

2004

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. Refer to page 2 for more information on the CARE Act.

## Background

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 de-

scribe: 1) characteristics of their organization; 2) the number and characteristics of clients they served; 3) the types of services provided; 4) the number of clients receiving these services; and 5) 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 information on the outcomes of their services.

This annual summary contains five sections describing how CARE Act funds are used in communities around the nation. The document includes data from provider agencies/organizations receiving CARE Act funds that reported CADR data in 2004. 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. Comparisons are made with CADR data reported in previous years.

## Data Limitations

Given the structure of the CADR, the specific CARE Act program that funded particular cli-



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Administration's HIV/AIDS Bureau,  
U.S. Department of Health  
and Human Services

ent 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 of the funding source. Note 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, and because the CADR does not collect client-level data with unique identifying information, there is no way of knowing that the counts of individuals served by one service provider are not also included in the counts of another service provider. Thus, aggregating the provider data to the national level results in duplicate client counts. ■

## The Ryan White CARE Act

For 15 years, the Ryan White CARE Act has provided services to people living with HIV/AIDS (PLWHA) who do not have the insurance or financial resources to pay for care. Reaching more than 500,000 people each year, the CARE Act was first enacted in 1990 and reauthorized twice (1996 and 2000). Reauthorization is anticipated in 2006 and as this report goes to press in July 2006, discussions are still ongoing.

The CARE Act fills gaps in care for PLWHA through the following local and State-level programs:

■ **Title I** provides grants to 51 Eligible Metropolitan Areas (EMAs) disproportionately affected by HIV/AIDS. Title I grants fund a variety of medical and support services.

■ **Title II** provides grants to States and territories to improve the quality, availability, and organization of HIV/AIDS health care and support services. Title II also provides access to medications through the AIDS Drug Assistance Program (ADAP).

■ **Title III** supports outpatient HIV early intervention services and ambulatory care. Unlike Title I and Title II grants, which are awarded to local and State governments that contract with other organizations to deliver services, Title III grants are awarded directly to provider service organizations. Title III also supports entities in their efforts to

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 IV** grants provide family-centered comprehensive care to children, youth, women, and their families and help improve access to clinical trials and research.

■ **The Special Projects of National Significance (SPNS) Program** supports the demonstration and evaluation of innovative models of HIV/AIDS care delivery for hard-to-reach populations.

■ **The AIDS Education and Training Centers (AETC) Program** supports education and training of health care providers through a network of 11 regional and 4 national centers.

■ **The HIV/AIDS Dental Reimbursement Program** provides reimbursements to dental schools, postdoctoral dental education programs, and schools of dental hygiene for uncompensated costs incurred in providing oral health treatment to patients with HIV disease.

■ **The Community-based Dental Partnership Program** supports access to oral health care services for HIV-positive individuals while providing education and clinical training for dental care providers, especially those located in community-based settings.

# Provider Information

Using data from section 1 of the CADR, this section describes characteristics of the CARE Act providers that reported data in 2004 (n=2,569). Where possible, comparisons are made with the provider organizations reporting CADR data in 2002 (n=2,696) and 2003 (n=2,647).

## REPORTING SCOPE

CARE Act providers have the option of reporting on eligible or funded services. When reporting on eligible services, providers submit data 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 provides a comprehensive picture of the services being delivered to HIV-positive clients by CARE Act-funded providers. More than three-quarters (88 percent) of all CARE Act providers in 2004 reported on all eligible services.

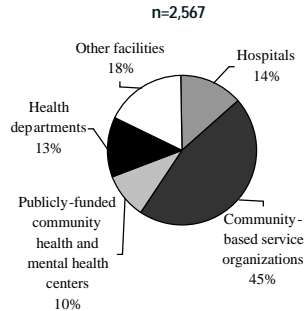
Conversely, if providers report on funded services, the data reported by providers include only those services that were actually paid for with CARE Act funding. This latter reporting category requires prior approval from HRSA project officers. In 2004, 11 percent (n=295) of providers reported only those services funded by the CARE Act.

## PROVIDER TYPE

A variety of organizations provide CARE Act services, including publicly-funded health centers, community-based organizations, and private medical practices (Figure 1 and Table 1). Almost half (45 percent) of all CARE Act providers in 2004 were community-based service organizations (CBOs). Hospitals comprised 14 percent of all CARE Act providers, while health departments made up 13 percent of providers in 2004. Collectively, publicly-funded community health centers and community mental health centers represented 10 percent of providers (n=244). CARE Act providers identified as substance abuse treatment centers, solo/group private

medical practices, multiple fee-for-service providers, people living with HIV/AIDS (PLWHA) coalitions, Veterans Administration (VA) facilities, or other provider types, comprised 18 percent (n=465) of providers in 2004. The types of organizations receiving CARE Act funding to provide services to people living with HIV/AIDS in 2002 and in 2003 were similar to those funded in 2004.

Figure 1. CARE Act Provider Types, 2004



Data on provider type were missing for 2 providers in 2004. 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 provider type reported as 'other'.

Table 1. CARE Act Provider Types, 2004

Provider Type	Total	Percent
Hospitals	360	14%
Publicly-funded community health and mental health centers	244	10%
Community-base service organizations	1,165	45%
Health departments	333	13%
Other facilities	465	18%
<b>Total</b>	<b>2,567</b>	<b>100%</b>

Data on provider type were missing for 2 providers in 2004. 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 provider type reported as 'other'. Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

## OWNERSHIP STATUS

The ownership status of CARE Act providers includes private, public, and faith-based organizations. Close to two-thirds (65 percent) of CARE Act providers were private, nonprofit (not faith-based) organizations in 2004 (Table 2). Twenty-three percent (n=592) of providers reported their ownership status as publicly owned (local, State, or Federal), and about four percent (n=113) of CARE Act providers were faith-based organizations.

Table 2. Ownership Status of CARE Act Providers, 2004

Ownership Status	Total	Percent
Public/local	334	13%
Public/state	240	9%
Public/federal	18	1%
Private, nonprofit (not faith-based)	1,656	65%
Private, for profit	138	5%
Unincorporated	6	<1%
Faith-based organization	113	4%
Other	62	2%
<b>Total</b>	<b>2,567</b>	<b>100%</b>

Percentages may not sum to 100 percent due to rounding error.

Data on ownership status were missing for 2 providers in 2004.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

## SOURCE OF CARE ACT FUNDING

Organizations reported which CARE Act programs provided funding for delivery of services. Organizations may have received funding directly from the Federal government as Ryan White CARE Act grantees, through subcontracts with CARE Act grantees, and/or through Title II funding from a consortium agency. Of the 2,569 providers submitting data for 2004, 1,439 providers received Title I funds; 1,398 providers received Title II funds; 454 providers received Title III-EIS funds; and 266 providers received Title IV funds. Thirty providers received Title IV-Youth funds in 2004 (Table 3).

Table 3. Source of CARE Act Funding, 2004

Source	Total	Percent
Title I	1,439	56%
Title II	1,398	54%
Title III	454	18%
Title IV	266	10%
Title IV - Youth	30	1%

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report

Many of these provider organizations received funding from more than one CARE Act program, and they may have also received funds from additional, non-Ryan White CARE Act sources (Table 4). Among providers in 2004, 70 percent (n=1,790) received funds from a single CARE Act source; 23 percent (n=577) received funds from two CARE Act sources; 7 percent (n=166) received funds from three CARE Act sources; and 1 percent (n=35) received funds from four CARE Act sources. Only one provider received funds from all five CARE Act sources in 2004.

Table 4. Distribution of CARE Act Funding Sources Among Providers, 2004

Source	Number	Percent
One	1,790	70%
Two	577	23%
Three	166	7%
Four	35	1%
Five	1	<1%
<b>Total</b>	<b>2,569</b>	<b>100%</b>

Percentages may not sum to 100 percent due to rounding error.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report

## TARGET POPULATIONS OF INTEREST

Providers were asked to identify any population group they specifically targeted for outreach efforts or service delivery during the reporting period. The 4 populations that providers most frequently targeted in 2004 were communities of color (65 percent), women (62 percent), injection drug users (49 percent), and gay, lesbian, and bisexual adults (49 percent). These and other target populations are shown in Table 5.

Table 5. Target Population of CARE Act Providers: 2002, 2003, and 2004

Target Populations of Interest	2004 (n=2,569)		2003 (n=2,647)		2002 (n=2,696)	
	Total	Percent	Total	Percent	Total	Percent
Migrant/farm workers	218	9%	234	9%	219	8%
Rural population other than migrant workers	515	20%	515	19%	509	19%
Women	1,582	62%	1,587	60%	1,553	58%
Children/child	720	28%	774	29%	771	29%
Communities of color	1,656	65%	1,710	65%	1,649	61%
Homeless	1,144	45%	1,186	45%	1,113	41%
Gay, lesbian, bisexual youth	635	25%	662	25%	632	23%
Gay, lesbian, bisexual adults	1,249	49%	1,270	48%	1,208	45%
Incarcerated persons	604	24%	637	24%	588	22%
All adolescents	581	23%	629	24%	569	21%
Runaway or street youth	285	11%	313	12%	292	11%
Injection drug users	1,258	49%	1,266	48%	1,245	46%
Non-injection drug users	1,016	40%	1,027	39%	971	36%
Parolees	676	26%	706	27%	626	23%
Other	293	11%	298	11%	325	12%

Providers may check as many target populations as apply.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

## RACIAL/ETHNIC MINORITY GROUP REPRESENTATION GREATER THAN 50%

For 2004, 36 percent (n=919) 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. Twenty-four percent (n=625) of providers reported that racial/ethnic minorities comprised more than 50 percent of their Board of Directors. Two percent (n=50) were solo or group health practices in which more than 50 percent of the clinicians were members of racial/ethnic minority groups. Thirty-four percent (n=879) of providers reported that although their boards and staffs were not composed of a majority of racial/ethnic minority group members, they historically serve racial/ethnic minorities in communities of color. The racial/ethnic group representation reported by providers remained essentially the same from 2002 to 2004 (Table 6).

## STAFFING

CARE Act providers reported 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. In 2004, 2,207 provider organizations reported a mean number of 7.6 paid FTE staff per provider, and 686 agencies reported a mean of 11.3 volunteer FTE staff per provider. The mean numbers of paid and volunteer FTE staffs have declined slightly since 2002 (Table 7).

## CARE ACT FUNDING AMOUNTS

The amount of CARE Act funds that providers reported receiving is presented in Table 8. The amounts may not match fiscal year awards because provider-reported funding may include carryover from the previous funding period and supplemental funding.

In 2004, 1,345 providers reported receiving \$602,715,292 through Title I of the CARE Act with a mean award of \$448,115 to deliver CARE Act services. Title II funds totaled \$771,321,950 among 1,233 providers, with mean funding of \$625,565. Providers in Title III-EIS (n=440) reported receiving a total of \$192,813,950, with a mean award of \$438,100, and providers in Title IV (n=277) reported receiving a total of \$76,366,146, with a mean award of \$275,690.

incurred by CARE Act providers, excluding funds from the Dental Reimbursement Program and the Community Based Dental Partnership Program. In 2004, 585 CARE Act providers reported \$47,936,428 in dental expenditures for their clients, with a mean expenditure of \$81,943. ■

## CARE ACT DENTAL EXPENDITURES

The dental expenditures presented in Table 8 include all CARE Act funds from all Titles that were used to pay for dental expenses

Table 6. Racial/Ethnic Minority Group Representation Among CARE Act Providers: 2002, 2003, and 2004

Racial/Ethnic Group Representation Greater than 50%	2004 (n=2,569)		2003 (n=2,647)		2002 (n=2,696)	
	Total	Percent	Total	Percent	Total	Percent
Board members	625	24%	668	25%	673	25%
Professional staff members	919	36%	959	36%	945	35%
Solo/group private health practice	50	2%	55	2%	65	2%
"Traditional" provider serving people of color	879	34%	893	34%	911	34%
Other agency type	473	18%	466	18%	463	17%

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

Table 7. CARE Act Provider Organization Staffing: 2002, 2003 and 2004

Staff	2004			2003			2002		
	Number of Providers	Mean Staff per Provider	Range	Number of Providers	Mean Staff per Provider	Range	Number of Providers	Mean Staff per Provider	Range
Paid	2,207	7.6	.01 - 130	2,295	7.9	.01 - 706	2,339	8.4	.01 - 780
Volunteer	686	11.3	.01 - 800	747	11.4	.01 - 800	746	11.8	.02 - 750

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

Table 8. CARE Act Funding Amounts, 2004

Care Act Program	Total (dollars)	Mean	Median
Title I (n=1,345)	\$602,715,292	\$448,115	\$173,269
Title II (n=1,233)	\$771,321,950	\$625,565	\$95,889
Title III (n=440)	\$192,813,950	\$438,100	\$411,888
Title IV (n=277)	\$76,366,146	\$275,690	\$86,682
Dental Expenditures (n=585)	\$47,936,428	\$81,943	\$20,327

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

# Client Information

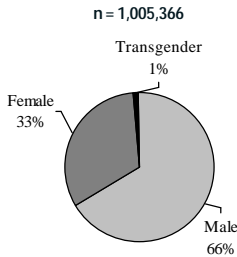
## CLIENTS SERVED<sup>1</sup>

CARE Act providers served 1,043,730 duplicated clients in 2004, including 309,865 duplicated new clients. Of the total duplicated clients served, 84 percent (n=878,078) were HIV-positive, while the remaining 16 percent (n=165,652) were HIV-affected.<sup>2</sup> Among new duplicated clients, 72 percent (n=224,641) were HIV-positive and 28 percent (n=85,224) were HIV-affected.<sup>3</sup>

## GENDER

In 2004, 66 percent of duplicated CARE Act clients were male, 33 percent were female, and 1 percent were transgender (Figure 2 and Table 9). Interestingly, the gender distribution varies by HIV status (positive or affected). Among duplicated HIV-positive clients, about two-thirds (68 percent) were male, and a smaller proportion (31 percent) were female. This is in contrast to HIV-affected clients: 54 percent were male, and 46 percent were female.

Figure 2. Gender of CARE Act Clients, 2004



Data on gender were unknown or unreported for 38,364 clients.

<sup>1</sup> Clients served are individuals who had at least one visit for any eligible service during the reporting period. Client counts are duplicated at the national and/or grantee level.

<sup>2</sup> Positive clients include infants under the age of 2, whose HIV status is indeterminate. Affected clients include those who are HIV-negative as well as those with unknown HIV status.

<sup>3</sup> "New" clients include clients whose first receipt of services from the provider agency occurred during the reporting period.

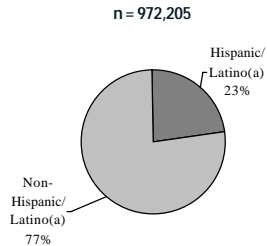
## AGE

Overall, 53 percent of the clients served in 2004 were in the age group 25 to 44 years, while 34 percent were in the age group 45 to 64 years. Findings were similar for HIV-positive clients: 56 percent were 25 to 44 years old while 37 percent of the clients were 45 to 64 years old. The situation was different for HIV-affected clients: 38 percent were 25 to 44, 15 percent were 45 to 64, and nearly half (45 percent) were under the age of 25.

## ETHNICITY

Twenty-three percent of all clients served in 2004 were Hispanic/Latino(a), and 77 percent were non-Hispanic/Latino(a) (Figure 3). Similarly, 21 percent of all HIV-positive clients served were Hispanic/Latino(a) and 79 percent were non-Hispanic/Latino(a). Among HIV-affected clients, 31 percent were Hispanic/Latino(a), and 69 percent were non-Hispanic/Latino(a). Ethnic identity was unknown for a large percentage (19 percent) of HIV-affected clients. The ethnicity of clients served in previous years was similar to the distribution in 2004. For example, 22 percent of all clients served in 2002 and 24 percent of all clients served in 2003 were Hispanic/Latino(a).

Figure 3. Ethnicity of CARE Act Clients, 2004



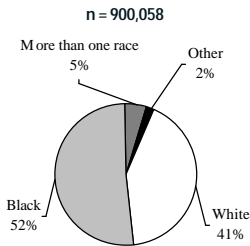
Data on ethnicity were unknown or unreported for 71,525 clients.

## RACE

For clients overall and for those who were HIV-positive, over 50 percent of the clients served by CARE Act providers in 2004 and previous years were members of racial minority groups.<sup>4</sup>

In 2004, Blacks comprised approximately 52 percent of clients served, both overall and among those who were HIV-positive. Whites comprised 41 percent of all clients and 42 percent of clients who were HIV-positive in 2004 (Figure 4 and Table 9).

Figure 4. Race of CARE Act Clients, 2004



Data on race were unknown or unreported for 143,672 clients. "Other" includes Asian, Pacific Islander, and American Indian or Alaska Native.

## HOUSEHOLD INCOME<sup>5</sup>

The percentage of all CARE Act clients with annual household incomes equal to or below the Federal Poverty Level (FPL) was 72 percent in 2004, an increase from 68 percent in 2002 and 69 percent in 2003 (Table 10). By HIV status, 71 percent of HIV-positive clients and 81 percent of HIV-affected clients had incomes at or below the FPL in 2004. CARE Act providers did not report the household income status for most HIV-affected clients.

<sup>4</sup> In 2002, the HIV/AIDS Bureau implemented an Office of Management and Budget (OMB) recommendation to collect ethnicity and race data separately. Because Ryan White CARE Act data are aggregated at the grantee and national levels, race and ethnicity data cannot be combined to determine the proportion of minority clients served.

<sup>5</sup> 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 contiguous States and D.C. Alaska and Hawaii FPL figures are slightly higher. (Source: <http://aspe.hhs.gov/poverty/02poverty.htm>).

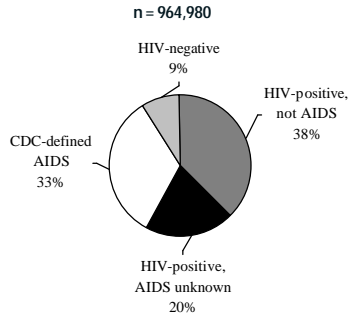
## HOUSING ARRANGEMENTS<sup>6</sup>

Providers reported that among all CARE Act clients in 2004, 78 percent had permanent housing arrangements, and 15 percent were non-permanently housed.<sup>7</sup> About 4 percent of all clients lived in institutions, and 3 percent were in some other living arrangement (Table 10). The distributions of housing arrangements by HIV status in 2004 are nearly identical to the overall distribution. The distribution of housing arrangements for CARE Act clients was essentially the same from 2002 to 2004.

## HIV/AIDS STATUS

Most clients receiving CARE Act services in 2004 were recorded in one of three categories: 1) HIV-positive, not AIDS (38 percent); 2) AIDS as defined by CDC (33 percent), or 3) HIV-positive, AIDS unknown (20 percent). This distribution of HIV/AIDS status is similar to that of previous years. Clients who were HIV-negative comprised 9 percent of all clients (Figure 5 and Table 11).

Figure 5. Client HIV Status, 2004



*continued on page 10...*

<sup>6</sup> The housing information reported in section 2 of the CADR describes the population served and does not imply CARE Act funding was used for housing.

<sup>7</sup> Permanent housing includes apartments, houses, foster homes, long-term residence, and boarding houses, if they are not time-limited. Non-permanent housing includes homeless, transient, or transitional housing. Institutional housing includes residential, health care, and correctional facilities.



Table 9. Gender, Age, Ethnicity, and Race of CARE Act Clients by HIV Status, 2004

Characteristic	Total		HIV-positive		HIV-affected	
	Number	Percent	Number	Percent	Number	Percent
<b>Total CARE Act Clients</b>	<b>1,043,730</b>	<b>100%</b>	<b>878,078</b>	<b>100%</b>	<b>165,652</b>	<b>100%</b>
<b>Gender</b>						
Male	668,087	66%	596,154	68%	71,933	54%
Female	331,918	33%	271,285	31%	60,633	46%
Transgender	5,361	1%	5,028	1%	333	<1%
Unknown/unreported	38,364	--	5,611	--	32,753	--
<b>Age</b>						
Less than 2 years	8,915	1%	2,319	<1%	6,596	5%
2 - 12 years	24,052	2%	9,288	1%	14,764	11%
13 - 24 years	74,800	7%	37,012	4%	37,788	29%
25 - 44 years	535,355	53%	484,603	56%	50,752	38%
45 - 64 years	342,665	34%	322,409	37%	20,256	15%
65+ years	15,927	2%	13,916	2%	2,011	2%
Unknown/unreported	42,016	--	8,531	--	33,485	--
<b>Ethnicity</b>						
Hispanic/Latino(a)	221,544	23%	180,433	21%	41,111	31%
Non-Hispanic	750,661	77%	660,256	79%	90,405	69%
Unknown/unreported	71,525	--	37,389	--	34,136	--
<b>Race</b>						
White	372,907	41%	324,829	42%	48,078	39%
Black	467,467	52%	404,574	52%	62,893	51%
Asian	8,113	1%	6,155	1%	1,958	2%
Pacific Islander	1,492	<1%	1,384	<1%	108	<1%
Native American/Alaska Native	7,444	1%	6,833	1%	611	<1%
More than one race	42,635	5%	33,544	4%	9,091	7%
Unknown/unreported	143,672	--	100,759	--	42,913	--

-- Unknown or unreported responses are not included in percentage calculations.

Percentages may not sum to 100 percent due to rounding error.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

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## ENROLLMENT STATUS

In 2004, 68 percent of HIV-positive clients were continuing to receive CARE Act care and treatment from their programs (up from 63 percent in 2002), while 22 percent were new to their programs (down from 26 percent in 2002) and 9 percent were inactive in their programs (unchanged from 2002). By contrast, 43 percent of HIV-affected clients were continuing clients in 2004 (up from 33 percent in 2002), 40 percent were new clients (down from 48 percent in 2002), and 16 percent had an inactive enrollment status (down from 19 percent in 2002) (Table 11).

## MEDICAL INSURANCE

In 2004, 55 percent of all CARE Act clients were covered by publicly-funded medical insurance, 31 percent had no medical insur-

ance, and 11 percent had private insurance (Table 11)<sup>8</sup> The distribution for HIV-positive clients is similar. Overall, medical insurance status among all CARE Act clients in 2004 is similar to that for 2002 and 2003. While a majority of HIV-affected clients had unreported medical insurance status, among those reported, 63 percent were covered by publicly-funded medical insurance (up from 51 percent in 2002), 25 percent had no insurance (up from 16 percent in 2002), and 10 percent had private insurance (compared to 9 percent in 2002). HIV-affected clients reported to have "Other" health insurance dropped from 24 percent in 2002 to 4 percent in 2004. ■

<sup>8</sup>Providers report the medical insurance that provides the most reimbursement if a client has more than one source of medical insurance.

Table 10. Household Income and Housing Arrangements of CARE Act Clients by HIV Status, 2004

Characteristic	Total		HIV-positive		HIV-affected	
	Number	Percent	Number	Percent	Number	Percent
<b>Total CARE Act Clients</b>	<b>1,043,730</b>	<b>100%</b>	<b>878,078</b>	<b>100%</b>	<b>165,652</b>	<b>100%</b>
<b>Household Income</b>						
Equal to or below FPL	524,831	72%	483,750	71%	41,081	81%
101-200% FPL	140,312	19%	134,200	20%	6,112	12%
201-300% FPL	40,776	6%	38,884	6%	1,892	4%
Greater than 300% FPL	27,750	4%	26,131	4%	1,619	3%
Unknown/unreported	310,061	--	195,113	--	114,948	--
<b>Housing Arrangements</b>						
Permanently housed	598,644	78%	552,699	78%	45,945	78%
Non-permanently housed	117,543	15%	107,827	15%	9,716	16%
Institution	27,565	4%	25,158	4%	2,407	4%
Other	19,860	3%	18,867	3%	993	2%
Unknown/unreported	280,118	--	173,527	--	106,591	--

-- Unknown or unreported responses are not included in percentage calculations.

Percentages may not sum to 100 percent due to rounding error.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

Table 11. HIV/AIDS Status, Enrollment Status, and Health Insurance Status of CARE Act Clients, 2004

Characteristic	Total		HIV-positive		HIV-affected	
	Number	Percent	Number	Percent	Number	Percent
<b>Total CARE Act Clients</b>	<b>1,043,730</b>	<b>100%</b>	<b>878,078</b>	<b>100%</b>	<b>165,652</b>	<b>100%</b>
<b>HIV/AIDS Status</b>						
HIV positive, not AIDS	362,797	38%	362,797	41%	-	-
HIV positive, AIDS unknown	193,199	20%	193,199	22%	-	-
CDC-defined AIDS	322,082	33%	322,082	37%	-	-
HIV-negative	86,902	9%	-	-	86,902	100%
Unknown/unreported	78,750	--	-	-	78,750	--
<b>Enrollment Status</b>						
Active, new to program	215,426	23%	180,557	22%	34,869	40%
Active, continuing in program	606,640	66%	569,891	68%	36,749	43%
Deceased	12,261	1%	11,782	1%	479	1%
Inactive	88,741	10%	74,691	9%	14,050	16%
Unknown/unreported	120,662	--	41,157	--	79,505	--
<b>Health Insurance and Coverage Status</b>						
Private	85,541	11%	80,695	11%	4,846	10%
Medicare	80,646	10%	78,791	10%	1,855	4%
Medicaid	287,990	36%	263,789	35%	24,201	49%
Other public**	72,930	9%	68,171	9%	4,759	10%
No insurance	251,492	31%	239,154	32%	12,338	25%
Other	22,484	3%	20,612	3%	1,872	4%
Unknown/unreported	242,647	--	126,866	--	115,781	--

- Data does not exist because the categories are mutually exclusive.

-- Unknown or unreported responses are not included in percentage calculations.

Percentages may not sum to 100 percent due to rounding error.

\*\* Other public health insurance includes State-funded plans, military health care (TRICARE/CHAMPUS or care provided by the Veterans Health Administration), the State Children's Health Insurance Program (SCHIP), and the Indian Health Service (IHS).

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

# Service Utilization

## SERVICE UTILIZATION FOR HEALTH CARE SERVICES

Case management and ambulatory/outpatient medical care were the most frequently utilized CAREAct services in 2004 (Table 12). CAREAct case management providers reported serving 367,074 HIV-positive clients in more than 4.2 million client visits in 2004. 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.

CARE Act providers reported that ambulatory/outpatient medical care services were used by 361,131 clients in 2.3 million client visits in 2004. In 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.

Table 12. Number of Clients Served and Total Visit for Health Care and Case Management Services, 2004

Services	Duplicated Clients Served	Total Visits
<b>Health Care Services</b>		
Ambulatory/outpatient medical care	361,131	2,341,018
Mental health care	84,227	531,829
Oral health care*	76,376	230,046
Substance abuse services: outpatient	36,070	551,844
Substance abuse services: residential	3,998	115,006
Rehabilitation services	1,959	23,057
Home health: para-professional care	3,849	163,712
Home health: professional care	4,013	53,711
Home health: specialized care	589	4,703
<b>Case Management Services</b>		
HIV-positive clients	367,074	4,173,378
HIV-affected clients	23,492	98,173

\*Does not include services by the Dental Reimbursement Program and the Community Based Dental Partnership Program.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

Clients used three other health care service categories frequently in 2004. First, mental health services were used by 84,227 clients in 531,829 visits. Next, providers provided oral health care services to 76,376 clients in 230,046 visits. Finally, outpatient substance abuse treatment services were used by 36,070 clients in 551,844 visits. Outpatient substance abuse services are defined as medical treatment and counseling to address substance abuse problems provided in an outpatient setting rendered by or under the supervision of a physician.

## NUMBER OF VISITS PER CLIENT BY SERVICE CATEGORY<sup>9</sup>

In 2004, the average number of visits for case management services was 13.9 for HIV-positive clients, down from 14.5 in 2003 and 6.3 for HIV-affected clients, down from 8 in 2003 (Table 13). For outpatient/ambulatory medical services, clients averaged 6.7 visits in 2004, down from 7 in 2002. Providers of outpatient substance abuse services reported an average number of 19.9 visits per client in 2004, down from 20.4 in 2002. Providers of mental health care services reported that on average, clients made 7.2 visits in 2004, down from 8 in 2002. Finally, for oral health care services, the average number of visits per client was 2.4 in 2004, down from 2.8 in 2002.

<sup>9</sup> A client may only be counted for one visit for each service per day. For residential substance abuse treatment, each day in a residence facility counts as one visit.

## UTILIZATION OF SUPPORT SERVICES

CARE Act providers also deliver an array of supportive services to HIV-positive and HIV-affected clients to promote entry into and retention in HIV primary medical care (Table 14). CARE Act providers delivered the highest number of support services (duplicated client counts) in 2004 to HIV-positive clients in the following service categories: food bank/home-delivered meals (117,526), client advocacy (117,032), health education/risk education (129,070), transportation services (106,055), and treatment adherence coun-

seling (124,000). Utilization of support services was somewhat different among HIV-affected clients. The highest number of support services (duplicated client counts) delivered to HIV-affected clients included outreach and health education/risk reduction - services designed to promote HIV counseling and testing and prevent further transmission of HIV among all CARE Act clients. For all categories of supportive services except outreach services, CARE Act providers reported serving larger numbers of HIV-positive than HIV-negative clients. ■

Table 13. Visits per Client by Type of Service, 2004

Type of Service	Number of Providers*	Average Visits per Client	Median Visits per Client	Range
<b>Health Care Services</b>				
Ambulatory/outpatient medical care	877	6.7	5.1	1 - 142
Mental health care	853	7.2	4.4	1 - 185
Oral health care**	542	2.4	2.1	1 - 13
Substance abuse services: outpatient	443	19.9	5.4	1 - 389
Substance abuse services: residential	88	29.2	11.9	1 - 180
Rehabilitation services	64	12.9	3.5	1 - 240
Home health: para-professional care	136	43.9	18.8	1 - 365
Home health: professional care	113	15.8	4.5	1 - 199
Home health: specialized care	41	7.8	2.0	1 - 78
<b>Case Management Services</b>				
HIV-positive clients	1,305	13.9	9.3	1 - 206
HIV-affected clients	480	6.3	3.2	1 - 91

\*The actual number of providers serving clients is higher. Data presented in the table are only for providers who reported complete data for both number of clients and number of visits. Some providers offer multiple services and may be included in more than one service category.

\*\*Does not include services by the Dental Reimbursement Program and the Community Based Dental Partnership Program.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

Table 14. Clients Who Received CARE Act Support Services by HIV Status: 2002, 2003, and 2004

Support Services	2004		2003		2002	
	HIV-positive	HIV-affected	HIV-positive	HIV-affected	HIV-positive	HIV-affected
Buddy/companion services	7,313	851	8,860	1,378	8,729	494
Child care services	3,077	2,591	3,694	2,668	3,230	2,932
Child welfare services	1,847	1,429	1,270	658	939	565
Client advocacy	117,032	7,478	108,843	8,422	113,363	9,382
Day/respite care for adults	4,852	266	5,872	205	5,049	493
Developmental assessment	3,874	1,289	3,416	1,182	2,856	1,277
Early intervention services Titles I&II	13,991	8,319	12,975	5,899	9,638	2,641
Emergency financial assistance	67,160	3,417	75,006	5,298	74,965	5,290
Food bank/home-delivered meals	117,526	5,304	117,119	6,437	113,673	6,758
Health education/risk reduction	129,070	34,285	115,599	34,853	111,716	76,045
Housing services	44,090	2,364	42,715	3,643	46,037	1,698
Legal services	23,739	1,283	22,488	1,096	21,679	934
Nutritional counseling	83,893	3,686	75,696	2,782	73,089	2,649
Outreach services	35,307	58,774	35,935	103,366	49,247	86,116
Permanency planning	3,908	1,259	4,098	1,451	5,596	1,593
Psychosocial support services	98,295	12,411	95,042	14,298	87,414	12,792
Referral: health care/ support services	89,795	9,069	88,532	11,898	86,690	36,291
Referral: clinical research	14,593	1,110	18,351	701	20,745	1,245
Hospice care: residential/in-home	1,885	326	1,353	196	1,245	119
Transportation services	106,055	5,683	116,672	7,627	100,185	5,486
Treatment adherence counseling	124,000	3,386	108,329	2,160	91,948	2,676
Other services	94,976	5,757	86,719	12,994	84,707	13,069

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

# HIV Counseling and Testing

## PROVIDER-RELATED SERVICES

In 2004, 31 percent of CARE Act providers (n=805) offered their clients HIV counseling and testing services, up from 28 percent (n=753) in 2002 (Table 15). These services include pretest counseling on the benefits of testing (including 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). Among providers in 2004, 48 percent (n=384) used CARE Act funds to provide these services, up from 43 percent (n=320) in 2002. About one-third, or 33 percent (n=266) of providers in 2004, offered partner notification services in 2004, down from 38 percent (n=283) in 2002.<sup>10</sup>

<sup>10</sup> 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 COUNSELING AND TESTING

CARE Act providers offering HIV counseling and testing reported important utilization data concerning the clients receiving these services. The numbers of infants tested during 2004 was 15,461 (Table 15). The results from data from 2002 to 2004 demonstrate that CARE Act-funded counseling and testing sites are highly proficient at getting clients to return for test results, and at linking HIV-positive clients to care.

In 2004, CARE Act providers delivered pretest counseling services to 854,229 clients, with 84.2 percent (n=719,076) receiving the services on a confidential basis and 15.8 percent (n=135,153) receiving the services anonymously (Table 16). Of all clients who received counseling services, 94.0 percent (n=802,599) were tested

Table 15. CARE Act Providers and HIV Counseling and Testing Services: 2002, 2003, and 2004

Program Characteristics	2004		2003		2002	
	Number	Percent	Number	Percent	Number	Percent
<b>Program provides HIV counseling and testing services</b>						
Yes	805	31%	771	29%	753	28%
No	1,764	69%	1,876	71%	1,942	72%
<b>Total</b>	<b>2,569</b>	<b>100%</b>	<b>2,647</b>	<b>100%</b>	<b>2,696</b>	<b>100%</b>
<b>Care Act funds used to support HIV counseling services</b>						
Yes	384	48%	374	49%	320	43%
No	421	52%	397	51%	433	57%
<b>Total</b>	<b>805</b>	<b>100%</b>	<b>771</b>	<b>100%</b>	<b>753</b>	<b>100%</b>
<b>Program offered partner notification</b>						
Yes	266	33%	272	35%	283	38%
No	539	67%	499	65%	470	62%
<b>Total</b>	<b>805</b>	<b>100%</b>	<b>771</b>	<b>100%</b>	<b>753</b>	<b>100%</b>

Testing Infants	2004		2003		2002	
	Number	Percent	Number	Percent	Number	Percent
Number of infants tested during reporting period	15,461		17,239		13,024	

Data on HIV counseling and testing services were missing for 1 provider in 2002.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

Table 16. Number of Persons Receiving HIV Counseling and Testing from CARE Act Providers: 2002, 2003, and 2004

Counseling and Testing Status	2004		2003		2002	
	Number	Percent	Number	Percent	Number	Percent
Received HIV pretest counseling	854,229	100%	722,188	100%	773,170	100%
Received HIV pretest counseling and HIV test	802,599	94.0%	673,291	93.2%	707,812	91.5%
Received HIV pretest counseling, HIV test, and posttest counseling	553,569	69.0%	450,928	67.0%	436,661	61.7%
Received HIV pretest counseling and HIV test was positive	16,793	2.1%	15,505	2.3%	15,691	2.2%
HIV test was positive; received posttest counseling	14,326	85.3%	12,558	81.0%	13,053	83.2%

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

for the HIV antibody during the reporting period, up 2.5 percent over 2002. Among clients tested for the HIV antibody, 2.1 percent (n=16,793) tested positive for HIV antibodies, a slight decrease from the average of 2.3 percent in previous years.

CARE Act providers were also concerned with providing prevention and/or treatment services to individuals after testing. Results for the past 3 years suggest that CARE Act programs are successful in getting clients who are tested to return for their results. Providers reported that in 2004, 69 percent (n=553,569) of those who received HIV pretest counseling and testing returned for posttest counseling, an increase of 7.3 percent over the return rate in 2002.

The benefits of early diagnosis that are lost if clients do not return for test results are especially costly to clients who test positive for the HIV antibody. CARE Act providers reported that among their clients who tested positive for the HIV antibody, 85.3 percent returned for their test results or posttest counseling services, an increase of 2.1 percent from 2002 to 2004.

Closer examination of the results, specifically at programs that used CARE Act funds to provide counseling and testing, shows that 92.7 percent of clients who receive pretest counseling were tested for HIV, up from 91.3 percent in 2002. Of those clients who were tested, 70.2 percent returned for their test results and posttest counseling, an increase of 8.1 percent over the return rate in 2002. Service providers reported that 2.6 percent of clients tested were positive for HIV antibodies, a slight increase from the average of 2.4 percent in previous years. The return rate for positive clients was 88.2 percent in 2004, an increase of 5.9 percent from the average of 82.3 percent in previous years. These data show that CARE Act providers achieve high rates of testing clients and getting them to return for their results or posttest counseling. Further, providers who used CARE Act funds specifically to provide counseling and testing services captured more HIV positive clients and had greater success at getting them to return. ■



# AIDS Drug Assistance Program

## CLIENTS SERVED

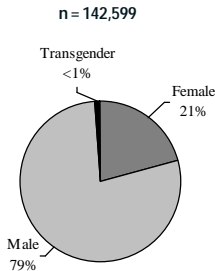
In 2004, 53 State and U.S. Territory AIDS Drug Assistance Programs (ADAPs) served 142,653 enrolled clients (Table 17). Twenty percent (n=28,305) of the clients served by ADAP in 2004 were newly enrolled during the reporting period, a decrease in the proportion of newly enrolled clients from 24 percent (n=136,345) of clients in 2002 and 21 percent (n=143,711) of clients in 2003.

## CLIENT CHARACTERISTICS

### GENDER

ADAP served about four times more male clients than female clients in 2004: 112,127 males (79 percent) compared to 30,274 females (21 percent). Less than one percent of clients were transgender (Figure 6).

Figure 6. Gender of Clients Served by ADAP, 2004



Data on gender were unknown or unreported for 54 clients. Percentages may not sum to 100% due to rounding error.

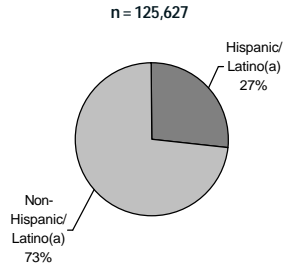
### AGE

Over half (58 percent) of ADAP clients served in 2004 were 25 to 44 years of age, down from 64 percent of ADAP clients served in 2002 in that age group. More than a third (38 percent) of ADAP clients in 2004 were adults age 45 to 66 years and 2 percent were adults age 65 or older.

### ETHNICITY

In 2004, 27 percent of ADAP clients were Hispanic/Latino(a) and 73 percent were not Hispanic/Latino(a), compared to 2002, when 23 percent of ADAP clients were Hispanic/Latino(a) and 77 percent were not Hispanic/Latino(a) (Figure 7).

Figure 7. Ethnicity of Clients Served by ADAP, 2004



Data on ethnicity were unknown or unreported for 17,026 clients.

### RACE

The distribution of ADAP clients by race was the same from 2002 to 2004. In 2004, Whites comprised 52 percent of clients, Blacks comprised 45 percent of clients, 2 percent of clients were Asian,

*continued on page 19...*

Table 17. Demographic Characteristics of Clients Served by ADAP: 2002, 2003, and 2004

Characteristic	2004		2003		2002	
	Number	Percent	Number	Percent	Number	Percent
<b>Total ADAP Clients</b>	<b>142,653</b>	<b>100%</b>	<b>143,711</b>	<b>100%</b>	<b>136,345</b>	<b>100%</b>
<b>Gender</b>						
Male	112,127	79%	112,721	78%	107,185	79%
Female	30,274	21%	30,805	21%	29,013	21%
Transgender	198	<1%	148	<1%	96	<1%
Unknown/Unreported	54	--	37	--	51	--
<b>Age</b>						
Less than 2 years	114	<1%	151	<1%	164	<1%
2 - 12 years	407	1%	472	<1%	450	<1%
13 - 24 years	3,174	2%	3,327	2%	3,468	3%
25 - 44 years	82,141	58%	86,652	60%	86,888	64%
45 - 64 years	53,514	38%	50,312	35%	43,119	32%
65+ years	3,176	2%	2,710	2%	2,167	2%
Unknown/Unreported	127	--	87	--	89	--
<b>Ethnicity</b>						
Hispanic/Latino(a)	33,983	27%	33,561	26%	28,470	23%
Non-Hispanic	91,644	73%	97,170	74%	96,403	77%
Unknown/Unreported	17,026	--	12,980	--	11,472	--
<b>Race</b>						
White	57,418	52%	59,693	52%	58,975	52%
Black	50,165	45%	51,826	45%	51,288	45%
Asian/Native Hawaiian/Pacific Islander	1,675	2%	1,500	1%	1,292	1%
Native American/Alaska Native	619	1%	601	1%	568	1%
More than one race	1,533	1%	958	1%	969	1%
Unknown/Unreported	31,243	--	29,133	--	23,065	--

-- Unknown or unreported responses are not included in percentage calculations.

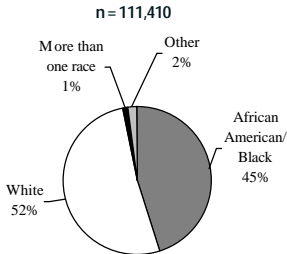
Percentages may not sum to 100 percent due to rounding error.

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2002, 2003, and 2004 CARE Act Data Reports.

...continued from page 17

Native Hawaiian, or Pacific Islander, 1 percent of clients were Native American or Alaska Natives, and 1 percent reported being of more than one race (Figure 8).

**Figure 8. Race of Clients Served by ADAP, 2004**



Data on race were unknown or unreported for 31,243 clients. "Other" includes Asian, Pacific Islander, and American Indian or Alaska Native.

## ADAP FUNDS AND EXPENDITURES

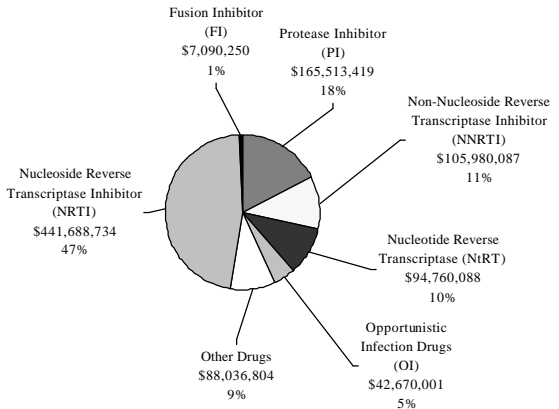
ADAP is funded through multiple sources, including CARE Act appropriations and non-CARE Act sources. In addition to Title II ADAP "earmark" funds (the largest component of CARE Act appropriations) and ADAP supplemental funds, State ADAPs may receive funds from Title I, Title II base, and other sources. Total ADAP funds may also include non-CARE Act sources such as Medicaid, Medicare, other Federal, State, or local gov-

ernment funding, other public payments, manufacturer rebates, private contributions, and client payments.

In FY2004, a total of \$748,872,000 was awarded to States and territories for AIDS Drug Assistance Programs; a 5 percent increase from FY2003. ADAPs reported receiving additional funding of \$402,435,389 from other sources, including State and local contributions of \$226,295,184 in 2004.

ADAP drug expenditures increased by 6 percent in 2004, from \$893,436,673 in 2003 to \$945,739,383. State ADAPs spent \$807,942,328, or 85 percent of 2004 total drug expenditures on antiretroviral medications: protease inhibitors (PI), nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), and nucleotide reverse transcriptase (NtRTI). NRTIs accounted for 47 percent of all drug expenditures in 2004, followed by PIs (18 percent), NNRTIs (11 percent), and NtRTIs (10 percent). Drugs used to prevent or treat opportunistic infections (OI) comprised 5 percent of ADAP drug expenditures in 2004 (Figure 9).

**Figure 9. Drug Expenditures by Drug Class, 2004**



Percentages may not sum to 100 percent due to rounding error.

Antiretroviral medications (PIs, NRTIs, NNRTIs, and NtRTIs) were the most commonly prescribed medications provided by State ADAPs in 2004 (Table 18). Because these drugs are prescribed in combination, a single client may have received multiple drugs. Tenofovir DF, Efavirenz, Lamivudine, and Zidovudine/Lamivudine were the four

most commonly prescribed drugs in 2004. Zidovudine/Lamivudine was the most frequently prescribed HIV medication by expenditure in 2004 (Table 19), accounting for 12 percent of the total drug expenditures in 2004. ■

**Table 18. Top Ten HIV Medications Prescribed by Number of Clients, 2004**

Generic Drug Name	Drug Class	Number of clients	Expenditures
Tenofovir DF	NRTI	46,202	\$94,760,088
Efavirenz	NNRTI	38,761	\$75,135,344
Lamivudine	NRTI	38,667	\$54,451,095
Zidovudine/Lamivudine	NRTI	36,835	\$114,788,389
Trimethoprim/Sulfamethoxazole	OI	32,071	\$1,225,393
Lopinavir/Ritonovir	PI	27,957	\$83,469,110
Ritonavir	PI	23,539	\$37,032,258
Stavudine	NRTI	22,724	\$30,566,208
Didanosine	NRTI	21,334	\$23,701,139
Atazanavir	PI	18,142	\$55,972,757

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

**Table 19. Top Ten HIV Medications Prescribed by Expenditure, 2004**

Generic Drug Name	Drug Class	Number of clients	Expenditures
Zidovudine/Lamivudine	NRTI	36,835	\$114,788,389
Tenofovir DF	NRTI	46,202	\$94,760,088
Lopinavir/Ritonovir	PI	27,957	\$83,469,110
Efavirenz	NNRTI	38,761	\$75,135,344
Abacavir/Zidovudine/Lamivudine	NRTI	14,490	\$72,498,749
Atazanavir	PI	18,142	\$55,972,757
Lamivudine	NRTI	38,667	\$54,451,095
Nelfinavir	PI	14,987	\$47,404,547
Ritonavir	PI	23,539	\$37,032,258
Abacavir	NRTI	17,141	\$33,419,259

Source: Health Resources and Services Administration, HIV/AIDS Bureau, 2004 CARE Act Data Report.

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