THE HENRY J. KAISER FAMILY FOUNDATION

HIV/AIDS

HIV/AIDS POLICY FACT SHEET

AIDS Drug Assistance Programs (ADAPs)

April 2005

What are ADAPs?

AIDS Drug Assistance Programs (ADAPs) provide FDA-approved HIV-related prescription drugs to, and pay for insurance coverage for, low-income people with HIV/AIDS who have limited or no prescription drug coverage. They are a critical source of medications for uninsured and underinsured people living with HIV/AIDS, reaching approximately 136,000 clients, or about 30% of people with HIV/AIDS estimated to be receiving care nationally.[1] In June 2004 alone, ADAPs provided medications to more than 94,000 clients and insurance coverage to thousands more.

ADAPs operate in 57 jurisdictions including all 50 states,[2] the District of Columbia, Puerto Rico, the U.S. Virgin Islands, three U.S. Pacific Territories (Guam, the Commonwealth of the Northern Mariana Islands, and American Samoa) and one Associated Jurisdiction (the Republic of the Marshall Islands). They began serving clients in 1987, when Congress first appropriated funds to help states purchase AZT—the only approved antiretroviral drug at that time. In 1990, they were incorporated into Title II of the newly enacted Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

Since Fiscal Year (FY) 1996, Congress has specifically earmarked funding in the CARE Act for ADAPs, which is allocated by formula to states.[3] ADAPs may also receive state funding and contributions from other sources, but this support is highly variable and largely dependent on local decisions and resources. ADAPs are not entitlement programs; annual federal appropriations and, where available, funding from other sources, determine how many clients ADAPs can serve and the level of services they can provide.

Each state administers its own ADAP, including the establishment of eligibility criteria, drug formularies, and other program elements. No minimum formulary or client income eligibility level is required under current law. As a result, there is wide variation in access to ADAPs and in the range of drugs offered across the country.

Eligibility Criteria

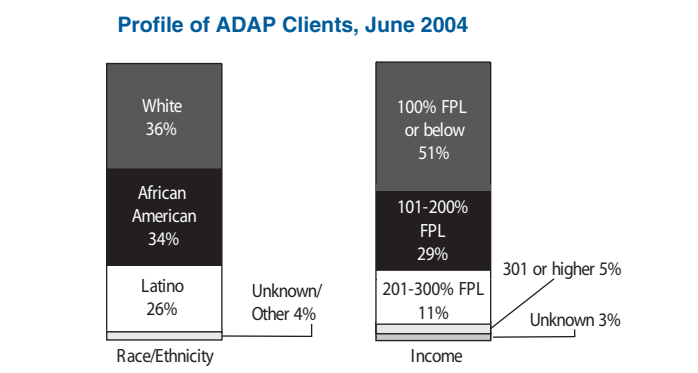
To be eligible for ADAPs, individuals must meet state-determined financial, and sometimes clinical, eligibility criteria, and have limited or no access to drug coverage. As of June 2004:

- All ADAPs require documentation of HIV status. Three reported using additional clinical criteria (e.g., specific CD4 counts or viral load ranges) and some use additional clinical criteria for access to particular drugs.
- Financial eligibility varies from a low of 125% of the Federal Poverty Level (FPL) in North Carolina to 500% FPL or more in 5 states – Delaware, Maryland, Massachusetts, New Jersey, and Ohio (in 2004, the federal poverty level was $9,310 for a single person).

Clients

The number of clients served by ADAPs has grown over time, increasing most significantly between 1996 and 1997, and more slowly since that time. ADAP clients are predominantly low-income and uninsured. Most are people of color, male, and many have indicators of advanced HIV disease. In June 2004:

- ADAPs provided medications to 94,577 clients across the country (thousands more had their insurance coverage paid for by ADAPs). Client utilization increased by 10% over June 2003.
- African Americans represented one-third (34%) and Hispanics one-quarter (26%) of ADAP clients. Asian/Pacific Islanders and Alaskan Native/American Indians combined represented 2%. White non-Hispanics represented 36%.
- More than three quarters (79%) of ADAP clients were men; over half (57%) were between the ages of 25 and 44.
- Most had incomes at or below 200% FPL (80%), including about half (51%) with incomes at or below 100% FPL.
- A majority of clients were uninsured, with only small percentages reporting some other source of coverage (15% private; 9% Medicare; 7% Medicaid and less than 1% with both Medicare and Medicaid).
- Half had CD4 counts of 350 or below at time of enrollment.



Note: American Samoa, District of Columbia, Guam, Maine, the Marshall Islands, N. Mariana Islands, and the U.S. Virgin Islands are not included. Percentages may not total 100% due to rounding.

Drug Expenditures and Prescriptions

ADAP drug expenditures and prescriptions filled have also grown. In June 2004:

- ADAP drug expenditures totaled $96.9 million, an increase of 25% over June 2003, and a greater rate of increase than in recent years.
- Per capita drug spending was $1,024, an increase of 14% over June 2003.
- ADAPs filled 377,271 prescriptions, an increase of 26% over the number of prescriptions filled in June 2003.
- The average expenditure per prescription was $257. Antiretrovirals (ARVs) accounted for the bulk of drug expenditures (87%), and expenditures per prescription were much higher for ARVs than non-ARVs ($348 compared to $92).

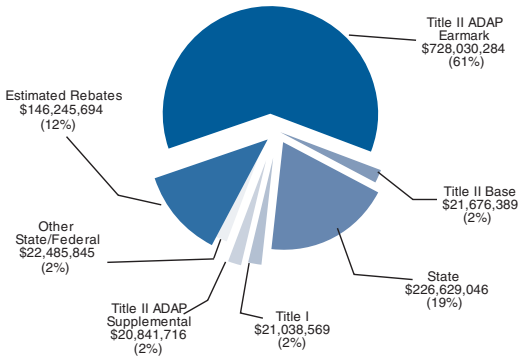
ADAP Budget

The budget has increased over time but more slowly in recent years:

- The national ADAP budget grew to $1.187 billion in FY 04, an increase of approximately $116 million or 11% over FY 2003. This compares to a 106% increase between FY 96 and FY 97.

- The federal ADAP earmark allocated under Title II of the Ryan White CARE Act is the largest component of the budget (61%). The earmark increased by 5% over FY 03, its smallest increase since it was created.[4] For the first time, state funding and drug rebates each accounted for higher dollar amount increases between FY 03 and FY 04 than the earmark. State funding has consistently been the second largest component of the national ADAP budget.
- Within states, funding from sources other than the earmark was highly variable. In FY 04, 2 ADAPs received only earmark funding; 40 received state general revenue support; 20 received Title II base funds; 9 received Title I funding; and 18 received ADAP supplemental treatment grants.
- Despite an increase in the overall national ADAP budget, 15 ADAPs experienced net decreases in their budgets, due to decreases in the non-earmark components of their funding.

National ADAP Budget, by Source, FY 2004
Total = $1.19 Billion



Note: National budget includes FY 2004 federal ADAP Earmark only for American Samoa, the Marshall Islands, the N. Mariana Islands. National budget includes FY 2004 federal ADAP Earmark and ADAP Supplemental only for Guam and the U.S. Virgin Islands.

Drug Formularies

ADAP formularies ranged from a low of 25 drugs offered in Louisiana to 479 in New York, and open formularies[5] in three states (Massachusetts, New Hampshire and New Jersey):

- While the majority of ADAPs cover all FDA-approved antiretrovirals, 17 do not, including one state (South Dakota) that does not provide any protease inhibitors. 42 ADAPs offer Fuzeon, the one approved fusion inhibitor; 10 do not.
- 15 ADAPs offer fewer than 10 of the 16 "A1" drugs highly recommended by the U.S. Public Health Service/Infectious Diseases Society of America (USPHS/IDSA) Guidelines for the prevention of opportunistic infections (OIs)[6] including one state (Louisiana) which does not provide any medications for OIs or other HIV-related conditions, and only covers ARVs on its formulary. 37 ADAPs cover 10 or more of these 16 drugs. 4 ADAPs cover all 16.
- 20 ADAPs offer drugs for the treatment of hepatitis C; and 24 offer hepatitis A and B vaccines.

Waiting Lists and Other Cost Containment Measures

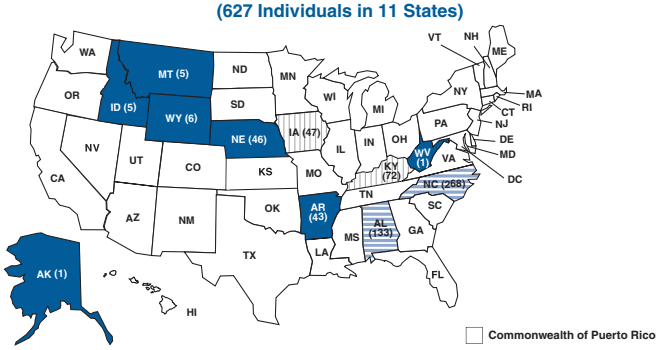
Due to budget shortfalls, some ADAPs have waiting lists and other cost containment measures in place. As of March 2005:

- 21 ADAPs had instituted cost containment measures including 11 with waiting lists totaling 627 individuals;
- 12 ADAPs have recently instituted other cost containment measures including: capped enrollment (3); capped enrollment for Fuzeon (4); reduced formularies (4); new or increased cost-sharing for clients (4); new eligibility requirements and/or lowered income eligibility (2); and monthly or annual per capita expenditure limits (2).
- 13 ADAPs anticipate the need to implement additional cost containment measures by the end of the current ADAP fiscal year (March 31, 2006), including five that already have such measures in place.
- In June 2004, President Bush announced the one-time availability of $20 million to provide medications to individuals in 10 states with waiting lists at that time.[7]

Drug Purchasing Models and Insurance Coverage

- All ADAPs but one participate in the 340B program, enabling them to purchase drugs at or below the statutorily defined 340B ceiling price.
- 27 ADAPs purchase drugs directly from wholesalers; 25 purchase drugs through a pharmacy network.
- 26 ADAPs use ADAP earmark funding to purchase health insurance and/or pay insurance premiums for people with HIV/AIDS, paying for coverage for 7,277 clients in June 2004. ADAPs spent $37.8 million on insurance coverage in 2004.
- 20 ADAPs paid for client insurance co-payments and deductibles in 2004.

State ADAPs with Waiting Lists, March 2005
(627 Individuals in 11 States)



States with waiting lists in place as of March 2005 (107 individuals—7 states).

States with individuals eligible for the President's $20 million ADAP Initiative who are not yet receiving medications (401 individuals—2 states), as of March 2005.

States with waiting lists in place as of March 2005 that also have individuals eligible for the President's Initiative not yet receiving medications (104 individuals not eligible for the initiative and 15 individuals eligible but not yet receiving medications—2 states).

Note: Data not reported by 5 ADAPs: American Samoa, Guam, N. Mariana Islands, Marshall Islands, and U.S. Virgin Islands.

The Future of ADAPs

ADAPs play a key role in the health care delivery system for uninsured and underinsured people with HIV/AIDS, providing prescription medications to those who cannot get them elsewhere and often serving as a gateway to a broader array of health care and supportive services including other Ryan White funded programs, Medicaid, and private insurance. As the number of people living with HIV/AIDS has increased, largely due to advances in HIV treatment, so too has the importance of and demand for ADAPs. Because of resource constraints, however, several ADAPs have waiting lists in place, or use other cost containment measures that may affect client access. In addition, access to ADAPs and the range of drugs offered vary significantly across the country. The challenge for ADAPs in meeting growing demand with limited resources will likely continue for the foreseeable future.

References

[1] CDC estimates that there are approximately 445,000 people living with HIV/AIDS in the U.S. who are receiving care. HRSA estimates that 136,000 clients were served by ADAPs in 2002, which represents approximately 30% of this estimate (see: Fleming, P., et.al., *HIV Prevalence in the United States*, *2000*, 9th Conference on Retroviruses and Opportunistic Infections, Abstract #11, Oral Abstract Session 5, February 2002; HRSA, HIV/AIDS Bureau, *Ryan White* CARE Act *AIDS Drug Data Report, 2002)*.

[2] The term "state" includes both states and territories.

[3] Three percent of the ADAP earmark is set aside for the ADAP Supplemental Treatment Drug Grant, grants to states with severe need.

[4] Not including the ADAP Supplemental, which represented 2% of the national ADAP budget in FY 04.

[5] Providing any FDA-approved HIV-related prescription drug.

[6] U.S. Public Health Service (USPHS) and Infectious Diseases Society of America (IDSA), *2001 USPHS/IDSA Guidelines for the Prevention of Opportunistic Infections in Persons Infected with Human Immunodeficiency Virus*, November 28, 2001.

[7] White House, *Press Release*, *Remarks by the President on Compassion and HIV/AIDS, Philadelphia, Pennsylvania*, June 23, 2004; White House, *Fact Sheet: Extending and Improving the Lives of Those Living with HIV/AIDS*, June 23, 2004.

Additional copies of this publication (#1584-06) are available at www.kff.org.
This fact sheet is part of the National ADAP Monitoring Project, an Initiative of the Kaiser Family Foundation and the National Alliance of State and Territorial AIDS Directors. It is based on data from the April 2005 *National ADAP Monitoring Project* report (#7288). The full report can be accessed at www.kff.org and www.nastad.org.