

Treatment ISSUES

The State of ADAP: Improvements and stresses continue

by Murray C. Penner

AIDS Drug Assistance Programs (ADAPs) provide life-saving HIV treatments to low income, uninsured, and underinsured individuals living with HIV/AIDS in all 50 states, the District of Columbia, the Commonwealth of Puerto Rico, and the majority of U.S. territories. Many ADAPs also pay “wrap-around” costs on behalf of eligible individuals for insurance (paying premiums, deductibles and co-payments) and Medicare Part D prescription drug benefit services.

ADAPs are a component of Part B of the federal Ryan White Program that provides necessary medical and support services to individuals living with HIV/AIDS without adequate health insurance coverage in all states, territories and associated jurisdictions. ADAPs are administered by states and territories, in most cases, by the state health department.

It's no secret that many ADAPs have been experiencing fiscal pressures as they work to serve the medication needs of people living with HIV/AIDS. This is particularly true since ADAPs depend significantly on annual, discretionary appropriations from Congress and in many cases, state general fund revenue. With unprecedented growth in expenses as a result of our nation's slow economic recovery, burgeoning ADAP utilization, and funding not keeping pace with the increased costs, many ADAPs have had little choice but to limit or even eliminate some services. Further, ADAPs have also been pressured by heightened national efforts focused on HIV testing and linkages into care, high drug costs, and new HIV treatment guidelines calling for earlier therapeutic

treatments. While this trend of access restrictions has continued for years, the overall health of the program has improved slightly and hope remains that this will continue throughout 2012.

Who is Served by ADAPs?

Despite the fiscal stresses that many ADAPs continue to experience, the program represents a tremendous success in serving the needs of people living with HIV/AIDS and has continued to grow despite minimal increases in federal funding. ADAP client enrollment and utilization reached their highest levels last year. Over 226,000 clients were enrolled in ADAPs nationwide, ranging from just over 100 clients in North Dakota to more than 41,000 clients in California. Typically, fewer clients are served in ADAPs than are enrolled at any given time—ADAPs served nearly 218,000 clients last year.

Many ADAP clients served are minorities, men, and people who have very low incomes. In June 2011, African Americans and Hispanics represented 59% (32% and 27%, respectively) of clients served. Non-Hispanic whites comprised 35% of clients served. Combined, Asians, Native Hawaiian/Pacific Islanders, and Alaskan Native/American Indians represented approximately 3% of the total ADAP population while multi-racial ADAP clients represented 1%. More than three-fourths of clients were men and an equal number had income levels at or below 200% of the Federal Poverty Level.

Forty-three percent of ADAP clients served last year were between the ages of 25 and 44, and for the first

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time since ADAPs began, 50% of clients served were between the ages of 45 and 64. As the population served by ADAPs “ages,” it stands to reason that ADAP clients previously ineligible for Medicare will become eligible due to their age. Medicare will then provide these eligible clients with comprehensive medical care, including prescription drug coverage through Medicare Part D. ADAPs are allowed to provide “wrap-around” assistance for these clients, such as paying cost-sharing requirements, including premiums, deductibles, and co-payments. Last year, 15% of ADAP clients had Medicare coverage and received wrap around assistance from an ADAP while another 6% of clients were “dually eligible” for both Medicare and Medicaid and received wrap around services from an ADAP.

How is ADAP Funded?

The national ADAP budget last year was nearly \$1.9 billion, an increase of approximately \$100 million (or 5%) over the previous year. Since 1996, when ADAPs began, the budget has grown nine-fold. The composition of each state’s ADAP budget varies.

Funding from the federal government through the Ryan White Program continues to represent the largest share of the national ADAP budget. However, it no longer drives budget growth as it did early on in the program’s history. The “ADAP earmark” with Ryan White from Congress was one-quarter of the national ADAP budget in 1996; rose to more than two-thirds (68%) of the national budget in 2000, and has most recently declined as a share of the overall budget to less than half (43%). The federal ADAP earmark is provided to all eligible jurisdictions (58 last year) based on a formula of living HIV (non-AIDS) and AIDS cases. Other federal funds allocated for ADAPs through the Ryan White Program are either awarded on a competitive basis or allocated as a result of demonstrated need.

In September 2011, ADAPs received \$40 million to address ADAP waiting lists and other unmet ADAP needs from the federal government. Appropriated by Congress in FY2011, ADAP emergency funding awards were made to 30 states, with funding amounts ranging from approximately \$75,000 in North Dakota to nearly \$7 million in Florida. As a result of receipt of this funding, Alabama, Florida, Georgia, Idaho, Louisiana, Montana, North Carolina, Ohio, South Carolina, Utah, and Virginia were able to reduce the overall number of individuals on their waiting lists.

Thirty-seven states contributed their own funding to their respective ADAP in the most recent budget year. While states are not required to contribute funding specifically to their ADAP, many have chosen to do so. Twenty-seven states also transferred money from their Ryan White Part B base funding to ADAP. State contributions accounted for \$306 million, or 16% of the overall ADAP budget in FY2011, an increase of 9% over the previous year.

Another important component of the national ADAP budget is revenue received from drug rebates. Nationally, this funding has risen from 6% of the budget when ADAPs began in 1996 to 33%, or \$619 million, last year. ADAPs must actively seek drug rebates and, while not all ADAPs do so because of varying state drug purchasing mechanisms, drug rebates accounted for a quarter or more of the ADAP budget in 26 states. This funding represents money that is returned to the state as a result of active filing of rebate claims with manufacturers based on past drug purchases.

What Access Restrictions Does ADAP Have?

ADAPs have established various cost containment measures in recent years in order to remain fiscally solvent. One obvious sign of these actions are waiting lists for medications. ADAP waiting lists reached their highest point in September 2011

with 9,298 individuals in 11 states eligible for ADAP yet unable to access a program. A signal of improvement to the ADAP crisis, while still unacceptable, this waiting list dropped to 3,949 individuals in 11 states in early March 2012. Over the course of 2011, 14 ADAPs reported an ADAP waiting list. Since that time, some ADAPs have been able to reduce the overall number of individuals on their waiting list. As states remove

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individuals from their waiting lists, however, they continue to add new individuals to their program. And, there are other individuals who are ineligible for ADAPs or who never present for services at ADAPs who also are in need of HIV medications.

Individuals who are on ADAP waiting lists may receive their medications either through Welvista, a non-profit pharmacy located in South Carolina, or through pharmaceutical company patient assistance programs (PAPs). In addition, individuals not eligible for an ADAP may qualify to receive their medications from PAPs. These programs are temporary and not designed to serve as an ongoing source of medications. For more information on patient assistance programs, please visit the Positively Aware website (www.positivelyaware.com/2011/11_02/copay_chart.shtml) or the Fair Pricing Coalition's website (www.fairpricingcoalition.org/projects/).

Many other ADAPs have instituted other cost containment measures that impacted the provision of medications to people living with HIV/AIDS. ADAPs continue to focus on establishing program efficiencies to create long-term program sustainability, implementing effective cost-containment measures, and coordinating with other payers to ensure the Ryan White Program "payer of last resort" requirements, while still meeting the needs of people seeking services from the program.

To see a current list of states with access restrictions please visit the National Alliance of State and Territorial AIDS Directors (NASTAD) website (www.NASTAD.org).

What About ADAP Drug Prices?

All ADAPs participate in the 340B program, a federal drug pricing program that provides lower cost drugs to eligible, public entities. In addition, NASTAD's ADAP Crisis Task Force (ACTF) negotiates directly with manufacturers for pharmaceutical pricing below the 340B price on behalf of all ADAPs. When such agreements are reached, they are provided to all states. As a result of participation in the 340B program, and additional rebates and discounts for ADAPs as a result of the ACTF agreements, ADAPs generally pay the lowest prices for HIV medications in the country.

There are currently agreements in place with all eight manufacturers of antiretroviral medications and with several other companies that manufacture other high-cost medications. In November



2011, recognizing the current fiscal ADAP crisis, the ACTF worked with antiretroviral manufacturers to reduce ADAPs' antiretroviral costs by an additional \$142 million from January 2012 through December 2013. The agreements include price freezes on most medications which have helped to reduce ADAP expenditures. The cumulative savings of the ACTF agreements from 2003 to 2011 is estimated at more than \$1.3 billion.

What Does the Future Look Like for ADAPs?

Since the release of final FY2011 Ryan White grant awards in September 2011, including \$40 million in ADAP emergency relief funding for states

with waiting lists or other cost-containment measures in place, some ADAPs were able to reduce the overall number of individuals on, or entirely eliminate, their waiting lists. Many ADAPs continue to struggle financially, including those without any cost-containment measures currently in place, and are beginning to anticipate the need for cost-containment measures and waiting lists in the ADAP grant year that began on April 1, 2012. As a result of these factors, waiting lists will likely grow until additional funding is received, which is expected soon.

New ADAP awards for FY2012, which will include an additional \$15 million appropriated by Congress, were anticipated by April 1.* In addition, the \$35 million in additional funding that President Obama announced on World AIDS Day has not yet been awarded. The Health Resources and Services Administration (HRSA), the federal agency responsible for administering the Ryan White Program, including ADAPs, is developing a distribution methodology that will require a competitive application by ADAPs. The ADAP awards are expected to be made in July 2012. It is still unknown as to which

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ADAPs will be eligible for this funding and when it will actually be awarded.

Finally, there are positive developments in the upcoming federal budget for ADAPs. President Obama's FY2013 budget proposal includes a \$67 million increase for ADAP over FY2012 levels, for a total of \$1 billion. The FY2012 ADAP earmark included in the FY2013 budget includes the \$35 million announced on World AIDS Day.

Since the Affordable Care Act was signed into law over two years ago, ADAPs have also been working to implement and preparing for areas of the law that directly impact them and that will likely provide some fiscal relief. Portions of the Affordable Care Act that impact ADAPs include:

- Medicaid eligibility expansion in 2014 which will eliminate the disability requirements for Medicaid.
- The expansion of the Centers for Medicare and Medicaid Services (CMS) Section 1115 Waiver which allows states to provide services under Medicaid to people living with HIV/AIDS without the current disability requirements.
- Increase in the number of individuals covered by insurance plans, including health exchanges and small group plans, in 2014.
- Pre-existing Condition Insurance Plans (PCIPs) which are currently in place in every state and will continue until December 31, 2013;
- Medicare Part D expenditures provided by ADAP on behalf of clients counting toward True Out Of Pocket (TrOOP) expenditures (which then allows clients to move through the "donut hole" and receive catastrophic Medicare Part D prescription drug coverage).

- Narrowing and closing of the Medicare Part D "donut hole" between now and 2020.
- An increase in the Medicaid rebate amount for purchased drugs.
- 340B pricing transparency.

These changes will lead to increased comprehensive care for ADAP clients and should result in fiscal relief for ADAPs. ADAPs have been working to build the infrastructure necessary to implement the provisions noted above.

In Summary

It is unclear yet how the infusion of additional federal funding and savings from ADAP Crisis Task Force agreements will ease the burden felt by the continued utilization increases in ADAP in 2012. State budgets are also being determined now and will impact the fiscal health of many ADAPs. Even with the positive developments over the last year, it is unlikely that ADAP waiting lists and cost-containment measures will be eliminated. As more people living with HIV/AIDS live longer and

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more productive lives, the demand for ADAP services continues to grow. Therefore, the need for additional state and federal funding for the program remains, as well as continued price freezes and additional discounts and rebates on the price of drugs that ADAPs purchase. Continued collaboration from all stakeholders is needed to ensure that ADAPs can thrive now, and be prepared to continue providing necessary wrap-around services after the Affordable Care Act is fully implemented in 2014.

*As of presstime, FY2012 ADAP grants had not been awarded.

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