, as they were in 1999, 2000, and 2001.

In 2002, combivir and nelfinavir were the most frequently prescribed HIV medications by expenditures, as they

were in 1999, 2000 and 2002. (Table 17). Together, these two drugs accounted for nearly a quarter of the total drug expenditures in 2002. It should again be noted that these drugs are prescribed in combination; therefore, a single client may have received multiple drugs. ■

## ADDITIONAL DATA ON HIV/AIDS

Table 16. Top Ten HIV Medications Prescribed by Number of Clients, 2002

| Generic Drug Name             | Drug Class | Number of Clients | Expenditures  |
|-------------------------------|------------|-------------------|---------------|
| Stavudine                     | NRTI       | 44,816            | \$61,415,240  |
| Combivir                      | NRTI       | 43,785            | \$123,917,630 |
| Lamivudine                    | NRTI       | 40,826            | \$53,315,661  |
| Efavirenz                     | NNRTI      | 36,334            | \$67,060,188  |
| Trimethoprim-sulfamethoxazole | OI         | 34,384            | \$1,336,355   |
| Nelfinavir                    | PI         | 23,500            | \$74,402,923  |
| Didanosine                    | NRTI       | 23,188            | \$28,691,619  |
| Ritonavir                     | NRTI       | 22,753            | \$65,002,382  |
| Tenofovir DF                  | NtRI       | 22,702            | \$30,986,434  |
| Nevirapine                    | NNRTI      | 22,119            | \$31,969,720  |
| Abacavir                      | NRTI       | 20,635            | \$37,016,236  |

Table 17. Top Ten HIV Medications Prescribed by Expenditure, 2002

| Generic Drug Name | Drug Class | Expenditures  | Number of Clients |
|-------------------|------------|---------------|-------------------|
| Combivir          | NRTI       | \$123,917,630 | 43,785            |
| Nelfinavir        | PI         | \$74,402,923  | 23,500            |
| Efavirenz         | NNRTI      | \$67,060,188  | 36,334            |
| Ritonavir         | NRTI       | \$65,002,382  | 22,753            |
| Stavudine         | NRTI       | \$61,415,240  | 44,816            |
| Trizivir          | NRTI       | \$55,436,010  | 17,246            |
| Lamivudine        | NRTI       | \$53,315,661  | 40,826            |
| Abacavir          | NRTI       | \$37,016,236  | 20,635            |
| Nevirapine        | NNRTI      | \$31,969,720  | 22,119            |
| Tenofovir DF      | NtRI       | \$30,986,434  | 22,702            |

### MORE CARE ACT DATA

Summary data describing the primary health care and enabling services provided through the CARE Act, the demographic characteristics of persons receiving these services, and the types of providers can be found on the HIV/AIDS Bureau Web site at: [hab.hrsa.gov/reports/data2a.htm](http://hab.hrsa.gov/reports/data2a.htm)

### INTEGRATED GUIDELINES FOR DEVELOPING EPIDEMIOLOGIC PROFILES

These guidelines have been developed by the CDC and HRSA to assist the persons who compile and interpret HIV prevention and care data for State, territorial, or local HIV/AIDS epidemiologic profiles. Visit the Centers for Disease Control and Prevention's Web site at: [cdc.gov/hiv/Epi\\_guidelines.htm](http://cdc.gov/hiv/Epi_guidelines.htm)

### STATE HEALTH FACTS

Information about new and cumulative AIDS cases, AIDS case rates, persons living with AIDS, AIDS deaths, HIV infections, HIV policies, Ryan

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## NOTES

1. Percentages may not sum to 100 percent due to rounding error.
2. Providers may check as many target populations as apply.
3. Affected clients include those who are HIV negative as well as those with unknown HIV status.
4. "New" clients include clients whose first receipt of services from the provider agency occurred during the reporting period.
5. Client counts are duplicated at the national and/or grantee level.
6. In 2002, HRSA HIV/AIDS Bureau implemented the Office of Management and Budget (OMB) recommendation that ethnicity and race data are to be collected separately. Due to the fact that Ryan White CARE Act data are aggregate at the grantee and national levels, these data are unable to be combined to determine the proportion of minority clients served.
7. The large percentage of clients for whom race was unknown is likely due to the change in federal reporting requirements to ask race and ethnicity questions separately. It is likely that large proportions of Hispanics do not identify with a race and are, therefore, reporting that their race is unknown.
8. Clients served include all individuals who had at least one visit for any eligible service during the reporting period.
9. "Other race" category includes Asian, Native Hawaiian or Other Pacific Islander, and American Indian or Alaska Native.
10. The federal poverty level (FPL) was \$18,100 for a family of four and \$8,860 for one person not in a family in 2002 for the 48 continuous states and D.C. Alaska and Hawaii FPL figures are slightly higher. (Source: <http://aspe.hhs.gov/poverty/02poverty.htm>).
11. Housing information as reported in section 2 of the CADR describes the population served and does not imply CARE Act funding was used for housing.
12. Permanent housing includes apartments, houses, foster homes, long-term residence, and boarding houses as long as they are not time-limited.
13. Non-permanent housing includes homeless, as well as transient or transitional housing.
14. Institution includes residential, health care, and correctional facilities.
15. Providers report the medical insurance that provides the most reimbursement if a client has more than one source of medical insurance.
16. Examples of Other Public medical insurance include State-funded insurance plans, military health care (CHAMPUS), State Children's Health Insurance Program (SCHIP), Indian Health Services, and Veterans Health Administration.
17. Case management services reference HIV positive clients only.
18. (\*) Data reported in this table are based on valid reports only. Valid data are defined as providers reporting complete data for both the number of clients served and number of visits.
19. For each service type, the actual number of providers serving clients is higher. However, the average number of visits per client was calculated only for those providers with valid data for number of clients served and number of client visits. Providers may offer multiple services; thus, a provider may be included in more than one service category.
20. A client may only have one visit for each service per day. For residential substance abuse treatment, each day in a residence facility equals one visit.
21. Other facility includes substance abuse treatment centers, solo/group private medical practices, providers reporting for multiple fee-for-service providers, PLWHA coalitions, VA facilities, and providers reporting provider type as "other".
22. Other includes Asian/Native Hawaiian/Pacific Islander.

White funding and funding for HIV prevention, and AIDS Drug Assistance Programs, including budget, client, and expenditure data. Visit the Kaiser Family Foundation's Web site at: [statehealthfacts.kff.org](http://statehealthfacts.kff.org)

## HRSA PUBLICATIONS

The HRSA Information Center currently stores over 200 publications on HIV/AIDS and thousands more on health care services for low-income, uninsured individuals and those with special health care needs. All publications are free of charge.

For access to Bureau publications and tools, visit <http://hab.hrsa.gov>. To order publications by phone, call the HRSA Information Center at 1-888-ASK-HRSA.

U.S. Department of Health and Human Services

Health Resources and Services Administration

HIV/AIDS Bureau

Web site: [hab.hrsa.gov](http://hab.hrsa.gov)

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