NATIONAL ADAP MONITORING PROJECT

ANNUAL REPORT
EXECUTIVE SUMMARY

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The National ADAP Monitoring Project is one component of NASTAD's National ADAP Monitoring and Technical Assistance Program which provides ongoing technical assistance to all state and territorial ADAPs. The program also serves as a resource center, providing timely information on the status of ADAPs, particularly those experiencing resource constraints or other challenges, to national coalitions and organizations, policy makers, and state and federal government agencies. NASTAD also receives support for the National ADAP Monitoring and Technical Assistance Program from the following companies: Auxilium Pharmaceuticals, Gilead Sciences, GlaxoSmithKline, Roche, Solvay Pharmaceuticals, Inc., Tibotec Therapeutics and Virco Labs, Inc.

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INTRODUCTION

The AIDS Drug Assistance Program (ADAP) has become a critical source of prescription drugs for low-income people with HIV/AIDS in the United States who have no or limited prescription drug coverage. In a given year, ADAPs reach approximately 136,000[1] clients, or about 30%[2] of people with HIV/AIDS estimated to be receiving care nationally. 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, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, three U.S. Pacific Territories (American Samoa, Guam and the Commonwealth of the Northern Mariana Islands) and one Associated Jurisdiction (the Republic of the Marshall Islands). In addition to helping to fill gaps in prescription drug coverage, ADAPs serve as a gateway to a broader array of healthcare and supportive services funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act[3] and to other sources of coverage including Medicaid, Medicare, and private insurance. As the number of people living with HIV/AIDS in the U.S. has increased, largely due to advances in HIV treatment, and drug prices have continued to rise, the importance of ADAPs has grown over time.

Still, of the 850,000 to 950,000 people estimated to be living with HIV/AIDS in the U.S., 42%-59% are not yet in the care system, including those who should be receiving highly active antiretroviral therapy (HAART) and other HIV-related medications.[4] The Centers for Disease Control and Prevention (CDC) estimates that, in 2003, 45% of people with HIV/AIDS eligible for HAART, as indicated by current treatment guidelines, were not receiving it.[5] The CDC and other federal partners are working to increase the number of people with HIV who know their status and get them into care through the *Advancing HIV Prevention* (AHP) Initiative, and this will likely result in an increasing number of people with HIV/AIDS needing to rely on ADAPs.[6,7]

This report of the National ADAP Monitoring Project, an initiative of the Kaiser Family Foundation and the National Alliance of State and Territorial AIDS Directors (NASTAD), provides the latest data on ADAPs across the country at an important time in the program's history. Nearly ten years have passed since the advent of highly active antiretroviral therapy (HAART), a development which significantly altered the clinical course of the epidemic and elevated the role of ADAPs in the United States. Many ADAPs have struggled to meet growing client demand, rising drug costs, and changing HIV treatment standards; limited resources have led some ADAPs to institute waiting lists or otherwise restrict access. Last year, in recognition of this challenge, President Bush announced the one-time availability of $20 million to provide medications to individuals on waiting lists in 10 states, which has served to alleviate their waiting lists.[8] However, other states now have waiting lists in place that are not eligible for the Initiative, and many states without waiting lists have limited access and services. Funding for the Initiative is due to end later this year, and has not been continued in FY 2005. States with individuals receiving medications through the Initiative are expected to begin transitioning them into their regular ADAP, raising concerns about how their medications will be financed.

There are also some important near term developments that stand to affect ADAPs. The CARE Act, under which ADAPs are authorized, is facing its third reauthorization this year and ADAPs are likely to figure prominently in discussions about its future structure. Among the many issues under discussion that directly involve ADAPs are: whether there should be an increased focus on primary medical care, including medications, within the CARE Act; whether minimum formularies and standard income eligibility criteria for ADAPs should be mandated across the country to address variations in access; and what longer term fixes for ADAP waiting lists and other cost containment measures might exist.

Additionally, the implementation of the new Part D Medicare Drug Benefit under the Medicare Modernization Act of 2003 (MMA) will change the way in which ADAPs interface with both Medicaid and Medicare and the role of ADAPs for people living with HIV/AIDS. Finally, both the federal and state governments are exploring ways to limit Medicaid spending, which could have significant implications for ADAPs, as more people with HIV/AIDS may need to access ADAP services. It is within this context that the latest findings on AIDS Drug Assistance Programs are presented.

Allocation of Federal Funding to ADAPs & State Match Requirements

Each year, Congress specifically earmarks federal funding for ADAPs within the Ryan White CARE Act (3% of the earmark is set aside for grants to states with severe need – see below). The formula used to allocate federal earmark funding to state jurisdictions each year is based on their proportion of the nation's estimated living AIDS cases. Estimated living AIDS cases are determined by the Centers for Disease Control and Prevention (CDC) and provided to the Health Resources and Services Administration (HRSA). To determine estimated living AIDS cases, CDC applies annual survival weights to the most recent 10 years of reported AIDS cases. A jurisdiction's proportion of estimated living AIDS cases is applied to the earmark to determine the award amount.

States with 1% or more of reported AIDS cases during the most recent two-year period must match (with non-federal contributions) their Ryan White Title II award, which includes the ADAP earmark, according to an escalated matching rate (based on the number of years in which the state has met the 1% threshold). The state match, however, is not required to be used for its ADAP, but may be in part or in whole, and may consist of in-kind or dollar contributions from the state. In FY 2004, 57 jurisdictions received federal ADAP earmark funding.

The CARE Act Amendments of 2000 included a new Supplemental Treatment Drug Grant, grants to states with "severe need". Three percent of federal ADAP earmark funding appropriated by Congress is set aside for ADAP supplemental awards. Award amounts are based on an eligible jurisdiction's proportion of estimated living AIDS cases among those states eligible for and applying to receive a supplemental grant. This proportion is applied to the number of dollars available under the supplemental grant to determine the award amount. States applying for supplemental grants must provide matching dollars in an amount equal to $1 for each $4 of federal funds provided in the grant, and the match must be put toward ADAP (in-kind contributions from the state such as office space, personnel, and other relevant expenses are allowable contributions to meet this required match). To be eligible for supplemental awards, states must have met one of the following criteria as of January 1, 2000:

- Financial eligibility at or below 200% of the Federal Poverty Level (FPL);
- Medical eligibility criteria in place (e.g., specific CD4 T-cell count or viral load);
- Limited formulary compositions for antiretrovirals; and/or
- Less than ten medications on formulary to treat opportunistic infections.

In FY 2004, 27 ADAPs were eligible for Supplemental Award funding and 18 applied; 9 eligible ADAPs did not apply either because they could not meet the state match requirement or did not require supplemental funding.

It is important to note that the ADAP fiscal year differs from the federal and state fiscal year periods. The ADAP fiscal year begins on April 1 and ends on March 31: the federal fiscal year begins on October 1 and ends on September 30; for most states, the state fiscal year begins on July 1 and ends on June 30. For example, the ADAP FY 2005 began on April 1, 2005 and will end on March 31, 2006. The Federal FY 2005 began on October 1, 2004 and will end on September 30, 2005. The State FY 2005, in most states, began July 1, 2004 and ends on June 30, 2005. ◗

Overview of ADAPs

The purpose of ADAPs, as stated in the Ryan White CARE Act, is to:

> …provide therapeutics to treat HIV disease or prevent the serious deterioration of health arising from HIV disease in eligible individuals, including measures for the prevention and treatment of opportunistic infections.[9]

ADAPs meet this purpose through two main activities: by providing FDA-approved HIV-related prescription drugs to people with HIV/AIDS and by paying for health insurance that includes HIV treatments. Eligible individuals are low-income people with HIV/AIDS who have limited or no prescription drug coverage.

ADAPs began serving clients in 1987, when Congress first appropriated funds ($30 million over two years[10]) to help states purchase AZT, the only FDA-approved antiretroviral drug at that time. In 1990, these federally-funded, state administered "AZT Assistance Programs" were incorporated into the newly created Ryan White CARE Act under Title II (grants to states) and became known as "AIDS Drug Assistance Programs." The CARE Act has become the nation's third largest source of federal funding for HIV care, after Medicaid and Medicare.[11] Since FY 1996, Congress has specifically earmarked funding within Title II of the CARE Act for ADAPs, which is allocated by formula to states.[12,13]

The federal ADAP earmark is the largest component of the overall national ADAP budget. It is also the largest funded component of the CARE Act, and was the only part of the CARE Act to receive federal funding increases in FY 2004 and FY 2005.[11,14] In addition to the federal earmark, ADAPs may receive funding from other sources, including state general revenue support,[15] funding from other parts of the CARE Act, and negotiated drug rebates, but these funding sources are highly variable and largely dependent on state and local policy decisions, differing ADAP program management strategies, and resource availability. The Health Resources and Services Administration (HRSA) of the Department of Health and Human Services is the federal agency that administers the CARE Act. Each state operates its own ADAP, and is given broad authority by the CARE Act to design its program, including determining client eligibility criteria, formularies, and other key program elements. No minimum formulary or client income eligibility level is required under current law.

Key Dates in the History of ADAPs

1987: First antiretroviral, AZT (an NRTI), approved by the FDA; Federal government provides grants to states to help them purchase AZT, marking beginning of federally-funded, state administered "AZT Assistance Programs"

1990: ADAPs incorporated into Title II of the newly created Ryan White CARE Act

1995: First Reauthorization of CARE Act; first protease inhibitor approved by FDA, and the highly active antiretroviral therapy (HAART) era begins

1996: Federal ADAP earmark created; first non-nucleoside reverse transcriptase inhibitor (NNRTI) approved by FDA

2000: Second Reauthorization of CARE Act, changes for ADAPs include: allowance of insurance purchasing and maintenance, flexibility to provide other limited services (e.g., adherence support and outreach), and creation of ADAP supplemental grants

2003: NASTAD's ADAP Crisis Task Force formed to negotiate with pharmaceutical companies on pricing of antiretroviral medications; first fusion inhibitor approved by FDA

2004: President's $20 Million ADAP Initiative announced to address ADAP waiting lists in 10 states

2005: Third Reauthorization of the CARE Act will be considered by Congress ◗

Like all Ryan White CARE Act programs, ADAPs serve as "payer of last resort"; that is, they provide prescription medications to (or pay for health insurance for) people with HIV/AIDS when no other funding source is available to do so. Demand for ADAPs depends on the size of the prescription drug "gap" that ADAPs must fill in their jurisdiction – larger gaps, such as in states that have less generous Medicaid programs, may strain ADAP resources further. But ADAPs are discretionary grant programs, not entitlements,[16] and their funding may not correspond to the number of people who need prescription drugs or the costs of medications. Therefore, annual federal appropriations, and where provided, state appropriations and contributions from other sources, determine how many clients ADAPs can serve and the level of services they can provide.

Survey Findings

The National ADAP Monitoring Project surveyed all 57 jurisdictions receiving Ryan White federal ADAP earmark funding in FY 2004; 52 of 57 ADAPs responded. The U.S. Virgin Islands, American Samoa, Guam, the Northern Mariana Islands, and the Marshall Islands did not respond; these jurisdictions represent less than 0.1% of estimated living AIDS cases.[17] Data in this report are from June 2004 and FY 2004,[18] unless otherwise noted. For example, supplemental data collection was conducted in early 2005 to assess the latest status of ADAP waiting lists and other cost containment measures. Analysis of trend data since 1996 is also presented (see box on "Methodology"). Major highlights and detailed findings are provided below, followed by charts and appendices. State-level data are provided in the appendices and on State Health Facts: www.statehealthfacts.org/r/hiv.

HIGHLIGHTS

- **Continued Growth in Clients, Drug Expenditures, Prescriptions**. The number of clients served, drug expenditures, and prescriptions increased between June 2003 and June 2004, primarily reflecting an increase in the national ADAP budget allowing ADAPs to serve more people with HIV/AIDS. Almost the entire national ADAP budget is spent on medications. While most states experienced increases in clients served (38 ADAPs), 13 had decreases. Forty-three ADAPs had increases in monthly drug expenditures; 8 had decreases. Between 1996 and 2004, client utilization increased by 217% in the 41 states reporting data over this period; drug expenditures increased at more than twice this rate over the period (591%). In general, both have slowed considerably over time, with the notable exception of drug expenditures over the last period – between June 2003 and June 2004, drug expenditures in these 41 states experienced their greatest annual rate of increase since 1998.

- **Waiting Lists and Other Cost Containment Measures Persist.** Due to ADAP budget shortfalls, some states have turned to waiting lists and other cost containment measures that affect client access. As of March 2005, 21 ADAPs reported having one or more cost containment measures in place, including 11 with waiting lists representing a total of 627 individuals (Alabama, Alaska, Arkansas, Idaho, Iowa, Kentucky, Montana, Nebraska, North Carolina, West Virginia, and Wyoming). Waiting lists fluctuate within and across states over time and many states have waiting lists in place for months, if not years. In addition to waiting lists, 12 ADAPs have recently instituted one or more other cost containment measures including:

  – 3 states capped enrollment but did not have individuals on waiting lists at the time of the survey (Indiana, South Dakota, and Utah)

  – 4 states capped enrollment for Fuzeon (Alabama, Georgia, New Hampshire, Texas)

  – 4 states reduced the number of drugs offered (Arkansas, Missouri, Utah, and Washington)

  – 4 states instituted new or increased cost-sharing for clients (Arkansas, Minnesota, Utah, Washington)

  – 2 states instituted new eligibility requirements and/or lowered income eligibility (New Hampshire, Washington)

  – 2 states instituted monthly or annual per capita expenditures limits (Oklahoma, South Dakota)

  – 13 ADAPs anticipate the need to implement additional cost containment measures by the end of the current ADAP fiscal year (March 31, 2006), including 5 that already have such measures in place.

- **The President's $20 Million ADAP Waiting List Initiative has Alleviated Waiting Lists in Eligible States.** In 2004, the President announced the one-time availability of $20 million to provide medications to individuals in 10 states with waiting lists at that time (see box on "$20 Million ADAP Waiting List Initiative").[8] Since October 2004, the Initiative has provided medications to more than 1,250 eligible individuals; an additional 416 eligible individuals in four states (Alabama, Iowa, Kentucky, and North Carolina) have not yet been processed to receive medications. Nine states, including Iowa and Kentucky, have a total of 211 people on their waiting lists who are not eligible for the Initiative. In addition, some states without waiting lists have turned to other cost containment measures that limit client access and/or have much more limited access to their programs, as measured by eligibility criteria and formulary composition (see below), and not all those in need of medications are counted on waiting lists.

ADAP Waiting Lists

Since the beginning of the AIDS Drug Assistance Program, many ADAPs have had to make difficult trade-off decisions between client access and services. In some cases, states have capped enrollment to their programs until more resources become available. When enrollment is capped, the next individual who seeks services cannot get them through the ADAP. States that have enrollment caps have often turned to waiting lists in order to facilitate client access when the program can accommodate them. In March 2005, 11 ADAPs had waiting lists, representing 627 people identified as needing services.

When an individual is on a waiting list, they may not have access to HIV-related medications. Or, they may have access through other mechanisms, but these are often unstable. Some individuals on waiting lists can get medications through other state pharmacy assistance programs, if their state has one, or through pharmaceutical manufacturer patient assistance programs (PAPs). PAPs, however, require people to apply often, sometimes as frequently every month, and separate applications must be sent to the manufacturer of each medication needed. For someone on a multiple drug regimen, this process can be quite cumbersome and may not provide the full range of drugs necessary for optimal clinical outcomes.

To date, no state has eliminated current clients from its ADAP when faced with the need to implement a waiting list for new applicants. Nevertheless, states with waiting lists are faced with many challenges, such as: how to monitor those on waiting lists; how to help those on waiting lists access prescription drugs through other programs, if available; whether criteria should be developed to bring people off waiting lists into services or whether new clients should be accommodated on a first come, first serve basis; and what kinds of future decisions could be made to reduce or eliminate the need for waiting lists, while least compromising access for all clients? For example, should a state add a newly approved medication to its formulary if that also would mean having to institute a waiting list.

In recognition of the challenge of waiting lists, in June 2004, President Bush announced the one-time availability of $20 million to provide medications to those on waiting lists in 10 states (see box on "$20 Million ADAP Waiting List Initiative"). This Initiative has reached many of the individuals on waiting lists in these states.

It is important to note that waiting lists are but one measure of unmet need for ADAP services. Some people who need ADAP services may not be counted on a waiting list. And, the level of services provided by ADAPs and the number of clients they serve varies across the country, so those receiving ADAP services in a state with a limited formulary may have unmet needs compared to others receiving services in a state with a more expansive formulary. ◗

Continued funding for the Initiative has not been made available for 2005, and it will end later this year. States with individuals receiving medications through the Initiative are expected to begin transitioning them onto their regular ADAP.

- **What You Get Depends on Where You Live: Variation in Access Across the Country.** Waiting lists are but one measure of unmet need for ADAP services – client access to ADAPs and the level of services available to them vary across the country. These variations are largely the result of resource constraints, with states often facing difficult trade-off decisions, such as between financial eligibility criteria and drugs offered. Variations in access include:
  - Client income eligibility for ADAPs ranges from 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.
  - ADAP formularies range from 25 drugs covered in Louisiana to nearly 500 drugs in New York and open formularies[19] in three states – Massachusetts, New Hampshire, and New Jersey.
  - 17 ADAPs do not provide all FDA-approved antiretroviral medications, including one (South Dakota) that does not provide any protease inhibitors.
  - 10 ADAPs do not cover Fuzeon, the only approved fusion inhibitor.

– 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) for the prevention of opportunistic infections (OIs).[20,21] One state (Louisiana) does not have any medications for OIs or any other HIV-related conditions on its formulary, and only covers ARVs.

- **National ADAP Budget Continues to Rise, but ADAP Earmark Growth Slows; State Funding and Drug Rebates Play Increasing Role**. The National ADAP budget has increased over time, although its rate of increase has remained fairly constant for several years (it rose by 11% between FY 2003 and FY 2004). In addition, the composition of the budget has changed since FY 1996, when the federal ADAP earmark began. Since that time, the earmark has grown into the main source of funding for ADAPs, followed by state general revenue support and manufacturers' drug rebates. Funding increases for the earmark have slowed in recent years, and between FY 2003 and FY 2004, the earmark experienced its smallest increase since it was initiated. In turn, state funding and drug rebates have become increasingly important sources of funding for ADAPs; for the first time since the ADAP earmark began, state funding increased more than the earmark between FY 2003 and FY 2004, followed by drug rebates; in all prior years, the earmark had the largest dollar increase. While state funding and drug rebates are playing a growing role, it is important to note that state funding is generally dependent on individual state decisions and budgets, and some drug rebates are dependent on negotiations by individual states or state coalitions. In addition, increases in drug rebates are in part a function of rising drug prices (since rebates are based on a percentage of drug price).
- **Within States, Funding From Sources Other than ADAP Earmark Highly Variable.** By definition, all eligible jurisdictions (57) receive federal ADAP earmark funding based on a formula. Other funding sources are also important, but fluctuate significantly and are largely dependent on individual state and local planning, policy, and/or legislative decisions, and resource availability. Not all ADAPs receive funding from other sources, and in FY 2004, two ADAPs received only ADAP earmark funding. Other sources of funding for ADAPs in FY 2004 were: Title II Base Funds[22] (20 ADAPs); Title II Supplemental Treatment Grants[23] (18 ADAPs); Title I EMA Funds[24] (9 ADAPs); State General Revenue Support[25] (40 ADAPs); and Drug Rebates[26] (36 ADAPs).
- **Some State ADAPs Experienced Budget Decreases**. Despite an increase in the national ADAP budget between FY 2003 and FY 2004 of 11%, some states experienced net budget decreases and/or decreases in key funding streams (other than the earmark):
  - 15 had net decreases in their overall budgets (six of these states have waiting lists in place)
  - 14 had decreases in Title II Base Funds
  - 15 had decreases in Title II Supplemental Treatment Grants[27]
  - 4 had decreases in Title I EMA Funds
  - 14 had decreases in State General Revenue Support
  - 6 had decreases in Drug Rebates

ADAP Cost Containment Measures and Other Strategies for Managing Costs

State ADAPs use a variety of strategies to contain costs, some of which may affect client access and services and others that may lead to a more efficient use of funding in an effort to serve more people. In some cases, states must implement cost containment measures, such as waiting lists, multiple times over the course of a year, depending on their fiscal situation and client demand. Cost containment measures used by ADAPs include:

- Lowering financial eligibility criteria;
- Limiting and/or reducing ADAP formularies;
- Instituting monthly or annual limits on per capita expenditures;
- Using drug purchasing strategies (discount programs, rebates, purchasing alliances and coalitions);
- Using ADAP dollars to pay for insurance coverage instead of medications directly;
- Seeking cost recovery through drug rebates and third party billing; and
- Using non-ADAP Ryan White CARE Act funds (e.g., Title II Base funds) for ADAPs. ◗

- **Antiretrovirals Are Bulk of ADAP Drug Expenditures and Most Expensive**. Antiretrovirals (ARVs) continue to represent the far majority of ADAP drug expenditures, in part due to their high utilization, but also to their cost – in June 2004, ARVs represented a greater share of expenditures (87%) than prescriptions filled (64%). Expenditure per prescription is significantly higher for ARVs ($348) than non-ARVs ($92). Some classes of ARV drugs account for higher per prescription expenditures than others, with fusion inhibitors topping the list ($1,215), followed by protease inhibitors ($431).

DETAILED FINDINGS

Clients, Drug Expenditures and Prescriptions

ADAP Clients

- In June 2004, ADAPs provided medications to 94,577 clients across the country (thousands more had their insurance coverage paid for by ADAPs; see below). Client utilization increased by 10% over June 2003. While most states experienced increases in clients served (38 ADAPs) between June 2003 and June 2004, 13 had decreases (see Appendix I). Between 1996 and 2004, client utilization increased by 217% in the 41 states reporting data over this period; the rate of increase has slowed in recent years (see Chart 4).
- More clients are enrolled in ADAPs than seek services in a given month, reflecting changing clinical needs, different prescription lengths, and fluctuation in the availability of other resources to pay for medications, with some individuals cycling on and off ADAP throughout a year. In June 2004, 133,572 clients were enrolled in ADAPs nationwide (see Chart 3), 71% of whom received medications from ADAPs in that month.
- As found in prior years, ADAP clients are predominantly low-income and uninsured. Most are people of color, male, and many have indicators of advanced HIV disease:
  - African Americans represented approximately one-third (34%) and Hispanics one-quarter (26%) of the national ADAP population in June 2004. Asian/Pacific Islanders, Alaskan Native and American Indians combined represented approximately 2% of the total ADAP population. White non-Hispanics represented 36% of ADAP clients (see Chart 9).
  - More than three-quarters (79%) of ADAP clients in June 2004 were men (see Chart 10).
  - Over half (57%) of clients were between the ages of 25 and 44; 38% were between 45 and 64 (see Chart 10).
  - Eight in ten (80%) of those served in June 2004 reported incomes at or below 200% of FPL; half of ADAP clients (51%) had incomes at or below 100% of FPL (see Chart 11). In 2004, the FPL was $9,310 (slightly higher in Alaska and Hawaii) for a family of one.
  - A majority of ADAP clients were uninsured, with few reporting any other source of insurance coverage – 15% private, 9% Medicare, and/or 7% Medicaid, with less than 1% reported being dual beneficiaries of both Medicaid and Medicare. These clients rely on ADAPs to fill the gaps in their coverage (see Chart 12).
  - Half of ADAP clients had CD4 counts of 350 or below at time of enrollment (see Chart 13).

ADAP Drug Expenditures and Prescriptions

- ADAP drug expenditures grew to $96,880,703 million in June 2004 (see Chart 2). If annualized, this represents approximately $1.163 billion, or most (98%) of the FY 2004 national ADAP budget. Drug expenditures increased by 25% over June 2003, a greater increase than in recent years. Forty-three states had increases in their monthly drug expenditures; 8 had decreases (see Appendix I). Drug expenditures increased by 591% since 1996, in the 41 states that reported data over this period, more than twice the rate of client growth in these states. Drug expenditures increased each year during this period but at slower rates compared to earlier years with the notable exception of the last period – between June 2003 and June 2004, expenditures in these 41 states experienced their greatest annual rate of increase since 1998 (see Chart 5).
- Per capita drug expenditures were $1,024 in June 2004, an increase of 14% over last year ($902 in June 2003). If annualized, this represents $12,288. Per capita expenditures in June 2004 ranged from $376 in Oregon to $1,519 in Maine (see ES Table 1 and Chart 6).

- ADAPs filled a total of 377,271 prescriptions in June 2004, an increase of 26% over the number of prescriptions filled in June 2003 (300,317) (see Appendix I).
- Antiretrovirals continue to represent the bulk of ADAP drug expenditures (87% in June 2004). While this is in part due to their high utilization, it is also related to their costs, as they represent a greater share of expenditures (87%) than prescriptions filled (64%). The 16 "A1" drugs highly recommended for the prevention of opportunistic infections accounted for 4% of June 2004 expenditures and 10% of prescriptions filled (see Chart 7 and Appendix I).
- The average expenditure per prescription in June 2004 was $257. It was significantly higher for ARVs ($348) than non-ARVs ($92). Some ARV drug classes accounted for higher per prescription expenditures than others, with fusion inhibitors topping the list ($1,215), followed by protease inhibitors ($431), nucleoside reverse transcriptase inhibitors ($318) and non-nucleoside reverse transcriptase inhibitors ($311). The "A1" OI drugs were $96 per prescription filled in June 2004 (see Chart 8).

Eligibility Criteria and Formularies

ADAP Eligibility Criteria

- All states require that individuals document their HIV status. Three states reported additional clinical eligibility criteria (e.g., specific CD4 or viral load ranges) (see ES Table 1).
- Financial eligibility for ADAPs ranged from a low of 125% FPL in North Carolina to 500% FPL or more in Delaware, Maryland, Massachusetts, New Jersey, and Ohio (see ES Table 1).

ADAP Formularies

- ADAP formularies vary significantly across the country, ranging from 25 drugs covered in Louisiana to close to 500 drugs covered in New York and open formularies[19] in three jurisdictions - Massachusetts, New Hampshire, and New Jersey (see ES Table 1).
- While the majority of ADAPs (35) cover all FDA-approved antiretrovirals on their formularies, 17 do not, including one state that does not provide any protease inhibitors (South Dakota). Forty-two ADAPs cover Fuzeon, the only approved fusion inhibitor, up from 33 in last year's report; 10 ADAPs do not cover Fuzeon (see ES Chart 5).
- Coverage of medications to prevent or treat opportunistic infections and other HIV-related conditions is highly variable across the country (see ES Chart 6):
  - 37 ADAPs cover 10 or more of the 16 drugs highly recommended ("A1") for the prevention of opportunistic infections by USPHS/IDSA,[20]

$20 Million ADAP Waiting List Initiative

On June 23, 2004, President Bush announced the one-time, immediate availability of $20 million to provide medications to individuals in 10 states with waiting lists as of June 21, 2004: Alabama, Alaska, Colorado, Idaho, Iowa, Kentucky, Montana, North Carolina, South Dakota, and West Virginia. These funds were made available through a reallocation of Department of Health and Human Services (DHHS) non-AIDS funding. Medications are being provided directly to individuals on waiting lists, not through ADAPs.

A total of 1,738 treatment slots are to be supported by the Initiative, reflecting the number of individuals on waiting lists in these 10 states at that time. Recipients can only receive medications that were included on their state's ADAP formulary as of June 21, 2004. States instituting waiting lists after this date are not eligible for the Initiative. In addition, not all individuals coming onto waiting lists in the 10 eligible states can be accommodated through the Initiative.

The Health Resources and Services Administration (HRSA) is coordinating the Initiative and has contracted with Chronimed Statscript, a pharmacy benefits manager (PBM), to directly purchase and distribute medications to eligible individuals. The first medications were delivered to eligible clients in October 2004; by March 2005, 1,257 individuals were being served through the Initiative.

The FY 2005 ADAP earmark represented an increase of $35.1 million over FY 2004, but did not include a continuation of the $20 million Initiative. Funding from the $20 million is due to end in 2005, and states are expected to transition clients from the Initiative onto ADAP during the ADAP fiscal year 2005, which began on April 1, 2005. ◗

including four ADAPs that cover all 16 (California, Massachusetts, New Hampshire, and New Jersey). Fifteen ADAPs cover fewer than 10 of these medications (it is important to note that ADAPs may cover slightly fewer than the full set of 16 because they cover equivalent medications, also highly recommended, on their formularies).

– One ADAP does not include any medications for OIs or other HIV-related conditions on its formulary, and only covers antiretrovirals (Louisiana).

– 20 ADAPs cover treatments for hepatitis C (HCV), a major co-morbidity for people with HIV, and considered to be an opportunistic infection [20,28] (see Chart 27).

– 24 ADAPs cover Hepatitis A and B vaccines, recommended for those at high risk and living with HIV[29] (see Chart 27).

Waiting Lists and Other Cost Containment Measures

As of March 2005, 21 states reported having one or more cost containment measures in place, including waiting lists:

- 11 had waiting lists totaling 627 individuals across the country (Alabama, Alaska, Arkansas, Idaho, Iowa, Kentucky, Montana, Nebraska, North Carolina, West Virginia, and Wyoming). Four of the states with waiting lists – Alabama, Iowa, Kentucky, and North Carolina – are eligible for the President's $20 million ADAP Initiative, but the 416 people with HIV/AIDS on their waiting lists have not yet been processed to receive medications. Nine states, including Iowa and Kentucky, have a total of 211 people on waiting lists who are not eligible for the Initiative. Iowa and Kentucky also have eligible individuals on their waiting lists (see ES Chart 1).
- 12 states have recently instituted one or more other cost containment measures (see ES Chart 2):
  – 3 states capped enrollment but did not have individuals on waiting lists at the time of the survey (Indiana, South Dakota, and Utah)
  – 4 states capped enrollment for Fuzeon (Alabama, Georgia, New Hampshire, Texas)
  – 4 states reduced the number of drugs offered (Arkansas, Missouri, Utah, and Washington)
  – 4 states instituted new or increased cost-sharing for clients (Arkansas, Minnesota, Utah, Washington)
  – 2 states instituted new eligibility requirements and/or lowered income eligibility (New Hampshire, Washington)
  – 2 states instituted monthly or annual per capita expenditures limits (Oklahoma, South Dakota)
  – 13 states anticipate the need to implement additional cost containment measures by the end of the current ADAP fiscal year (March 31, 2006), including 5 that already have such measures in place.
- Waiting lists have been in place in some states for several months, if not years, and there is significant fluctuation in the size of waiting lists within and across states over time. Based on bi-monthly surveys conducted between July 2002 and March 2005 (20 surveys overall):
  – The number of people on waiting lists ranged from a low of 537 in 7 states to a high of 1,629 in 11 states; the average was 837 (see ES Table 2 and ES Chart 4).
  – The number of states with waiting lists in any given survey period ranged from a low of six to a high of 11 (see ES Chart 3).
  – 18 ADAPs had waiting lists in place at some point over the period including one state (Alabama) that had a waiting list in each period; seven ADAPs had waiting lists in 10 or more of the survey periods.
  – The highest number of individuals on any one state's waiting list was 891 (North Carolina); the lowest was one (Alaska, Idaho, and Montana). North Carolina had the highest average number of people on its waiting list over the period (396), followed by Alabama (198). The lowest average was four, in Guam and Wyoming.
- Continued funding for the President's $20 Million ADAP Waiting List Initiative has not been made available for 2005, and its funding for medications for individuals in the 10 eligible states will end later this year. At that point, states with individuals receiving medications through the Initiative must begin to transition them onto their ADAP.

ADAP Budget

- The national ADAP budget reached $1.187 billion in FY 2004, an increase of 11%, or $116.5 million, over FY 2003. Since FY 1996, the national ADAP budget has grown by 492% (see Chart 16).[30]
- In FY 2004, the ADAP earmark represented the largest component of the national ADAP budget (61%),[31] followed by state general revenue support (19%), and drug rebates (12%). Other sources of funding each represented 2% or less of the budget (see Charts 14, 17, 19, and 21).
- The composition of the budget has shifted over time (see Chart 15):
  - The ADAP earmark has risen from just 26% of the budget in FY 1996, the year it began, to 61% in FY 2004.
  - State support decreased from 25% in FY 1996 to 19% in FY 2004, but has increased significantly in amount and has been the second largest source of funding over the entire period. It is important to note that state funding is generally dependent on individual state decisions and budgets.
  - Drug rebates rose from 5% to 12% of the budget. The rise of drug rebates as a source of revenue is an important development that is in part due to the need for states to seek additional funding as client demand continues, and to the growing sophistication of states and the ADAP Crisis Task Force in working to obtain rebates. It is important to note that some drug rebates are dependent on negotiations by individual states or state coalitions, and rebate increases are in part a function of rising drug prices (since rebates are based on a percentage of drug price).
  - Title II base funding and funding from Title I EMAs each represent much smaller proportions of the budget today than they did in FY 1996, and were also the only two funding sources in the national ADAP budget that were less in FY 2004 than in FY 1996.
- Although the ADAP earmark continues to increase, its growth has slowed over time. As a result, state funding and drug rebates are playing an increasing role in the national ADAP budget. For the first time since the earmark began, state funding increased by a greater amount than the earmark, followed by rebates, between FY 2003 and FY 2004.
  - The ADAP earmark increased by $35.1 million, or 5%, over FY 2003, its smallest increase since it began in FY 1996.
  - State funding increased by $54.7 million over FY 2003, an increase of 32%, its greatest increase since 1997.
  - Drug rebates increased by $36.3 million, or 33%, over FY 2003, and reached their highest level to date.
- Title II base funding decreased between FY 2003 and FY 2004, and has been decreasing since FY 1998 (see Chart 18). Title I EMA funding increased between FY 2003 and FY 2004, reversing three years of steady decline (see Chart 20), although the number of Title I EMAs contributing to ADAP decreased from 12 in FY 2003 to nine in FY 2004.
- By definition, all eligible jurisdictions (57) receive federal ADAP earmark funding based on a formula, but not all ADAPs receive funding from other sources, which are often dependent on individual state and local planning, policy, and/or legislative decisions, as well as resource availability. In FY 2004, 2 ADAPs received only ADAP earmark funding (the District of Columbia and Maine). The breakdown of other sources of funding across the country was as follows (among the 52 ADAPs reporting data):
  - Title II Base Funds: 20 ADAPs received funding, 32 did not
  - Title II Supplemental Treatment Grants: 18 ADAPs received funding, 34 did not
  - Title I EMA Funds: nine ADAPs received funding, 43 did not
  - State General Revenue Support: 40 ADAPs received funding, 12 did not
  - Drug Rebates: 36 ADAPs received funding, 16 did not
- Additionally, despite an increase of 11% in the national ADAP budget between FY 2003 and FY 2004, the ADAP budget decreased in some states, due to fluctuations in other funding streams (see Appendix X):

– Overall Budget: 37 ADAPs had increases, 15 had decreases

– Title II Base Funds: Six ADAPs had increases; 14 had decreases

– Title II Supplemental Treatment Grants: three ADAPs had increases; 15 had decreases

– Title I EMA Funds: Five ADAPs had increases, four had decreases

– State General Revenue Support: 27 ADAPs had increases, 14 had decreases

– Drug Rebates: 29 ADAPs had increases, six had decreases

- State contributions to ADAPs ranged from 0%, in the 12 states that did not provide any state support, to more than half (58%) of the ADAP budget in one state; Title II base funding ranged from 0% to 57%; Title I funding ranged from 0% to 56%; ADAP supplemental funding ranged from 0% to 11%; and drug rebates ranged from 0% to 29% (see Appendix VIII).

ADAP Crisis Task Force

The ADAP Crisis Task Force was formed by a group of the largest AIDS Drug Assistance Programs, convened by NASTAD, in December 2002 to address resource constraints. Beginning in March 2003, the Task Force met with the eight companies that manufacture antiretroviral (ARV) drugs. The goal of the meetings was to obtain multi-year concessions on HIV/AIDS drug prices, to be provided to all ADAPs across the country. Agreements have been reached with all eight manufacturers to provide supplemental rebates and discounts (in addition to mandated 340B rebates and discounts – see chart 25), price freezes, and free products to all ADAPs nationwide. The Task Force estimated savings of $65 million for ADAPs in 2003. During 2004, the Task Force expanded its negotiations to include companies that manufacture high-cost non-ARV drugs. Additional agreements were obtained during 2004 and previous agreements were extended and/or enhanced. The Task Force estimated savings of $90 million for ADAPs in 2004.

The Task Force also coordinates its efforts with the Fair Pricing Coalition (a coalition of organizations and individuals working with pharmaceutical companies regarding pricing of ARV drugs for all payers) and other community partners. Current members of the Task Force include representatives from ADAPs in Arizona, California, Florida, Kentucky, New Jersey, New York, North Carolina, Texas, and Utah. ◗

Drug Purchasing Models and Insurance Coverage

ADAP Drug Purchasing Models

- The federal 340B program enables ADAPs to purchase drugs at or below the statutorily defined 340B ceiling price.[32] All but one ADAP (51 of 52 reporting data) participate in the 340B program.
- ADAPs may purchase drugs either directly from wholesalers or through retail pharmacy networks and then apply to drug manufacturers for rebates. As of June 2004, 27 ADAPs reported purchasing directly from wholesalers; 25 reported purchasing through a pharmacy network and then seeking rebates (see Chart 25).
- Direct purchase model 340B ADAPs can choose to participate in the HRSA Prime Vendor Program,[32] which was created to negotiate pharmaceutical pricing below the 340B price. Eleven of the 27 ADAPs that directly purchase drugs reported participating in the Prime Vendor Program in June 2004 (see Chart 25).

ADAP Insurance Purchasing/Maintenance and Other Insurance Coverage Options

- The Ryan White CARE Act allows states to use ADAP earmark dollars to purchase health insurance and pay insurance premiums for individuals eligible for ADAP, provided the insurance has comparable formulary benefits to that of the ADAP.[33] Twenty-six states reported that they used ADAP funds for insurance purchasing and maintenance efforts, representing $37.8 million or 3% of the ADAP FY 2004 budget. In June 2004, 7,277 ADAP clients were served by such arrangements (see Chart 23). These strategies appear to be cost effective – in June 2004, spending on insurance represented an estimated $433 per capita, significantly less than per capita drug expenditures in that month ($1,024). It is important to note that other CARE Act programs (Title I, Title II base) may also purchase and maintain insurance coverage for eligible individuals.
- ADAPs can also use a portion of their earmark dollars to pay for client insurance co-payments and deductibles,[34] as 20 ADAPs reported doing in FY 2004 (see Chart 23).

CONCLUSION

The AIDS Drug Assistance Program plays a critical 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. ADAPs are serving more clients as funding permits and adapting to changing treatment environments. However, ADAPs are highly sensitive to changes in federal, state, and other resources, as well as to client demand and increases in drug costs. Because of resource constraints, 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 of meeting a growing demand with limited resources will likely continue for the foreseeable future.

Methodology

Since 1996, the National ADAP Monitoring Project, an initiative of the Kaiser Family Foundation (KFF) and the National Alliance of State and Territorial AIDS Directors (NASTAD) has been surveying all states and territories receiving federal ADAP earmark funding through the Ryan White CARE Act (the number of jurisdictions receiving such funding has increased over the course of the project). In FY 2004, 57 jurisdictions received earmark funding and all 57 were sent the ADAP survey; 52 of 57 ADAPs responded. The U.S. Virgin Islands, American Samoa, Guam, the Northern Mariana Islands, and the Marshall Islands did not respond; these jurisdictions represent less than 0.1% of estimated living AIDS cases.[17]

The survey is sent to states on an annual basis. It requests data and other program information for a one month period (June), the fiscal year, and for other periods as specified. After the survey is sent out, extensive follow-up is conducted by NASTAD to ensure completion by as many ADAPs as possible.

Data used in this report are from June 2004 and FY 2004, unless otherwise noted. For example, some data are supplemented through other NASTAD data collection efforts, such as its bi-monthly "ADAP Watch" survey. Due to differences in data collection and data availability across ADAPs, some ADAPs did not answer all survey questions. Where trend data are presented, only states that provided relevant data in all periods are included. In addition, in some cases, ADAPs have provided revised program data from prior years and these revised data are used where possible. Therefore, data from prior year reports may not be comparable for assessing trends. This year's report includes drug rebates as part of the national ADAP budget, which was not done in prior year reports (drug rebates were considered separately). In this report, all prior year budgets have been recalculated to include drug rebates for comparison purposes.

Every effort has been made to ensure that the annual report represents the current status of ADAPs as reported by survey respondents; however, some information may have changed between data collection and this report's release. Data issues specific to a particular ADAP are provided on relevant charts and tables. ◗

REFERENCES

1 HRSA, HIV/AIDS Bureau, *2002 Ryan White CARE Act Annual Data Summary*, available at: http://hab.hrsa.gov.

2 CDC estimates that there are approximately 445,000 people living with HIV/AIDS in the U.S. who are receiving care. The 136,000 clients served by ADAPs in 2002 represent 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, for CDC estimates; and HRSA, HIV/AIDS Bureau, *Ryan White CARE Act AIDS Drug Data Report, 2002* for 2002 ADAP client utilization).

3 Public Law No. 101-381.

4 Fleming, P., Byers, R., Sweeney, P., Daniels, D., Karon, J., Janssen, R., *HIV Prevalence in the United States, 2000*, 9th Conference on Retroviruses and Opportunistic Infections, Abstract #11, Oral Abstract Session 5, February 2002.

5 Teshale, E., Kamimoto, L., Harris, N., Li, J., Wang, H., McKenna, M., *Estimated Number of HIV-infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States*, 12th Conference on Retroviruses and Opportunistic Infections, Abstract #167, Oral Abstract Session 42, February 2005.

6 CDC, "Advancing HIV Prevention: New Strategies for a Changing Epidemic – United States, 2003", *MMWR*, Vol. 52, No. 15, April 2003.

7 HRSA, *Memo*, *CDC/HRSA Advisory Committee on STD and HIV Prevention and Treatment Information Request*, May 7, 2004.

8 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.

9 Pub. L. 101-381; Pub. L. 104-146, SEC. 2616. [300ff-26].

10 HRSA, HIV/AIDS Bureau, Personal Communication, March 15, 2005.

11 Kaiser Family Foundation, *Fact Sheet: U.S. Federal Funding for HIV/AIDS: The FY 2006 Budget Request*, February 2005.

12 The term "state" is used in this report to include states, territories and associated jurisdictions.

13 Three percent of the ADAP earmark is set aside for the ADAP Supplemental Treatment Drug Grant, grants to states with severe need. See box on "Allocation of Federal Funding to ADAPs & State Match Requirements".

14 HRSA, HIV/AIDS Bureau, CARE Act Funding History, Available at: http://hab.hrsa.gov/.

15 Some of these funds must be provided to ADAPs, due to state matching fund requirements. See box on "Allocation of Federal Funding to ADAPs & State Match Requirements".

16 Funding for entitlement programs, such as Medicaid and Medicare, generally changes (increases or decreases) based on the number of eligibles who enroll in these programs and the costs of providing them care.

17 HRSA, *Estimated Living Cases with AIDS in All States and Territories, July 1, 1994 – June 30, 2004,* December 9, 2004.

18 The federal fiscal year and ADAP fiscal year periods differ – see box on "Allocation of Federal Funding to ADAPs & State Match Requirements."

19 Providing any FDA-approved HIV-related prescription drug.

20 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.

21 These guidelines were developed to address the prevention of opportunistic infections, although many of the recommended medications are also used to treat opportunistic infections. Last year, for the first time, the U.S. Public Health Service released guidelines specific to the treatment of opportunistic infections. Because these guidelines were released after data were collected for this report, ADAP formularies were not assessed against them at this time.

22 States receive CARE Act Title II base funds based on a formula and they are not required to allocate these funds to ADAPs. In FY 2004, total Title II base funding available for distribution to states was $285,366,000.

23 Three percent of the ADAP earmark is set aside for ADAP supplemental grants for eligible jurisdictions – see box on "Allocation of Federal Funding to ADAPs & State Match Requirements."

24 Under the Ryan White CARE Act, a Title I Eligible Metropolitan Area's (EMA's) Ryan White HIV Services Planning Council can decide to allocate Title I dollars to their state's ADAP to serve clients within their EMA.

25 Most of the states that provided general revenue support made decisions to do so. States may also be required to provide matching funds for receipt of federal Ryan White dollars in some cases. See box on "Allocation of Federal Funding to ADAPs & State Match Requirements."

26 ADAP Crisis Task Force negotiations have resulted in negotiated agreements with manufacturers that include supplemental rebates beyond 340B discounts. Some ADAPs (11) that purchase drugs through a direct purchase mechanism (no rebates) are now receiving supplemental rebates as a result of these negotiations. The 25 ADAPs that purchase drugs through a retail pharmacy network also receive supplemental rebates.

27 Although the ADAP earmark increased in FY 2004, and thus so did the 3% ADAP Supplemental Grant funding set-aside, $1.7 million was utilized from the ADAP Supplemental set-aside to fund legislative provisions requiring overall Title II awards to states to be equal to that of last year. This resulted in a decrease in most ADAP Supplemental awards to states.

28 CDC, *Frequently Asked Questions and Answers About Coinfection with HIV and Hepatitis C Virus*. Available at: www.cdc.gov/hiv/pubs/facts/HIV-HCV_Coinfection.htm.

29 CDC, "Sexually Transmitted Diseases Treatment Guidelines, 2002", *MMWR*, Vol. 51, No. RR-6, May 2002.

30 Previous National ADAP Monitoring Project reports did not include drug rebates as part of the national budget; in this report, all prior year budgets have been adjusted to include drug rebates for comparison purposes.

31 Not including the ADAP supplemental, a 3% set aside of the total amount earmarked for ADAPs by Congress.

32 HRSA, Pharmacy Services Support Center, "What is the 340B Program?" Available at: http://pssc.aphanet.org/about/whatisthe340b.htm.

33 HRSA, HIV/AIDS Bureau, Policy Notice 99-01, "The Use of the Ryan White CARE Act Title II ADAP Funds to Purchase Health Insurance."

34 HRSA, HIV/AIDS Bureau, DSS Program Policy Guidance No. 2, "Allowable Uses of Funds for Discretely Defined Categories of Services," Formerly Policy No. 97-02, First Issued: February 1, 1997, June 1, 2000.

ES TABLE 1: Summary ADAP Profile

State	Financial Eligibility as % of FPL	Medical Eligibility (CD4=CD4 Cell Count, VL=Viral Load)	Total Number of Drugs on Formulary	Nucleoside Reverse Transcriptase Inhibitors (12 drugs approved)	Protease Inhibitors Covered (9 Drugs Approved)	Non-nucleosides Covered (3 Drugs Approved)	Fusion Inhibitors Covered (1 Drug Approved)	OI Prophylaxis Covered (16 PHS Recommended Drugs)	Other Medications Covered	Total FY 2004 Est. Budget (Federal/State Sources)	State Contribution	State $ Contribution as % of Total Budget	ADAP Clients Served In June 2004	June 2004 Per Capita Drug Expend.	Cost-Containment Measures in Place as of March 2005
Alabama	250%		35	12 (10)	9 (8)	3	1 (0)	7	3	$9,216,638	$560,000	6%	1,220	$902	Frozen program enrollment; waiting list for Fuzeon; waiting list for President's Initiative-eligible individuals
Alaska	300%		68	12 (10)	9 (7)	3	0	15 (14)	29	$555,000	$14,398	3%	35	$950	waiting list
American Samoa	NR	NR	NR	NR	NR	NR	NR	NR	NR	$2,314	NR	NC	NR	NC	
Arizona	300%		83	12 (10)	9 (8)	3	1	9 (6)	49 (5)	$9,392,903	$1,000,000	11%	845	$931	
Arkansas	300%	CD4<350 or VL>55,000	52	12 (10)	8	3	1	10 (11)	18	$5,017,445	—	0%	376	$1,026	waiting list; reduced formulary; cost sharing
California	400%		152	12 (10)	9 (8)	3	1	16 (14)	112	$231,770,465	$65,926,750	28%	18,263	$1,159	
Colorado	300%		46	12 (9)	9 (6)	3	1 (0)	13 (0)	9 (0)	$9,640,532	$980,839	10%	667	$835	
Connecticut	400%		190	12 (10)	9 (7)	3	1	14 (13)	151 (147)	$15,724,925	$606,678	4%	1,112	$1,156	
Delaware	500% - sliding		230	11 (9)	9 (8)	3	1	14	190 (187)	$3,262,722	$10,000	0%	226	$839	
District of Columbia	400%		72	12 (9)	9 (7)	3	1	9 (8)	38 (36)	$13,842,594	—	0%	809	$1,022	
Florida	350%		65	12 (10)	9 (8)	3	1	9	31 (28)	$90,456,773	$9,000,000	10%	9,558	$714	
Georgia	300%	CD4≤350 or, if CD4>350, VL≥55,000 (CD4<500, VL>20,000)	55	12 (10)	9 (8)	3	1 (0)	10 (11)	19	$39,779,664	$11,305,339	28%	3,820	$875	waiting list for Fuzeon
Guam	NR	NR	NR	NR	NR	NR	NR	NR	NR	$94,332	NR	NC	NR	NC	
Hawaii	400%		92	12 (10)	9 (8)	3	0	14	53 (54)	$2,524,512	$440,000	17%	223	$968	
Idaho	200%		42	11 (10)	8	3	0	13 (14)	3	$1,242,476	$177,500	14%	100	$1,327	waiting list
Illinois	400%		81	12 (10)	9 (8)	3	1	12 (13)	44 (36)	$42,723,229	$10,100,000	24%	3,234	$945	
Indiana	300%		93	12 (10)	9 (8)	3	1 (0)	7 (9)	61 (46)	$9,440,661	$2,850,737	30%	13	$1,371	Capped enrollment
Iowa	200%		39	12 (10)	9 (8)	3	1	6	8	$1,382,030	—	0%	203	$708	waiting list for President's initiative–eligible individuals and non eligible individuals
Kansas	300%		53	12 (10)	9 (8)	3	1	7	21	$3,153,495	$400,000	13%	535	$761	
Kentucky	300%		51	12 (10)	9 (8)	3	0	8 (9)	18	$4,995,297	$90,000	2%	555	$868	waiting list for President's initiative–eligible individuals and non eligible individuals
Louisiana	200%		25	12 (10)	9 (8)	3	1	0	0	$15,883,405	—	0%	1,654	$698	
Maine	300%		38	12 (10)	9 (8)	3	1	8 (14)	5 (6)	$833,383	—	0%	42	$1,519	
Marshall Islands	NR	NR	NR	NR	NR	NR	NR	NR	NR	$2,314	NR	NC	NR	NC	
Maryland	500%		113	12 (9)	9 (8)	3	1	15	73 (65)	$29,809,288	—	0%	1,989	$1,202	
Massachusetts	<$50,000 net annual income (<$50,000 gross annual income)		open formulary	12 (10)	9 (8)	3	1	16 (14)	open formulary	$22,363,789	$2,447,990	11%	2,291	$517	
Michigan	450%		191	12 (10)	9 (8)	3	1	14 (13)	152 (140)	$13,202,763	—	0%	1,075	$1,067	
Minnesota	300%		127	12 (10)	8 (7)	3	1	12 (11)	92 (91)	$6,155,523	$911,129	15%	597	$405	cost-sharing; reapplication every 6 months
Mississippi	400%		49	12 (10)	9 (8)	2	1	10	15 (16)	$8,777,477	$750,000	9%	769	$925	
Missouri	300%		268	12 (10)	9 (8)	3	1	11 (12)	232 (241)	$13,536,796	$2,069,000	15%	1,402	$822	Reduced formulary
Montana	330%		142	12 (10)	9 (8)	3	1 (0)	11	106 (102)	$460,518	$27,894	6%	53	$766	waiting list

Data in parentheses are from the prior report, if states made changes since that time.

The 2004 Federal Poverty Level (FPL) was $9,310 (slightly higher in Alaska and Hawaii) for a household of one.

NR indicates not reported.

NC indicates not calculated due to missing data.

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ES TABLE 1: Summary ADAP Profile

State	Financial Eligibility as % of FPL	Medical Eligibility (CD4=CD4 Cell Count, VL=Viral Load)	Total Number of Drugs on Formulary	Nucleoside Reverse Transcriptase Inhibitors (12 drugs approved)	Protease Inhibitors Covered (9 Drugs Approved)	Non-nucleosides Covered (3 Drugs Approved)	Fusion Inhibitors Covered (1 Drug Approved)	OI Prophylaxis Covered (16 PHS Recommended Drugs)	Other Medications Covered	Total FY 2004 Est. Budget (Federal/State Sources)	State Contribution	State $ Contribution as % of Total Budget	ADAP Clients Served In June 2004	June 2004 Per Capita Drug Expend.	Cost-Containment Measures in Place as of March 2005
Nebraska	200%		104	12 (10)	9 (8)	3	0	7 (2)	73 (4)	$1,611,155	$150,000	9%	181	$702	waiting list
Nevada	400%		65	12 (10)	9 (8)	3	1 (0)	10	30 (27)	$6,089,625	$1,350,947	22%	614	$847	
New Hampshire	300%	CD4<350 or currently on ARV therapy or currently has a designated OI	open formulary	12 (10)	9 (8)	3	1 (0)	16 (14)	open formulary	$2,632,038	—	0%	183	$1,120	New medical eligibility and formulary restrictions*; waiting list for Fuzeon
New Jersey	500%		open formulary	12 (10)	9 (8)	3	1	16 (14)	open formulary	$64,284,345	$13,672,540	21%	4,705	$1,268	
New Mexico	300%		101	12 (10)	9 (8)	3	0	12	65	$5,169,982	$3,000,000	58%	327	$1,018	
New York	<$44,000 gross annual income		479	12 (10)	9 (8)	3	1	15 (13)	440 (439)	$205,912,206	$33,000,000	16%	12,484	$1,502	
North Carolina	125%		58	12 (10)	9 (8)	3	1	11	22	$30,559,609	$11,120,817	36%	1,843	$1,238	Waiting list for President's Initiative-eligible individuals
North Dakota	400%		92	12 (9)	8 (7)	3	0	14 (13)	55	$244,085	—	0%	19	$758	
N. Mariana Islands	NR	NR	NR	NR	NR	NR	NR	NR	NR	$4,627	NR	NC	NR	NC	
Ohio	<$46,550 gross annual income		86	12 (10)	9 (8)	3	1	10 (11)	51 (41)	$11,467,773	$7,843	0%	1,271	$609	
Oklahoma	200%		52	12 (10)	9 (8)	3	1 (0)	13 (14)	14 (13)	$5,412,761	$786,000	15%	533	$733	Annual per capita expenditure limit
Oregon	200%		62	12 (10)	9 (8)	3	1	14	23	$6,925,989	—	0%	656	$376	
Pennsylvania	<$30,000 gross annual income		75	12 (10)	9 (8)	3	1	13 (14)	37 (39)	$46,335,324	$13,545,108	29%	2,971	$1,350	
Puerto Rico	200% (certified as indigent)	None (CD4<350 or VL>10,000)	126	12 (10)	9 (7)	3	1	14 (13)	88 (84)	$30,445,509	$2,093,000	7%	3,154	$857	
Rhode Island	400%		66	12 (10)	9 (7)	3	1	10 (11)	31	$2,661,506	—	0%	315	$808	
South Carolina	300%		54	11 (10)	9 (8)	3	1	10	20	$13,939,209	$500,000	4%	1,531	$730	
South Dakota	300%		44	12 (10)	0	3	0	9	20	$551,360	—	0%	40	$826	Annual per capita expenditure limit; capped enrollment
Tennessee	300%		93	12 (10)	9 (8)	3	1	12 (9)	56 (50)	$13,018,438	$1,000,000	8%	474	$767	
Texas	200%		40	12 (10)	9 (8)	3	1 (0)	8 (7)	10 (11)	$88,265,314	$29,918,504	34%	8,060	$802	waiting list for Fuzeon
Utah	400%		36	10	9 (8)	3	1	9 (14)	4	$2,679,455	$90,000	3%	170	$683	Capped enrollment; reduced formulary; cost-sharing
Vermont	200%		91	12 (10)	9 (8)	3	1	13 (12)	47 (43)	$777,007	$175,000	23%	99	$415	
Virgin Islands	NR	NR	NR	NR	NR	NR	NR	NR	NR	$687,763	NR	NC	NR	NC	
Virginia	300%/333% in Northern VA		67	12 (10)	9 (8)	3	1	13 (14)	29 (25)	$19,272,421	$2,612,200	14%	1,812	$1,098	
Washington	300%		171	10	9 (8)	3	1	12 (11)	136 (115)	$15,396,314	$3,742,723	24%	926	$719	Reduced formulary; lowered income eligibility; cost-sharing
West Virginia	250%		33	12 (10)	9 (8)	3	0	5	4 (5)	$2,087,428	$40,000	2%	151	$1,144	waiting list
Wisconsin	300%		68	12 (10)	9 (8)	3	1	14 (12)	29 (19)	$4,850,190	$93,610	2%	357	$721	
Wyoming	200%		78	11 (10)	9 (8)	3	0	14	40 (24)	$422,847	$62,500	15%	35	$1,423	waiting list

* New Hampshire will only reimburse for non-ARV treatments if a patient is currently receiving ARV therapy.

Data in parentheses are from the prior report, if states made changes since that time.

The 2004 Federal Poverty Level (FPL) was $9,310 (slightly higher in Alaska and Hawaii) for a household of one.

NR indicates not reported.

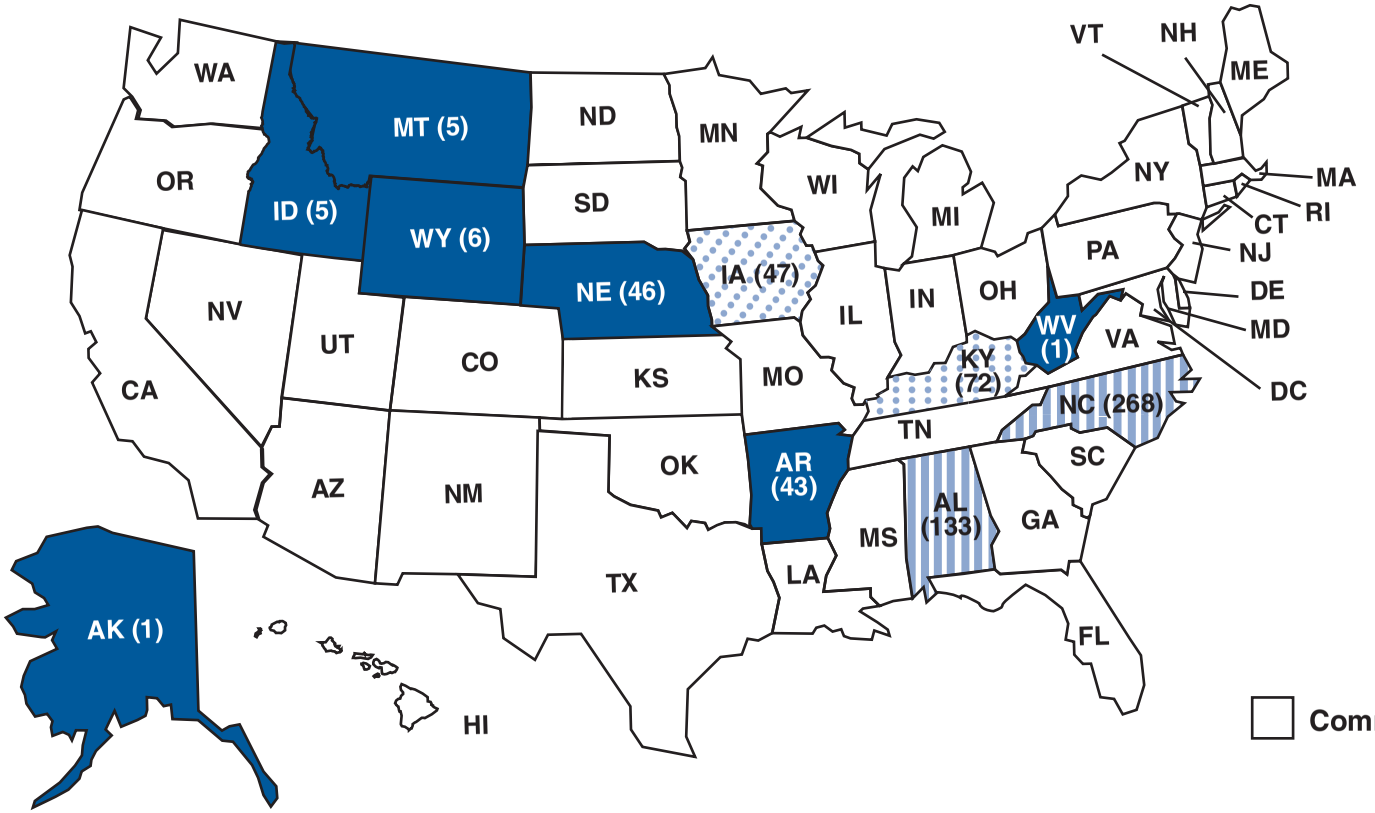
NC indicates not calculated due to missing data.

ES TABLE 2: Trends in ADAP Waiting Lists, by Survey Period and State, July 2002 – March 2005

State/Territory*	Jul–02	Oct–02	Dec–02	Jan–03	Feb–03	Mar–03	Apr–03	May–03	Jun–03	Aug–03	Sep–03	Nov–03	Jan–04	Mar–04	May–04	Jul–04	Sep–04	Nov–04	Jan–05	Mar–05	# of Periods w/ Waiting Lists	Average # of People on Waiting List
Alabama	250	175	175	175	175	175	104	104	90	89	107	141	247	304	395	353	393	244	126	133	20	198
Alaska										1			4	9	7	8	12	4	5	1	9	6
American Samoa																						
Arizona																						
Arkansas															3		11	31	30	43	5	24
California																						
Colorado									12	28	80	130	190	292	310						7	149
Connecticut																						
Delaware																						
District of Columbia																						
Florida																						
Georgia																						
Guam			4	4	4	4	4														5	4
Hawaii																		7			1	7
Idaho													3	5	13	24	34		1	5	7	12
Illinois																						
Indiana	30	34	34	34	34	34				47	48	47									9	38
Iowa															6	31	46	12	39	47	6	30
Kansas																						
Kentucky	50	62	121	121	121	121	141	141	130	135	165	140	140	123	113	138	191		27	72	19	119
Louisiana																						
Maine																						
Marshall Islands																						
Maryland																						
Massachusetts																						
Michigan																						
Minnesota																						
Mississippi																						
Missouri																						
Montana	2	2	8	8	8						4	1	4	4	8	10	14		6	5	14	6
N. Mariana Islands																						
Nebraska			8	8	15	15	29	29	30	36	30	30						15	27	46	13	24
Nevada																						
New Hampshire																						
New Jersey																						
New Mexico																						
New York																						
North Carolina	715	776	150	150	217		50					96	126	449	716	891	524	493	325	268	15	396
North Dakota																						
Ohio																						
Oklahoma																						
Oregon	18	18	9	9	9	145	236	236	220	228	228	24									12	115
Palau																						
Pennsylvania																						
Puerto Rico																						
Rhode Island																						
South Carolina																						
South Dakota	43	43	43	43	43	43	49	49	49	52	50		49	43	23	28	36				16	43
Tennessee																						
Texas																						
US Virgin Islands																						
Utah																	11				1	11
Vermont																						
Virginia																						
Washington																						
West Virginia							9	9	10	12	14	21	28	34	35	35	35	5	1	1	14	18
Wisconsin																						
Wyoming																		2	5	6	3	4
Total # People on Waiting Lists	**1108**	**1110**	**552**	**552**	**626**	**537**	**622**	**568**	**541**	**628**	**726**	**630**	**791**	**1263**	**1629**	**1518**	**1307**	**813**	**592**	**627**		**837**
Total # of States with Waiting Lists	**7**	**7**	**9**	**9**	**9**	**7**	**8**	**6**	**7**	**9**	**9**	**9**	**9**	**9**	**11**	**9**	**11**	**9**	**11**	**11**	**18**	

Note: States in bold eligible for June 2004 $20 Million ADAP Initiative

ES Chart 1: State ADAPs with Waiting Lists, March 2005
(627 Individuals in 11 States)



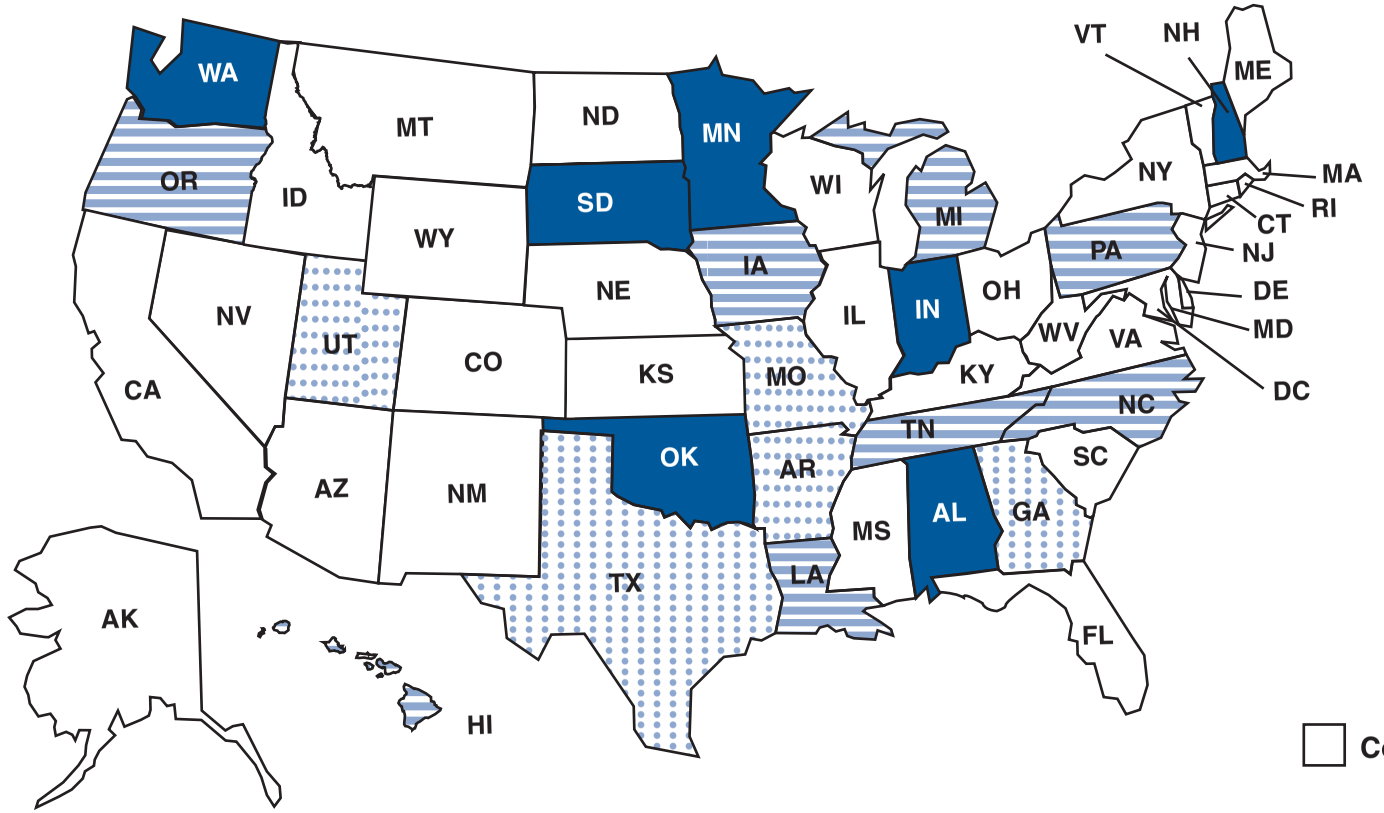
States with waiting lists in place as of March 2005 (107 individuals—7 states).

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, the N. Mariana Islands, Marshall Islands, and U.S. Virgin Islands.

ES Chart 2: State ADAPs with Current or Planned Cost-Containment Measures (other than waiting lists), March 2005



Commonwealth of Puerto Rico

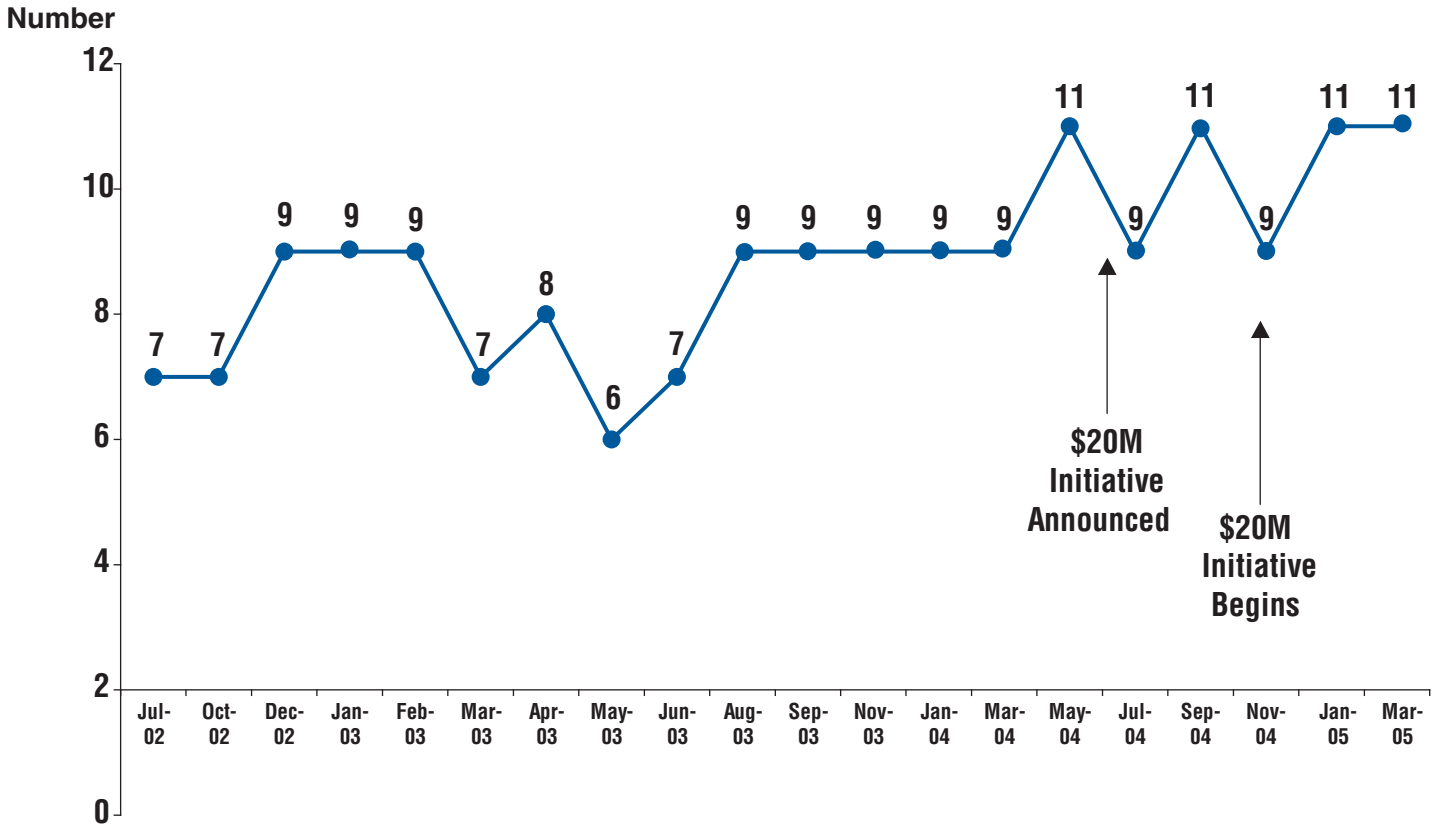
States/territories with cost-containment measures in place (7 states), as of March 2005.

States/territories with current cost-containment measures in place and anticipate the need to implement additional measures in FY 2005 (5 states), as of March 2005.

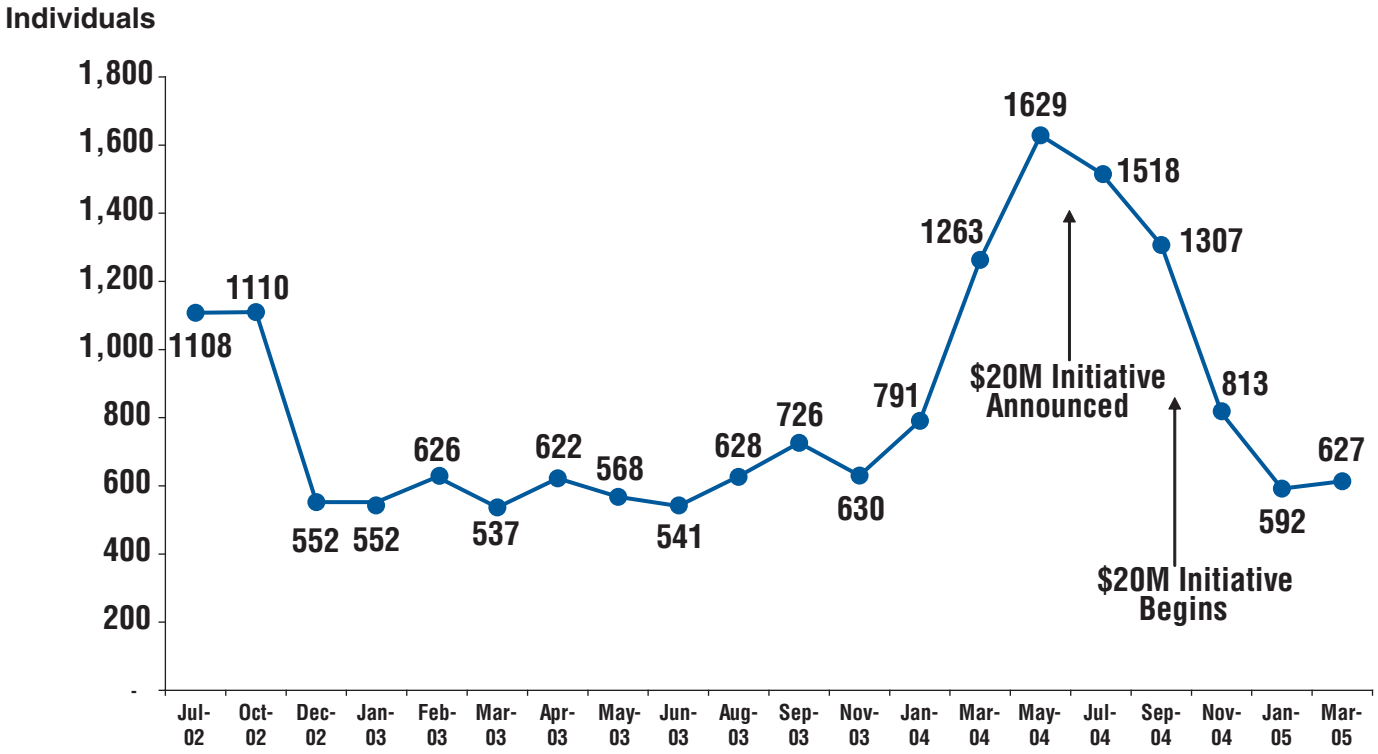
States/territories without current cost-containment measures in place but anticipating the need to implement them in FY 2005 (8 states), as of March 2005.

Note: The ADAP Fiscal Year runs from April 1 through March 31. Data not reported by 5 ADAPs: American Samoa, Guam, the N. Mariana Islands, Marshall Islands, and U.S. Virgin Islands.

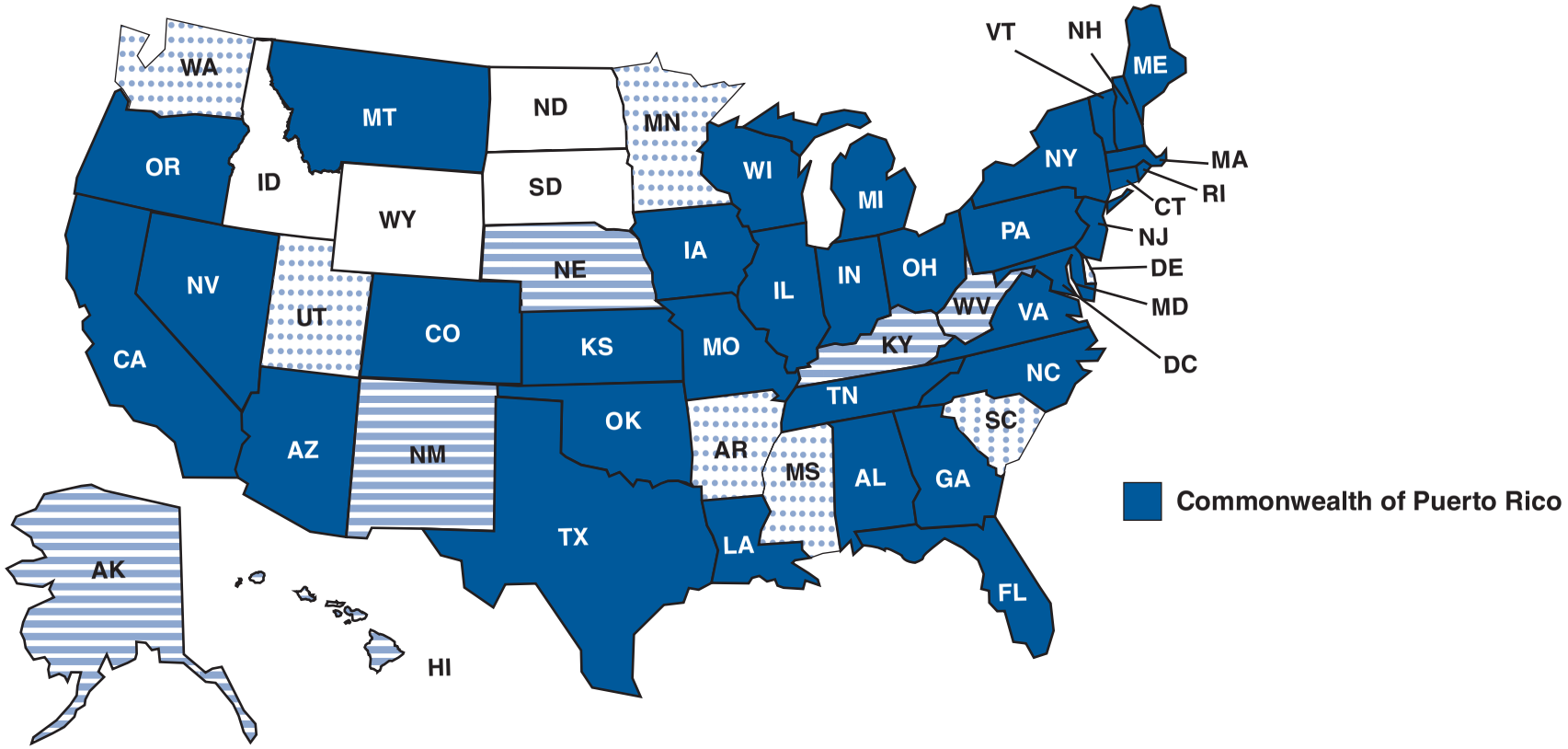
ES Chart 3: Number of States with ADAP Waiting Lists by Survey Period, July 2002–March 2005



ES Chart 4: Number of People with HIV/AIDS on ADAP Waiting Lists by Survey Period, July 2002–March 2005



ES Chart 5: State ADAP Formulary Coverage of Approved Antiretroviral Drugs, as of September 2004



Formulary covers all approved ARVs in all four drug classes, NRTIs, NNRTIs, PIs, and Fusion Inhibitor (35 states)

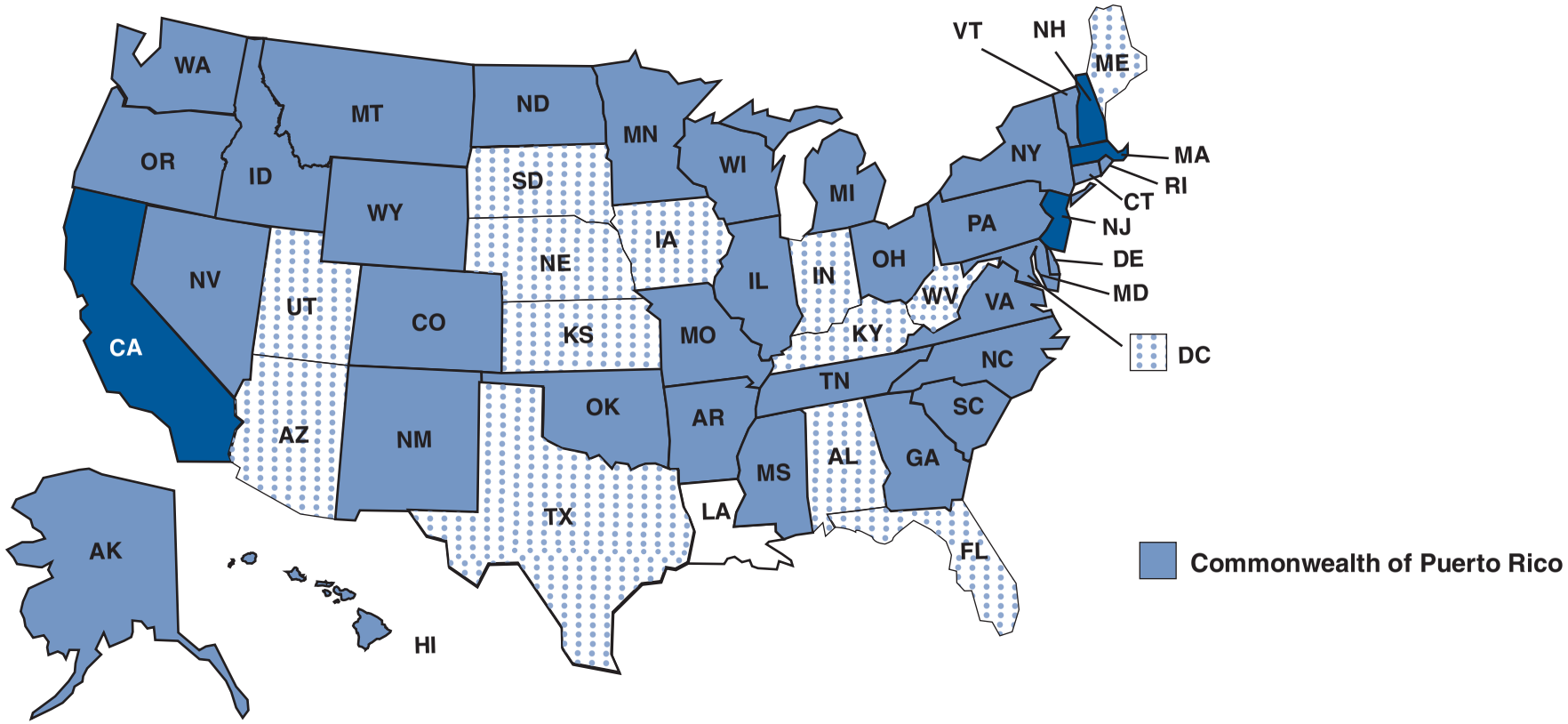
Formulary covers all approved NRTIs, NNRTIs, PIs, but not approved Fusion Inhibitor (6 states)

Formulary covers approved Fusion Inhibitor but not all approved NRTIs, NNRTIs, and PIs (7 states)

Formulary does not cover approved Fusion Inhibitor or all approved drugs in other classes (4 states)

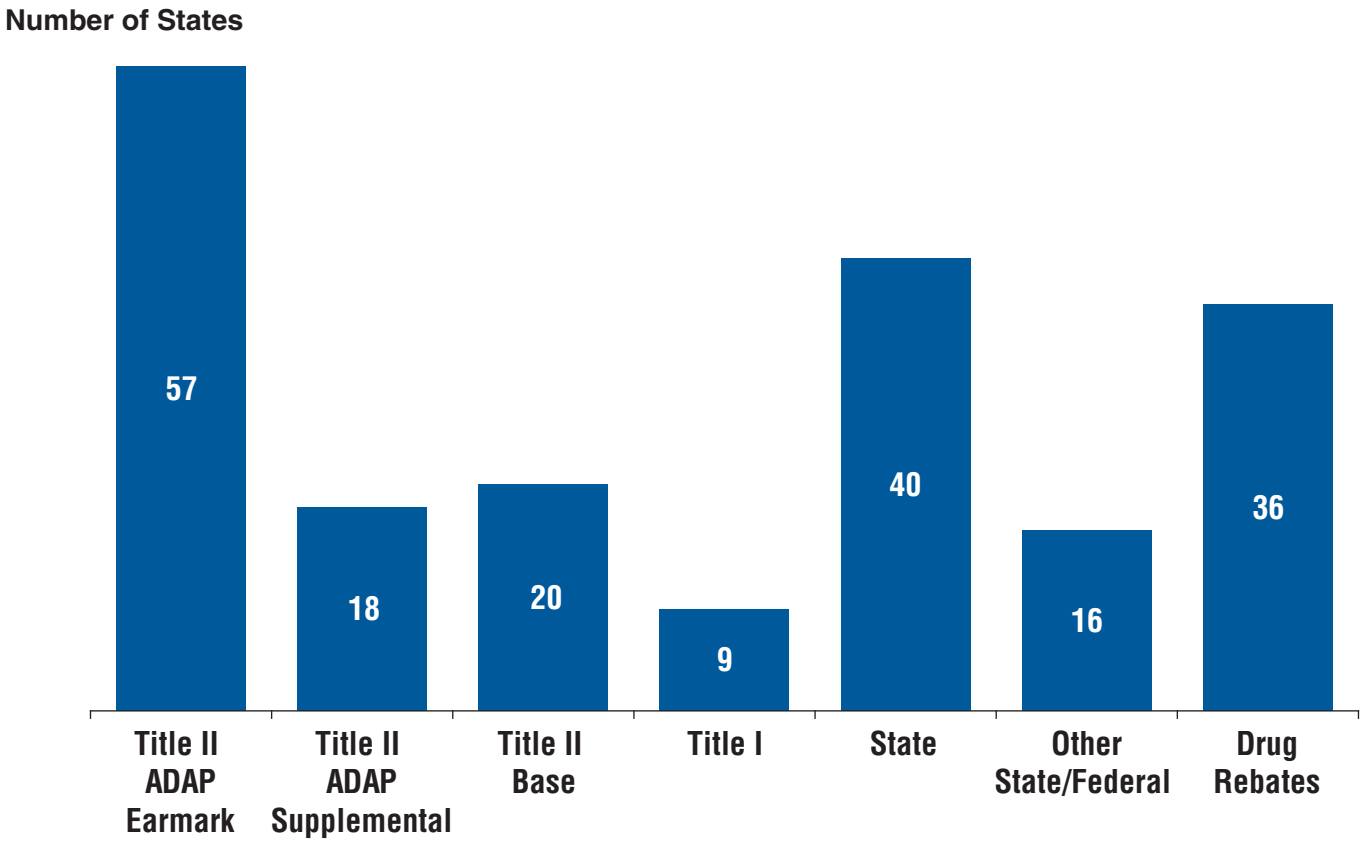
Note: Data not reported by 5 ADAPs: American Samoa, Guam, the N. Mariana Islands, Marshall Islands, and U.S. Virgin Islands; see ES Table 1 for detailed information on ADAP formulary composition.

ES Chart 6: State ADAP Formulary Coverage of Drugs Recommended for the Prevention of Opportunistic Infections (OIs), as of September 2004



Notes: Data not reported by 5 ADAPs: American Samoa, Guam, the N. Mariana Islands, Marshall Islands, and U.S. Virgin Islands; see ES Table 1 for detailed information on ADAP formulary composition.

ES Chart 7: Number of ADAPs by Funding Source, FY 2004



Note: American Samoa, Guam, the Marshall Islands, N. Mariana Islands, and U.S. Virgin Islands did not report data and are not included in all categories above, except Title II ADAP Earmark and Title II ADAP Supplemental.

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