NATIONAL ADAP MONITORING PROJECT

INTERIM TECHNICAL REPORT

March 1998

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The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering AIDS health care, prevention, education and supportive service programs funded by state and federal governments. State AIDS Directors in all 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and the U.S. Pacific Islands are represented by NASTAD with an office in Washington, D.C. Programs administered by NASTAD members serve every population affected by and infected with HIV.

The AIDS Treatment Data Network (ATDN) is a national, not-for-profit, community- based organization. Treatment education and counseling services for men, women and children with AIDS and NIV are supported by extensive, comprehensive and up-to-date informational databases about AIDS treatments, research studies, services, and accessing care.

The Kaiser Family Foundation, based in Menlo Park, California, is an independent national health care philanthropy that is not associated with Kaiser Permanente or Kaiser Industries.

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The principal authors of this report are Arnold Doyle, Richard Jefferys and Joseph Kelly.

The National ADAP Monitoring Project

In an effort to monitor the rapidly changing fiscal and scientific environments in which state AIDS drug assistance programs (ADAPs) are operating, and the impact of these changes on the programs and the individuals that they serve, the National Alliance of State and Territorial AIDS Directors (NASTAD) was commissioned by the Henry J. Kaiser Family Foundation, Menlo Park, CA to conduct a two-year National ADAP Monitoring Project. NASTAD is uniquely qualified to monitor the situation of state ADAPs as it is an association of the individuals who direct AIDS prevention, care and treatment services at the state level. NASTAD's co-funded partner in the project, the AIDS Treatment Data Network (ATDN), is one of the most highly respected HIV/AIDS treatment information centers in the nation; ATDN maintains an on-line information library of the most recent treatment advances in HIV/AIDS, as well as detailed information on publicly- and privately-funded sources of reimbursement for HIV/AIDS treatments, including ADAPs.

Through the National ADAP Monitoring Project, NASTAD and ATDN will produce summary and comprehensive technical annual reports on the status of state ADAPs, with follow-up reports at six-month intervals. This March 1998 status update report provides an analysis of state ADAPs based on a national survey completed in October and November 1997. The findings provide an update of information presented in State AIDS Drug Assistance Programs: A National Status Report on Access produced by NASTAD and ATDN and published by the Kaiser Family Foundation on July 10, 1997. This current report is available for downloading from the Internet at http://www.aidsinfonyc.org/adap. This Internet site, developed by ATDN, also contains detailed descriptive information about every state ADAP including program eligibility, application procedures, access and drug coverage. NASTAD and ATDN can be reached at the following addresses:

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Executive Summary

AIDS Drug Assistance Programs (ADAPs) are state-administered drug reimbursement programs that provide access to HIV/AIDS medications for low income, uninsured and underinsured individuals. Funded through the federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and by many states, these programs form one link in the continuum of publicly financed health care for lower income individuals living with HIV/AIDS, along with other CARE Act-funded programs, Medicaid, Medicare and local indigent health care programs. ADAPs operate in all fifty states, the District of Columbia and Puerto Rico.

These programs, initially intended to provide a safety net of temporary prescription drug coverage for lower income, uninsured or inadequately insured people living with HIV/AIDS, are now being called upon to fill a steadily growing gap in drug coverage for the HIV-infected population. Increases in numbers of clients utilizing ADAP services, the approval of new, promising and expensive anti-HIV treatments, the acceptance of combination therapy as the standard of care, rising ADAP expenditures, and restrictions on access to other public health care programs have moved ADAPs to further expand their umbrella of coverage. This raises the concern of whether ADAPs are able to adequately fill the growing gap in prescription drug coverage for people living with HIV/AIDS.

The National Alliance of State and Territorial AIDS Directors (NASTAD), in collaboration with the AIDS Treatment Data Network (ATDN), was commissioned by the Henry J. Kaiser Family Foundation to conduct a two-year National ADAP Monitoring Project. This Interim Technical Report provides an update of the data presented in the first National ADAP Status Report, released July 1997, and continues our efforts to track developments in the rapidly changing environment surrounding HIV/AIDS health care and therapy access. The update describes trends in the number of individuals served by ADAPs; drug expenditures; the fiscal status of ADAPs; and responsiveness to changes in treatment recommendations. A comprehensive update review of these programs is scheduled for release in Fall 1998.

Methods

In September 1997, a National ADAP Update survey was distributed to the 52 jurisdictions receiving Ryan White CARE Act Title II ADAP funds. The survey response rate was 100%, with all fifty-two jurisdictions reporting. Here are the major findings:

Update in the Number of Clients Served

The overall number of clients served by ADAPs continues to increase, although program growth is occurring at different rates across states, including some declines:

- Nationally, states report that 43,494 unduplicated clients were served by ADAPs during July 1997 compared to 37,506 clients in January 1997 Ò a 16% increase. When compared to data from the July 1996 period, there has been a 39% increase in the number of clients served.
- Thirty-nine states report increases in the number of clients served in July 1997 compared to January 1997. Six states report increases in clients served of 50% or more: Alaska, Delaware, Georgia, Louisiana, Rhode Island and South Carolina.
- Ten states report no growth or actual decreases in clients served: Connecticut, Idaho, Massachusetts, Mississippi, Montana, North Dakota, Oregon, South Dakota, Tennessee, and Virginia.

Expenditure Update

ADAP program expenditures, including expenditures for antiretroviral drugs, continue to grow as do the number of prescriptions filled by ADAPs.

- Forty-two states report increases in monthly ADAP expenditures, when July 1997 data are compared to January 1997. Fifteen of those states reporting increases of 50% or greater. Those states are Alaska, Delaware, Florida, Indiana, Iowa, Louisiana, Missouri, Nebraska, New Hampshire, North Carolina, Ohio, Rhode Island, South Carolina, Vermont and Wisconsin.
- Monthly ADAP expenditures increased 36% nationally, from $19.5 million in January 1997 to $26.6 million in July 1997. A comparison with data from the previous national ADAP survey indicates a 78% growth in monthly expenditures by ADAPs nationally when July 1996 are compared to July 1997 data.
- States report that the total number of prescriptions filled for all drugs on ADAP formularies increased by 24% from 105,236 in January 1997 to 130,336 prescriptions filled in July 1997. Notably, the number of protease inhibitor prescriptions filled by state ADAPs increased by 75% from 12,530 to 21,951 when comparing the same time periods.
- States report a 38% growth in expenditures for antiretroviral drugs from $15 million in January 1997 to $20.7 million in July 1997. There was a reported 20% growth in expenses related to other formulary drugs (including drugs for the prevention and treatment of opportunistic infections) from $4.8 million in January 1997 to $5.7 million in July 1997.

ADAP Budget Update Since the Last Report

The total national ADAP budget (including all sources) increased from $385 million to $422 million since the last report. This represents an overall increase of 9.6% or $37.1 million. The increase includes a 9% increase in federal and state funds, from $358.5 million to $390.8 million. Moreover, a number of state programs secured additional FY 1997 funding:

- Thirty-six states now supplement federal dollars with state-specific fiscal support (6 additional states since the last report).
- Thirteen states realized increased state/local general revenue support over the six-month period Ò Arizona, the District of Columbia, Florida, Indiana, Kentucky, Louisiana, Massachusetts, Minnesota, Nevada, Oklahoma, Pennsylvania, Tennessee, and Vermont.
- Six states provide the vast majority (78%) of ADAP funds provided by statesÒ California, Illinois, Louisiana, Massachusetts, New York, and Pennsylvania.
- Sixteen states do not provide any funds specifically for ADAP and therefore rely solely on federal funding to provide ADAP services. These 16 states are: Alaska, Arkansas, Delaware, Idaho, Iowa, Kansas, Michigan, Mississippi, Montana, Nebraska, New Hampshire, North Dakota, Oregon, Rhode Island, South Dakota and Wyoming.

Emergency Cost-Containment Measures Continue

Despite an overall increase in the national ADAP budget, there continues to be disparity in the diversity of funding sources that are available to and utilized by ADAPs and many states are relying on emergency measures to continue to meet client demand and expenditures. Twenty-three states are currently curtailing ADAP services or facing budget shortages which may result in reduced services early in 1998. For example:

- Thirteen states report that they will exhaust their ADAP budgets before the next round of federal funds is available on April 1, 1998. These states are: Alabama, Alaska, Arizona, Colorado, Idaho, Kansas, Kentucky, Maine, North Carolina, Puerto Rico, Texas, West Virginia and Wyoming. At the time of the last report, eleven states reported anticipated budget shortfalls, six of which continue to do so.

- Fifteen states report that they are maintaining waiting lists for entry to ADAP or for access to protease inhibitors (this is the same number of states which reported such waiting lists at the time of the first report, 12 of which continue to do so and three report waiting lists for the first time). The nine states which currently report waiting lists for entry to ADAP are: Alabama, Florida, Georgia, Indiana, Mississippi, Montana, Nevada, South Carolina and South Dakota. In addition, North Carolina has stopped authorizing new clients for program participation since September 1997, although the program does not maintain a waiting list. The seven states which currently maintain waiting lists for clients to access protease inhibitors from the ADAP are: D.C., Idaho, Kentucky, Maine, Mississippi, Oklahoma, and Nevada (Nevada also has a waiting list for entry to ADAP).

ADAP Formularies and Responsiveness to Evolving Standards for Clinical Practice

At a time of rapid advances in the clinical management of HIV/AIDS and finite resources, states report efforts to: expand formulary coverage, broaden provider and community input in formulary development, and respond to federal treatment guidelines.

- Forty-five states report that they have formal ADAP advisory bodies in place that assist in making formulary decisions and, in some cases, decisions regarding the administration and structure of the ADAP.
- Forty-two states have changed their formularies since our previous report. Forty-nine states now cover the most recently FDA-approved protease inhibitor, nelfinavir (Viracept). Two ADAPs (Arkansas and South Dakota) currently do not cover any protease inhibitor. Forty-four states cover the first approved NNRTI, nevirapine (Viramune).
- Fifteen states report expanding the ADAP formulary to cover the eleven approved anti-viral drugs referenced in the antiretroviral guidelines, in addition to the states already providing coverage for these treatments. States have taken other actions in response to the PHS/NIH guidelines, including updating state/local treatment guidelines and developing provider education programs.
- Ten states added drugs for the treatment and prevention of opportunistic infections (OIs). However, there continues to be significant disparity among ADAPs in their coverage of OI treatment/prophylaxis. Only two state ADAPs cover the 14 drugs strongly recommended for the prevention of OIs in the PHS/IDSA guidelines.

Relationship of ADAP to Medicaid and Private Insurance Coverage

The relationship between ADAP, Medicaid and private insurance has come under increased scrutiny as states seek to maximize non-ADAP sources of pharmacy benefits in order to reduce the burden on ADAP. Some states utilize insurance continuity programs to reduce the burden on their ADAP and provide stable access to health care services. In order to monitor emerging trends, states were asked to describe efforts to ensure that ADAP is the payer of last resort, discuss areas of cooperation between Medicaid and ADAP, and assess the impact of Medicaid coverage on the state ADAP. For example:

- Approximately 7 percent of ADAP clients served in July 1997 were also current Medicaid beneficiaries (including those in the spenddown process). The reported percentage of ADAP clients estimated to have Medicaid benefits varies greatly from state to state. Twenty-one states reported that no active ADAP clients were Medicaid beneficiaries.
- Thirty-nine ADAPs indicate that they have mechanisms to cross-check/coordinate client eligibility with the state Medicaid program. Twenty ADAPs report that they routinely back-bill Medicaid when an ADAP client receives retroactive Medicaid benefits.
- Approximately 7 percent of ADAP clients served in July 1997 had private health insurance that provides some level of prescription drug coverage, although this percentage varied greatly by state.

Introduction

1997 was a year of many challenges for state AIDS Drug Assistance Programs (ADAPs). These programs continued, in most cases, to see large increases of new clients using program services for the first time, and increases in the percentage of clients who were accessing expensive triple antiretroviral drug therapy through ADAP. The federal government and many state governments significantly increased funding for ADAPs in fiscal year (FY) 1997, yet these increases did not keep pace with demand in some jurisdictions.

The year was also marked by the release of draft federal clinical guidelines on the use of antiretroviral therapies, as well as updated guidelines on the use of therapies to prevent HIV-related opportunistic infections (OIs). State ADAPs were under significant pressure to provide the standard of care as outlined in these guidelines to an ever-growing client population. The state AIDS programs that administer ADAPs were also challenged to distribute the new guidelines to medical providers in their jurisdictions, to facilitate provider and consumer education, and to ensure that ADAP clients were receiving the new standard of HIV care.

ADAPs provide access for people living with HIV/AIDS to medications that treat HIV disease and prevent and treat opportunistic infections. State ADAPs serve as a critical lifeline for many low-income individuals living with HIV/AIDS in the United States who do not have public health insurance or adequate private health insurance. Despite a 106% increase in federal and state ADAP funding nationally in 1997, 13 state programs are facing potential budget shortfalls before the end of the current Ryan White CARE Act Title II fiscal year (March 31, 1998). Additionally, 15 states continue to maintain waiting lists for enrollment into their ADAPs, and/or for access to protease inhibitors. It is uncertain whether expected increases in federal ADAP funding for FY 1998 will ameliorate these ADAP access problems in the coming year.

Since publication of the previous NASTAD/ATDN national ADAP status report, released in July 1997, many ADAPs that were not providing coverage for all of the FDA-approved antiretrovirals-including protease inhibitors-have modified their formularies to provide coverage for these treatments, although coverage gaps still remain in several states. Currently, only two state ADAPs (Arkansas and South Dakota) do not cover protease inhibitors. However, coverage of drugs for the treatment and prevention of opportunistic infections (OIs) has not kept pace with the increases in coverage of HIV antiretroviral drugs. Great disparity still exists among the states in their coverage of OI treatment and prophylaxis through ADAP.

Over the past year, increasing attention has been given to the impact that access to Medicaid and private insurance within a state has on ADAP. Some state AIDS programs have been very successful in tapping into state high risk insurance pools in order to purchase health insurance coverage for ADAP clients. Through this mechanism, ADAP clients gain access to not only prescription drug coverage, but other primary medical care services as well-all at substantially less cost to state and federal governments. Administrative and legal barriers, however, have prohibited several states from implementing these cost-effective programs in their jurisdictions.

A proposed initiative to examine the feasibility of expanding access to Medicaid to non-disabled, low-income individuals living with HIV has not been implemented on the federal level due to concerns regarding the potential cost of such an expansion. Notwithstanding, many agree that extending limited Medicaid benefits to non-disabled people with HIV may significantly lessen the coverage gap that ADAPs currently attempt to fill, thereby lessening the burden on these programs.

1997 has been a year of significant challenge and of some marked success for state ADAPs. Increased access to effective treatments in many states and sharply declining death rates nationwide are, in part, a testament to the positive impact of these programs. This report will examine the current status of ADAPs nationwide in light of these challenges and successes, and highlight specific issues that are likely to impact on ADAPs throughout the coming year.

The ADAP Update Survey

In September 1997, a national ADAP update survey was distributed to all state and territorial AIDS programs receiving Ryan White CARE Act Title II ADAP funds. Survey responses were collected and analyzed throughout October and November 1997. The survey response rate was one hundred percent (100%), with fifty-two jurisdictions reporting.

State AIDS programs were asked to provide updated information regarding their state-administered ADAP in the following categories:

- Trends in Monthly Clients Served and Expenditures
- ADAP Budget Update For FY 1997
- Emergency Cost-Containment Measures/ADAP Budget Shortages
- ADAP Administrative Changes
- Formulary/Advisory Committee Update
- Efforts to Implement The Federal Clinical Guidelines
- Linkages Between ADAP, Medicaid and Private Insurance

The findings from this status report update are based on this point-in-time survey. The authors continue to recognize that the national ADAP situation is dynamic with budgets, access criteria and approved drugs changing throughout the course of a year. Up-to-date state-by-state ADAP information is available on the project's Internet website: http://www.aidsinfonyc.org/adap.

Trends in Clients Served and Expenditures

Nationally, states reported that 37,506 unduplicated clients were served by ADAPs in January 1997 while 43,494 used ADAP services during July 1997. This represents a 16% increase in clients served nationally in the first half of 1997. Compared with data from NASTAD/ATDN's previous report (published July 10, 1997) which indicated that 31,371 clients were served by ADAPs during July 1996, there has been at 39% growth in clients served between July 1996 - July 1997.

Thirty-nine states reported increases in the number of clients served during the first six months of 1997. Six states reported increases in clients served of 50% or more: Alaska, Delaware, Georgia, Louisiana, Rhode Island and South Carolina. ADAPs nationally experienced an average increase of approximately 998 additional clients per month during the first six months of 1997 Ò and for the whole year (July 1996 to July 1997), an increase of approximately 1,015 additional clients per month..

Reports from a few states that had previously experienced sharp increases in numbers of clients served throughout 1996 and the first half of 1997 indicate at least a temporary slowing in increased client utilization of ADAP services. In addition, ten states reported no growth or actual decreases in clients served comparing figures from January and July 1997 (Connecticut, Idaho, Massachusetts, Mississippi, Montana, North Dakota, Oregon, South Dakota, Tennessee and Virginia). NASTAD/ATDN will continue to monitor patterns in ADAP client services and will report on any new trends in the next National ADAP Update in mid-1998.

Monthly ADAP expenditures increased 36% nationally, from $19.5 million in January 1997 to $26.6 million in July 1997. Forty-two states reported increases in monthly ADAP expenditures during the same time period, with 15 of those states reporting increases of 50% or greater. Those states are Alaska, Delaware, Florida, Indiana, Iowa, Louisiana, Missouri, Nebraska, New Hampshire, North Carolina, Ohio, Rhode Island, South Carolina, Vermont and Wisconsin. Nationally, states reported a 78% growth in monthly ADAP expenditures between July 1996 and July 1997.

Four states reported decreases in monthly ADAP expenditures in the range of 14% and 52% during the time period (Minnesota, Mississippi, Oregon and South Dakota). In the cases of Minnesota and Oregon, these decreases in ADAP expenses are likely due to program policies which have sought to transition low-income eligible individuals from ADAP into more stable and cost-effective private health insurance purchasing and continuity programs. Mississippi ADAP faced a severe budget shortage in the reporting period which led the program to reduce the number of clients served. South Dakota has also experienced a severe ADAP budget shortage which continues to delay the state's ADAP ability to cover protease inhibitors for eligible clients.

Per client expenditures have increased nationally since the last report. The average per client expenditure among ADAPs nationally over the first six months of 1997 was approximately $571 per month or $6,848 annualized. That average is up from the figures reported for the last six months of 1996 which were approximately $506 per month or $6,072 annualized. Monthly clients served and program expenditures listed by state are contained in Appendix I.

State ADAPs reported that the total number of prescriptions filled for all drugs on ADAP formularies increased by 24% nationally from 105,236 in January to 130,336 prescriptions filled in July 1997. The average number of prescriptions filled per client increased only slightly between January and July 1997 Ò from an average of 2.8 to 3.0 prescriptions filled per ADAP client nationally in those months. Notably, the number of protease inhibitor prescriptions filled by state ADAPs increased by 75% from 12,530 to 21,951 during the same time period.

NASTAD/ATDN asked state ADAPs to report, for the first time, the breakdown of monthly expenditures for antiretroviral drugs (including protease inhibitors) and expenditures for all other formulary drugs for January 1997 and July 1997. Nationally, states reported a 38% growth in expenditures for antiretroviral drugs from $15 million in January to $20.7 million in July 1997. There was a reported 20% growth in expenses related to other formulary drugs (including drugs for the prevention and treatment of opportunistic infections) from $4.8 million in January to $5.7 million in July 1997.

The tables located in Appendix II list the monthly expenditures for antiretrovirals and all drugs, the number of prescriptions filled by ADAPs by state, and average number of prescriptions filled per client among ADAPs.

ADAP Budget Update

FY 1997 National ADAP Budget (Update) Federal and State Resources		
Source	**Funding**	**Percent**
Title II ADAP Supplemental (Federal):	$167 million	42.73%
State Funds	$118.1 million	30.22%
Title II Base (Federal)	$67.6 million	17.29%
Title I (Federal)	$24.2 million	6.21%
Miscellaneous Federal/State Funds:	$13.9 million	3.55%
Total Federal/State Funds	$390.8 million	100%

In the previous NASTAD/ATDN national ADAP report states were asked to estimate fiscal year 1997 ADAP budgets from all revenue sources. Since that time, a number of state programs have secured additional funding for the fiscal year, largely from increased state general revenue contributions but including other sources such as one-time only transfers of funds. This update

report contains a revised budget for fiscal year 1997 which accounts for additional resources obtained by ADAPs during the last six months.

ADAPs are funded largely by federal and state resources which accounted for $390.8 million nationally in FY 1997. Federal funds, provided through the Ryan White CARE Act, total $272.7 million (or 69.8%) and state funds total $118.1 million (or 30.2%) of the national ADAP budget. This represents an additional $32.2 million in federal and state funds reported by ADAPs since the previous NASTAD/ATDN report in July 1997.

One element remained constant between the two budget status reports: the FY 1997 federal ADAP supplemental funding of $167 million, the largest budget category in the national ADAP funding system. Taken together, federal and state support for ADAPs nationally increased 106% from $189.8 million in 1996 to $390.8 million in 1997.

Thirty-six states now supplement federal dollars with state-specific fiscal support for ADAP (6 more states since the previous report). ADAPs which realized increased state/local general revenue support in the last six months included: Arizona, the District of Columbia, Florida, Indiana, Kentucky, Louisiana, Massachusetts, Minnesota, Nevada, Oklahoma, Pennsylvania, Tennessee and Vermont. Arizona, Florida, Minnesota, Nevada and Tennessee were among the states which reported ADAP contributions for the first time in FY 1997. Although state funding support for ADAPs has increased among low, moderate and high AIDS incidence states, the vast majority of funds provided by states nationwide (78%) is provided by just six high incidence states Ò California, Illinois, Louisiana, Massachusetts, New York and Pennsylvania.

Sixteen states do not provide funds specifically for ADAP and therefore rely solely on federal funding to provide ADAP services. These 16 states are: Alaska, Arkansas, Delaware, Idaho, Iowa, Kansas, Michigan, Mississippi, Montana, Nebraska, New Hampshire, North Dakota, Oregon, Rhode Island, South Dakota and Wyoming. A table in Appendix III illustrates the comparison of state contributions to federal ADAP dollars.

Some states draw upon additional sources of funding to supplement their ADAP budgets, although these other sources are chiefly used to recover costs and are not uniformly used by all states. These additional cost recovery mechanisms include obtaining rebates from pharmaceutical manufacturers and private health insurance recovery. These other resources amounted to $31.2 million. The breakdown of specific state budgets for ADAP in FY 1997 is contained in Appendix III.

FY 1997 National ADAP Budget (Update) Federal and State Resources		
Source	**Funding**	**Percent**
Drug Rebates	$22.6 million	72%
Insurance Recovery	$8 million	26%
Miscellaneous Other Sources	$.6 million	2%
Total Other Funds	$31.2 million	100%

Emergency Cost-Containment Measures/ADAP Budget Shortages

Although the national ADAP budget continued to grow throughout FY 1997, a steady stream of state ADAPs reported struggles to keep pace with client demand and program costs. Throughout FY 1997, 22 states instituted at least one emergency measure to contain growth of ADAP clients and costs, according to survey responses. These measures included:

- 12 states which transferred funds from other federal- or state-funded HIV care, prevention or other health programs to ADAP (D.C., Indiana, Iowa, Kansas, Kentucky, Maine, Mississippi, Nebraska, Nevada, New Mexico, West Virginia and Wyoming);
- 10 states which capped program enrollment (Alabama, Florida, Georgia, Indiana, Mississippi, Montana, Nevada, North Carolina, South Carolina and South Dakota);
- 9 states which capped or restricted access to protease inhibitors (D.C., Florida, Idaho, Kentucky, Maine, Mississippi, Missouri, Nevada and Oklahoma).

NASTAD/ATDN asked states if their ADAP will exhaust all currently budgeted operating funds for FY 1997 prior to the end of the Ryan White Title II fiscal year (March 31, 1998). Thirteen states reported that they would exhaust their budgets before the next round of federal funds is available. Nearly all of these states reported that they expect to run into shortages during the first three months of 1998. These states are: Alabama, Alaska, Arizona, Colorado, Idaho, Kansas, Kentucky, Maine, North Carolina, Puerto Rico, Texas, West Virginia and Wyoming. Colorado reports that it will discontinue providing HIV drugs to its ADAP clients temporarily beginning in January 1998 at which time clients will obtain their medications from drug company patient assistance programs.

In order to avert a budget shortfall Ò which is prohibited by most state programs Ò ADAPs frequently report implementing service limitations. The most common measure to control program growth is maintaining waiting lists for client entry to ADAP or for accessing protease inhibitors. Nine states report that they are currently maintaining waiting lists for entry to ADAP: Alabama, Florida, Georgia, Indiana, Mississippi, Montana, Nevada, South Carolina and South Dakota. The number of individuals on formal ADAP waiting lists (as of October 1997) varies significantly from state to state, e.g., 680 individuals in Florida, 250 in South Carolina and 14 in South Dakota. In addition, North Carolina has stopped authorizing new clients for program participation since September 1997, although the program does not maintain a waiting list.

Seven states also report that they are currently maintaining a waiting list for clients to access protease inhibitors from the ADAP. These states are D.C., Idaho, Kentucky, Maine, Mississippi, Nevada and Oklahoma.

A total of 23 states currently fit in one or more of these categories Ò curtailing ADAP services or facing budget shortages which may result in reduced services early in 1998.

Administrative Changes

States were asked to report any significant changes in the administration of their ADAPs since the previous national ADAP report. Nineteen states (37%) indicated some type of change, including changes in formulary management. Examples of reported changes include:

- Alaska: The state completed a competitive contract process for a contractor to manage the ADAP. This entity is responsible for the purchase and distribution of drugs to clients, data tracking and reports, and budget monitoring.
- California: The California Office of AIDS implemented a centralization of the entire state ADAP during October 1997. Client eligibility authorization continues to be processed at the local level.

- Illinois: Effective April 1997, the state ADAP converted to a Public Health Service (PHS) discounted drug purchasing system.
- Massachusetts: Effective January 1997, Massachusetts ADAP began using a Pharmacy Benefits Manager (PBM) for the purchase and distribution of formulary drugs.
- Oregon: The state AIDS office integrated the administration of the ADAP and the state Insurance Continuation program, moving significant numbers of ADAP clients into private insurance coverage.
- South Carolina: The state has upgraded its pharmacy's software to better track ADAP client data and utilization trends.
- Virginia: The state AIDS office has implemented an extensive state-wide database for ADAP, to assist with tracking clients, expenditures and cost projections.

Other states reported changes in the ADAP formulary, implementation of more efficient data management systems, and the hiring of additional administrative personnel. ADAP formulary changes are described more fully beginning on page 19.

Changes in Eligibility Criteria

Several states also reported changes in their financial eligibility criteria since the previous NASTAD/ATDN report. Alaska increased the income ceiling for ADAP eligibility from 200% to 300% of the Federal Poverty Level (FPL). Mississippi, while preserving their entrance criteria at 200% of FPL, established a more generous exit criteria, in this case 300% of FPL. Michigan increased financial eligibility from 185% to 362% of FPL. A somewhat smaller adjustment was made by North Carolina, from 110% to 125% of FPL. Vermont ADAP no longer bases its assessment of financial eligibility on gross income; net available income is counted instead and a number of deductions are allowed. Oregon ADAP lowered its financial eligibility slightly from a sliding scale arrangement to a flat 250% of FPL, in order to standardize eligibility for all their state medical assistance programs.

Several states also revised medical eligibility for access to their ADAPs due to changes in the clinical management of HIV disease. Historically, CD4 cell counts have frequently been used by ADAPs when assessing eligibility. The advent of viral load testing has diminished the role of CD4 cell counts as a prognostic marker in HIV disease and most ADAPs have adapted their policies accordingly. Alabama, Florida, Idaho, Kentucky, Nevada and South Carolina continue to use a CD4 count of less than 500 as an eligibility requirement although exceptions can usually be requested. Maine, Mississippi and Puerto Rico set a threshold for CD4 or viral load, and meeting either requirement establishes eligibility.

ADAP Formulary Update

Access to treatment through ADAP is contingent upon efficient and appropriate formulary management. As outlined in the previous NASTAD/ATDN report, drug formularies vary widely from state-to-state. Responses to our latest survey indicate that many states are intensifying their efforts to ensure the timely availability of newly approved antiretroviral drugs. However, several states continue to cite fiscal concerns that have delayed the addition of antiretroviral drugs to the ADAP formulary. The inability of some states to accurately project the fiscal impact of formulary changes has been noted as contributing to this problem. In addition, policies regarding the coverage of drugs for the prevention and treatment of opportunistic infections remain highly inconsistent from state to state. Finally, rapidly changing clinical standards and/or differences in formulary decision-making processes at the local level may also contribute to the disparities in ADAP formulary coverage.

Advisory Committee Update

Formal ADAP advisory committees currently operate in forty-five states, to assist in making decisions regarding the administration, structure and scope of the ADAP. Alaska, Kentucky, Montana and Wisconsin continue to use an informal advisory network. Vermont, which previously had a formal advisory committee, is reorganizing and temporarily relying on the health department for all ADAP-related directives.

Formulary management decisions generally fall within the purview of ADAP advisory committees. Irregularity of committee meetings is one of the potential obstacles to the timely addition of newly approved drugs to ADAP formularies. To address this problem, nine states (Alaska, Colorado, Illinois, Minnesota, New Hampshire, Oregon, South Carolina, Utah and West Virginia) now have standing recommendations to add all newly FDA-approved antiretroviral medications without further consultation with their advisory committees. Michigan and Mississippi have increased the number of advisory committee meetings to try to help their ADAPs keep pace with the rapidly changing HIV/AIDS treatment environment.

To probe this issue further, we asked state AIDS programs to report the average length of time it takes to add a new drug to the ADAP formulary, garnering the following responses:

one to four weeks	26 states (50%)
one to two months	11 states (21%)
two to three months	6 states (12%)
three to six months	5 states (10%)
other*	4 states (7%)

* Other periods cited included 'no average time' and 'varies considerably.'

States were also asked how their ADAPs are made aware of the FDA-approval of HIV/AIDS-related medications. The majority of states (92%) rely on treatment newsletters and pharmaceutical company representatives. The latter is usually a field representative whose job involves actively seeking ADAP reimbursement for HIV/AIDS-related pharmaceuticals. Advisory committee members were cited by 36 states as sources of information on new drugs. ADAP consumers in 31 states also play a role in this regard. Eighteen states listed a variety of other potential sources of new drug information, including AIDS advocacy organizations, the Public Health Service, local AIDS Clinical Trial Units, local advisory groups, physicians, and the Internet.

Changes in Formularies

In terms of specific formulary management activities, forty-two states have either added and/or deleted drugs since the previous NASTAD/ATDN report. Forty-nine states now report covering the most recently approved protease inhibitor, nelfinavir (Viracept). Nelfinavir was approved for marketing by the FDA in March 1997. An updated ADAP formulary chart which lists all drugs covered by each state is included in Appendix IV with new drugs added since the previous report indicated in bold.

Delavirdine (Rescriptor) is a new anti-HIV drug in the class known as non-nucleoside reverse transcriptase inhibitors (NNRTIs). Delavirdine was approved in April 1997 and thirty-nine states report adding this drug to their formulary. The first NNRTI drug to be approved was nevirapine (Viramune) which received clearance in June 1996. Forty-four states are covering nevirapine,

leaving eight states (Alabama, Arkansas, Idaho, Iowa, Louisiana, Pennsylvania, Puerto Rico and Tennessee) that have yet to add any NNRTI anti-HIV drugs to their formularies.

Rhode Island and Minnesota became the first ADAPs to add hydroxyurea to their formularies. Hydroxyurea is an inexpensive anti-cancer drug that early studies have shown to act synergistically with the nucleoside analog antiretroviral ddI (Videx). The usefulness of this drug in the HIV treatment armamentarium continues to be studied.

Two states remain without protease inhibitor coverage: Arkansas and South Dakota. Arkansas reports that protease inhibitors will be added to the ADAP formulary effective April 1, 1998. For South Dakota's program, the issue is primarily economics; the program's ADAP budget is less than $140,000 which is exhausted rather quickly covering the existing formulary for current clients.

Eleven states added drugs for the treatment and prevention of OIs. However, there was little commonality to be found among states in terms of the specific drugs added in this category. Drugs added included prophylaxis and treatments for HIV-related infections, antibiotics, pain relievers and antidiarrheals. Of the 35 drugs added by these 11 states, all but three were approved prior to 1997.

Kansas was one of only two states to report deleting a drug, specifically clofazimine (Lamprene), which is no longer recommended as a first line treatment for Mycobacterium avium complex (MAC). North Dakota both deleted and added drugs from its formulary, removing clofazimine along with twenty other drugs used in the treatment of opportunistic infections and adding ten other HIV-related medications. Thirteen states (25%) continue to cover clofazimine, which is occasionally used as a salvage therapy in MAC disease.

Clinical Guidelines on HIV Treatment

In June 1997, 'Draft Guidelines on the Use of Antiretroviral Agents in HIV-infected Adults and Adolescents' were released by the Public Health Service in collaboration with the National Institutes of Health and the Henry J. Kaiser Family Foundation. This document represents the first effort by the Federal government to distill the many recent breakthroughs in HIV treatment into cohesive guidelines for the use of antiretroviral drugs. These guidelines will be regularly updated to include new information - in fact a November 1997 update has already been released - and these documents are available on the Internet via the HIV/AIDS Treatment Information Service at http://www.hivatis.org.

The impact of these data on the effectiveness of combination antiretroviral therapy, usually including protease inhibitor drugs, is already being felt by ADAPs nationally, notwithstanding the previous absence of guidelines on the subject. Now that officially sanctioned recommendations are available, it is likely that ADAP utilization trends will further shift towards the three drug combinations preferred by the guidelines panel. Anticipating these trends, we asked states to report on any steps taken by ADAP in response to the currently available guidelines. Responses are summarized in the table below:

Expand the ADAP formulary to cover the 11 approved anti-HIV drugs	15 states (29%)
Update existing local/state HIV/AIDS treatment guidelines	14 states (27%)
Develop educational programs/materials about the guidelines for local physicians	32 states (62%)

Incorporate the guidelines into new/existing utilization review and/or monitor prescribing	14 states (27%)
Modify/develop prior authorization processes based on the guidelines	7 states (13%)
Other*	10 states (19%)

* Other responses cited included: Working with AIDS Education and Training Centers (AETCs) to educate medical providers; encouraging participation in the New Antiretroviral Treatment Guidelines conference call held in September 1997; changes in eligibility criteria for access to protease inhibitors; considering the implementation of a treatment form to assist doctors when prescribing protease inhibitors; sending the information to all ADAP enrollees; conducting a drug utilization review study; and sending the guidelines to all prescribing physicians.

Drug utilization review (often referred to by the acronym DUR) is a mechanism for assessing the appropriateness of any prescription that a program is requested to reimburse. DUR has a checkered history, as it is often associated with attempts by Managed Care Organizations to limit skyrocketing prescription drug costs. However, in the context of the HIV treatment guidelines, states are using DUR as an innovative strategy to monitor the inappropriate prescription of antiretroviral drugs. Misuse of antiretrovirals can lead to the swift emergence of drug resistance and treatment failure - an outcome detrimental both to the health of the individual, the public health, and the fiscal health of the ADAP, since the program would have to pay for the more complex regimens required by these circumstances. Although there is ample literature describing the problem of mis-prescribing or 'professional non-compliance,' physicians have not always responded well to such interference in their prescribing practices. The ADAP Monitoring Project will request feedback from the 14 states implementing DUR in our next survey.

Prior authorization is another mechanism that is used to control drug utilization. In this case permission to prescribe a particular drug or combination of drugs is obtained prior to the issuance of a prescription. According to data gathered from the previous NASTAD/ATDN report, prior authorization was being used by nine ADAPs: Delaware, Hawaii, Michigan, New Hampshire, New York, Oklahoma, Texas, Vermont and Virginia. Protease inhibitor utilization is monitored in this way in Hawaii, Oklahoma and Vermont. Virginia also required prior authorization for any protease inhibitor other than indinavir (Crixivan), and any combination of a protease inhibitor with an NNRTI drug. However, Virginia is among the seven ADAPs (the others are DC, Michigan, Nevada, Rhode Island, South Carolina and Texas) that report reviewing the issue of prior authorization in light of the new guidelines.

Opportunistic Infection Guidelines

Also in June 1997, the Public Health Service (PHS) in collaboration with the Infectious Disease Society of America (IDSA) released 'Guidelines for the Prevention of Opportunistic Infections in Persons Infected with HIV.' This document reviewed and updated the recommendations made by PHS and IDSA in 1995. States were asked whether their ADAP had responded to these updated guidelines in any of the following ways:

Expand the ADAP formulary to cover all 14 strongly recommended drugs	9 states (17%)
Update existing local/state HIV/AIDS treatment guidelines	9 states (17%)

Develop educational programs/materials about the guidelines for local physicians	24 states (46%)
Incorporate the guidelines into new/existing utilization review and/or monitor prescribing	10 states (19%)
Modify/develop prior authorization processes based on the guidelines	2 states (4%)
Other*	14 states (27%)

* Other responses cited included: provide patient education materials; all drugs are already covered with the exception of isoniazid (by California, which has a separate program for access to TB medications including isoniazid); working with AIDS Education and Training Centers (AETCs) to educate medical providers; mailing guidelines to case managers, health district epidemiologists and advisory committee members; implementing program to purchase opportunistic infection medications with Ryan White money for individual contractors delivering services; and three states were 'unsure at this time.'

Upon further review of each state's ADAP formulary, only two state ADAPs (New York and Illinois) cover all 14 of the strongly recommended OI prophylaxis drugs in the guidelines (TMP/SMX, dapsone, pyrimethamine, isoniazid, clarithromycin, azithromycin, fluconazole, itraconazole, amphotericin B, ganciclovir, foscarnet, cidofovir, acyclovir, sulfadiazine). California covers all except for isoniazid, because this drug is available to people with HIV through a separate tuberculosis-specific state program. Additionally, people living with HIV in the states that did not report covering these 14 drugs through their ADAPs may have access to some of these medications through local pharmacy assistance programs and/or state-wide TB programs.

Ancillary Efforts to Provide Access

NASTAD/ATDN also requested information on any ancillary efforts undertaken by state ADAPs to ensure that people with HIV have access to the new clinical standard of care. Twenty-three states noted extensive use of pharmaceutical industry patient assistance programs. Eight states reported collaborative efforts with other Ryan White CARE Act Title II-funded programs, primarily HIV care consortia, to provide funding for additional medication needs and/or health insurance continuation. Seven states containing Emergency Metropolitan Areas (EMAs) that receive Ryan White CARE Act Title I dollars listed collaborative efforts with these programs to ensure medication coverage beyond that available through the state ADAP. Although covered more extensively in other survey questions, four states (8%) also listed their insurance continuation programs as another strategy for ensuring people with HIV have access to the new standards of care.

Viral load testing is an important monitoring tool referenced extensively in the new guidelines on the use of antiretroviral drugs. Two states specifically reported efforts to ensure coverage of viral load testing for ADAP clients. Alaska requires that Title II-funded consortia cover necessary viral load testing for any ADAP clients they enroll. Louisiana has a state appropriation designed, in part, to provide such coverage for ADAP clients. New York's ADAP Plus program covers viral load testing and other primary care and diagnostic services.

Other innovative strategies being implemented by states in response to the new standard of care included:

- A study of access to protease inhibitors in communities of color in Colorado.
- A statewide treatment education program that trains peer educators in Massachusetts.
- Revision of case management training curricula to include information on the new standards of care in Michigan. Similar quarterly case manager trainings were reported in Ohio.
- Washington state has contracted with their AIDS Education and Training Center (AETC) to produce a 30-minute training video on new HIV treatment strategies.
- New Mexico provides clinical trial referrals as an additional service through an organization called Partners in Research/New Mexico.

Medical Criteria/Restrictions On Access To Formulary Drugs

Despite a general trend towards formulary expansion among ADAPs, several programs continue to have medical criteria in place that restrict access to specific formulary drugs. For the most part, the criteria appear to be driven by cost containment priorities rather than any desire to guide clinical management of ADAP clients. Arkansas limits its five available antiretrovirals to people with less than 500 CD4 cells. Although access to Florida ADAP is capped, when slots do become available only those clients with less than 350 CD4 cells and viral loads over 10,000 copies may access protease inhibitors. Georgia reports implementing the following medical access criteria:

CD4	bDNA	PCR	Drugs available
<350	Any	Any	2RTIs + PI or NNRTI / 1 RTI + PI + NNRTI
350-500	>10,000	>20,000	2RTIs + PI or NNRTI / 1 RTI + PI + NNRTI
350-500	<10,000	<20,000	2 RTIs
>500	>30,000	>60,000	2 RTIs
>500	<30,000	<60,000	none,/font>

- RTI=nucleoside analog reverse transcriptase inhibitor
- NNRTI=non-nucleoside reverse transcriptase inhibitor
- PI=protease inhibitor
- PCR=Roche Diagnostics Amplicor HIV-1 viral load test
- bDNA=Chiron branched DNA viral load test

These criteria conflict with the PHS/NIH Guidelines on the Use of Antiretroviral Agents (referenced earlier) which specifically state that two RTI drugs are no longer recommended for HIV treatment. In contrast, both Idaho and Tennessee report amending their guidelines to remove a requirement that clients initiate therapy with two RTIs prior to receiving a protease inhibitor.

Texas ADAP continues to restrict RTI antiretrovirals to those with less than 500 CD4 cells. For access to protease inhibitors, Texas requires clients to have a viral load of over 10,000 copies but does not specify a CD4 count. Virginia has instituted a medical exception form for clients who do not meet current requirements for access to protease inhibitors: a CD4 count of 500 or less or a viral load of over 10,000 copies.

NASTAD/ATDN will continue to monitor developments in the area of medical access criteria which is expected to be revisited by states as a result of ongoing updates and evolution of clinical practice guidelines and by anticipated ADAP funding increases in FY 1998.

The Interface Between ADAP, Medicaid and Private Insurance

Background

During the late 1980's and early 1990's, ADAPs (and the precursor AZT Assistance Programs) acted as a temporary 'bridge' between private insurance and the state Medicaid program. The role that ADAPs played in filling the coverage gap between insurance and Medicaid followed the natural course of HIV disease at the onset of the epidemic: many individuals living with HIV infection were working, middle-class men who eventually became too ill to maintain employment, lost their jobs, subsequently lost their health insurance and eventually became totally disabled in the later stages of the illness. Many of these individuals would move in sequence from private insurance coverage, to ADAP, to Medicaid.

This 'progression paradigm' may no longer hold true, for several reasons. With the advent of highly effective antiretroviral therapies, many individuals with HIV are no longer progressing so quickly-and in some cases showing almost no progression-towards severe illness, disability and death. People with HIV/AIDS are living longer, as indicated in the recent reports of declining AIDS death rates. People living with HIV infection are maintaining health longer, due to the impact of effective antiretroviral therapies. This means that many individuals are not becoming disabled and under those circumstances will not qualify for disability-based health care programs like Medicaid.

The demographics of the epidemic have changed as well, with increasing cases of AIDS reported in communities of color, among women and among substance abusers. This demographic shift may mean that more people with HIV/AIDS are from populations that are less likely to be privately insured. According to the CDC, approximately 225,000 uninsured people (i.e., individuals without private or public insurance) are currently living with HIV in the United States. These individuals have limited options for accessing promising new HIV therapies; among the few options are state ADAPs, manufacturer patient assistance programs, and local indigent care programs.

Individuals with HIV/AIDS are living longer, staying healthier and, anecdotally, are staying on the rolls of ADAPs for a longer period of time. With more restrictive Medicaid eligibility criteria being implemented at the federal and, in some cases, the state level, some individuals (e.g., injection drug users, certain classes of immigrants) may no longer be eligible for access to Medicaid and other public health care programs. The coverage gap that ADAPs are being called upon to fill is steadily widening.

NASTAD/ATDN asked states to estimate ADAP client income levels based on federal poverty guidelines. Using the number of clients served by ADAPs in July 1997, the survey indicated that 49% (19,671) of ADAP clients served nationally that month earned less than 100% of the federal poverty level (FPL) (<$7,890 per year) and nearly 34% (13,513) earned between 101% and 200% of FPL ($7,890 - $15,780 per year). Taken together, an estimated 83% (33,184) of the nation's ADAP clients earn less than 200% of FPL. The state-by-state breakdown of estimated client income levels is included in a table in Appendix V.

In order to ameliorate the increased demand on ADAPs, proposals to expand Medicaid coverage to non-disabled individuals living with HIV are being discussed at the national and state levels. In early 1997, the Clinton Administration proposed examining the feasibility of extending Medicaid benefits-including prescription drug benefits-to non-disabled people with HIV through a Medicaid demonstration/waiver process. After closely examining the potential cost of a Medicaid expansion, however, the Administration initially determined that it could not move forward with this process on a national level. Current Administration policy dictates that any Medicaid

expansion waiver must pass a 'budget neutrality' test; i.e., the cost of the expansion must be offset by cost savings within the Medicaid program. Health Care Financing Administration actuaries have estimated that an expansion of services for non-disabled individuals living with HIV would result in significant additional outlays of federal and state dollars for Medicaid.

Efforts are now underway to examine the viability of Medicaid expansion on a state by state basis. In a few jurisdictions, efforts to expand Medicaid coverage at the state level are in the preliminary stages of discussion.

Many states are also attempting to expand access to private health insurance for persons who rely on Ryan White CARE Act programs for access to health care and prescription drugs. To this end, some states have established insurance continuity programs and/or insurance purchasing programs. The degree to which a state can access expanded health care coverage through private insurance for people living with HIV is impacted by several factors including the availability of funding for insurance continuity/purchasing programs, the existence of high-risk insurance pools in states, restrictions on the use of federal Ryan White ADAP funds for the purchase of insurance, and state insurance laws.

ADAP and Medicaid

Traditionally, there has not been a seamless continuum of health care access as individuals move between private insurance, ADAP, Medicaid and other public programs like Medicare. Coordination between these programs to ensure that an individual retains access to adequate health care, or at least access to prescription drugs, has often been uneven or non-existent. In this section, we will discuss the type and level of coordination specifically between ADAPs, state Medicaid programs and private insurance, based on survey responses of the state agencies that administer ADAP.

In the vast majority of states, the ADAP and Medicaid programs are housed in different administrative departments. In the three states (Minnesota, Connecticut, Pennsylvania) where the ADAP-administering agency and Medicaid are located and operated in the same state department, there tends to be a high level of cooperation and coordination between the two programs. In general, cooperation between state Medicaid programs and ADAPs historically has occurred in the following areas:

- Coordination of eligibility;
- 'Back-billing' of the Medicaid program for coverage of ADAP clients who obtain retroactive Medicaid coverage for expenses incurred by ADAP during the retroactive Medicaid coverage period;
- ADAP providing prescriptions for Medicaid beneficiaries who exceed the monthly Medicaid prescription limit;
- Presence of Medicaid officials on ADAP advisory boards;
- More recently, a few ADAPs have worked with their state Medicaid programs to assess the feasibility of extending limited Medicaid benefits to non-disabled individuals living with HIV.

Examples of coordination between ADAP and Medicaid in these areas are discussed below, based on information provided by state AIDS programs:

Eligibility Coordination

Under the burden of increasing client enrollment and soaring expenditures, many ADAPs have sought to ensure that ADAP clients who become eligible for Medicaid benefits are moved as quickly as possible onto the Medicaid rolls. Thirty-nine ADAPs indicated that they have some mechanism to cross-check/coordinate client eligibility with the state Medicaid program.

Mechanisms to cross-check Medicaid eligibility include direct access to the Medicaid client database and eligibility screening by case managers. Some of these ADAPs (Arizona, Kansas, Massachusetts) require that an individual prove he/she is not eligible for Medicaid benefits before applying for ADAP. Alabama ADAP requires that clients apply for Medicaid and ADAP simultaneously. Seventeen ADAPs reported screening all ADAP applicants for potential Medicaid eligibility at the time of ADAP application.

According to data gathered from the survey, approximately seven percent (7%) of July 1997 utilizing clients nationally were also current Medicaid beneficiaries (including those in the spenddown process). The percentage of ADAP clients estimated to be on Medicaid varies greatly from state to state. For example, Maryland estimated that two percent (2%) of its July 1997 utilizing client population was on Medicaid, compared to an estimate of ten percent (10%) in Nebraska, twenty-two percent (22%) in Texas, and sixty percent (60%) in West Virginia. Twenty-one states reported that no utilizing ADAP clients were also on Medicaid.

The exact eligibility or benefit status of the ADAP clients who were reported to be on Medicaid is unclear, based on the gathered data. Many of these clients may be in the spenddown process or, as in the case of Texas, may be utilizing ADAP services when their monthly Medicaid prescription benefit is exhausted. Tennessee ADAP, which reported no utilizing ADAP clients on Medicaid, has structured its program as a segue into TennCare (the Tennessee Medicaid managed care system) and therefore has no reported overlap of clients.

Coordination of Prescription Benefits

Some state Medicaid programs limit the number of prescriptions an eligible client may receive each month. For example, Medicaid beneficiaries in Mississippi are limited to five prescriptions per month, beneficiaries in Oklahoma, South Dakota and Texas are limited to three prescriptions per month. Texas ADAP coordinates prescription coverage closely with the state Medicaid program via on-line access to the Medicaid database, and covers prescriptions for dual eligibles once an individual has exhausted her/his monthly Medicaid drug benefit. This coverage coordination system is structured so that Medicaid pays for the more costly antiretroviral drugs (e.g., protease inhibitors). Mississippi and Oklahoma previously covered prescriptions for Medicaid/ADAP clients who had exhausted their monthly Medicaid drug benefit, but recently discontinued this practice due to funding shortages.

Back-Billing

Twenty ADAPs stated that they routinely back-bill Medicaid when an ADAP client receives retroactive Medicaid benefits (ADAPs generally have 90 days from the date of service to bill for these funds). Back-billing is accomplished either through an electronic inter-program billing system or through a manual billing procedure. This process allows ADAPs to recoup funds expended for ADAP clients during the retroactive Medicaid coverage period, and helps to ensure that ADAPs are the payer of last resort.

Other Areas of Cooperation

Seven ADAPs (Alaska, D.C., Florida, Massachusetts, Minnesota, North Dakota, Wyoming) reported that a representative of the state Medicaid program sits on the ADAP advisory committee and/or acts as an advisor to the ADAP program. In most cases, the representative is the Medicaid pharmacist. Three ADAPs (Florida, Maine, New York) indicated that they are in the preliminary stages of discussion with their state Medicaid program regarding expansion of Medicaid benefits to non-disabled individuals living with HIV.

Assessing the Impact of Medicaid Coverage on State ADAPs

Is an ADAP more 'burdened' in a state that has a Medicaid program without a medically needy coverage category, with a low spenddown income eligibility threshold, and/or monthly prescription

limits? NASTAD/ATDN asked state AIDS programs to identify Medicaid policies in their states that may result in increased demand on ADAP. Eighteen states provided responses to this survey question. Their responses fell into two general categories:

Medicaid Eligibility Requirements

Mental/physical disability requirement- Individuals receiving combination therapies are staying healthier longer. Some programs report that these individuals are remaining on the ADAP rolls for a longer period of time; these individuals cannot qualify for Medicaid because they do not meet the disability requirement.

No 'Medically Needy' Eligibility Category/Spenddown Issues

Individuals with HIV/AIDS who meet the physical/mental disability requirement may have incomes that exceed the limit required to qualify for Medicaid benefits. Most states have a medically needy eligibility category that allows disabled individuals to spenddown to a state-determined income eligibility level. However, several state AIDS programs report that many clients cannot meet spenddown requirements due to low income eligibility thresholds. Some states simply do not have a medically needy program, an optional category of Medicaid coverage, thereby potentially increasing the burden on ADAP.

Monthly Prescription Limits

Several state Medicaid programs impose limits on the number of prescriptions that beneficiaries may obtain each month. Some ADAPs report that inadequate prescription drug coverage through Medicaid increases the burden on their programs.

We also conducted a preliminary analysis of the impact that less expansive Medicaid access in some states may have on the state ADAP. We reviewed each state's Medicaid program in order to determine the relative expansiveness of the overall program. For the purposes of our analysis, a 'limited' Medicaid program was defined as having one or more of the following characteristics:

- No medically needy eligibility category;
- Low spenddown income eligibility threshold (<50% of FPL); and/or
- Monthly prescription limits with no exceptions for chronic illnesses (e.g., HIV/AIDS).

Twenty-three states were identified through this process as having 'limited' Medicaid programs. We then identified those states that had indicated some level of restricted access to their ADAPs. For the purpose of our analysis, ADAPs with restricted access included those that reported one or more of the following access problems:

- Waiting lists for or limited ADAP enrollment;
- Waiting lists for or limited access to protease inhibitors;
- Expected budget shortfall.

Twenty-four states were identified as having ADAPs with restricted access. Our analysis found that 19 of the 23 states (83%) with 'limited' Medicaid programs, as defined by our analysis criteria, also were states with restricted ADAP access. These 19 states are: Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Georgia, Idaho, Kentucky, Maine, Mississippi, Nevada, North Carolina, Oklahoma, South Carolina, South Dakota, Texas, West Virginia, and Wyoming. The four states with 'limited' Medicaid access that did not also meet the restricted ADAP criteria were Delaware, Illinois, New Mexico and Tennessee. Conversely, five states (D.C., Indiana, Kansas, Montana, and Puerto Rico) met our definition of restricted ADAP access but did not meet the 'limited' Medicaid program criteria. Finally, the remaining twenty-four states met neither the criteria for having a 'limited' Medicaid program nor the criteria for having restricted ADAP access (see the Table on page 32).

While this is a cursory analysis of a rather complex issue, it suggests that those states with less expansive Medicaid programs are by and large the same states that have set limits on access to their ADAPs. ADAPs may, in fact, be more burdened in states that have less expansive Medicaid programs. A more detailed analysis of the impact of multiple variables on ADAP fiscal stability is warranted, including both the impact of Medicaid access issues and the diversity of ADAP funding sources.

States with 'limited' or less expansive Medicaid coverage and restricted ADAP access (19 states)

Alabama	Alaska	Arizona	Arkansas	Colorado
Florida	Georgia	Idaho	Kentucky	Maine
Mississippi	Nevada	North Carolina	Oklahoma	South Carolina
South Dakota	Texas	West Virginia	Wyoming	

States with 'limited' or less expansive Medicaid coverage but which do not have restricted ADAP access (4 states)

Delaware	Illinois	New Mexico	Tennessee

States with restricted ADAP access but which do not have 'limited' or less expansive Medicaid coverage (5 states)

D.C.	Indiana	Kansas	Montana	Puerto Rico

States which do not have restricted ADAP access or 'limited' Medicaid coverage (24 states)

California	Connecticut	Hawaii	Iowa	Louisiana
Maryland	Massachusetts	Michigan	Minnesota	Missouri
Nebraska	New Hampshire	New Jersey	New York	North Dakota
Ohio	Oregon	Pennsylvania	Rhode Island	Utah
Vermont	Virginia	Washington	Wisconsin	

Private Insurance and ADAP

ADAP and private insurance interface on several different levels. As mentioned previously, ADAPs have often served as a bridge program for individuals with HIV/AIDS who move from private insurance coverage to Medicaid. Some ADAPs cover prescription drugs for clients who have inadequate/limited drug coverage under private insurance policies (e.g., policies with yearly drug benefit caps). Many state AIDS agencies operate insurance assistance programs to augment and/or replace services provided through ADAP and other Ryan White and/or state-funded HIV care programs.

Based on survey responses from states that provided estimates of the number of ADAP clients having private insurance coverage, approximately seven percent (7%) of clients nationally who utilized ADAP services in July 1997 had private health insurance that provides some level of

prescription drug coverage. The percent of clients with prescription drug coverage on ADAP varies greatly from state to state, based on reported figures. For example, ninety-one percent (91%) of Minnesota ADAP clients have drug coverage through private insurance (including those covered through the state high-risk insurance pool) and in Oregon, seventy percent (70%) of clients were estimated to have insurance prescription drug coverage. Fifty-one percent (51%) of ADAP clients in Washington state were estimated to have some prescription drug coverage, twenty percent (20%) in D.C., ten percent (10%) in Kansas and one percent (1%) or less in Arizona, Hawaii, Maine, Nevada, North Carolina, South Carolina and Virginia. Several states (Alabama, Colorado, Florida, Idaho, Mississippi, Oklahoma, Tennessee, Texas, Utah) estimated that no July 1997 utilizing clients had drug coverage through private insurance. In some of these states, individuals with private health insurance that pays for a portion of prescription drug costs are not eligible for ADAP.

Insurance Continuity/Purchasing Programs

Ryan White CARE Act grantees are permitted to use Ryan White Title I and Title II funds to pay insurance premiums, deductibles and co-pays for eligible, low income individuals with HIV/AIDS. Many states use Title II dollars and/or state funds to continue health insurance for people who are on COBRA, or who have an insurance policy and can no longer afford to pay the premium. These types of programs are generally referred to as 'insurance continuity' programs. Eligibility for this type of assistance varies greatly from state to state, but is often synonymous with state ADAP eligibility criteria. States have found insurance continuity programs to be a cost-effective means of maintaining not only an individual's prescription drug coverage but also a full range of health care benefits. Anecdotally, however, many states report that fewer and fewer individuals are coming into the Ryan White/state HIV care system with private insurance. For this reason, some state AIDS offices suggest that insurance continuation programs, although cost-effective, are not being as highly utilized as expected.

In addition to paying premiums, deductibles and co-pays for existing policies, some states have initiated insurance purchasing programs. Although these programs are considered under the umbrella of insurance continuity, the state actually purchases a health insurance policy-usually with a minimum standard of benefits-for eligible individuals, pays the premium, and will generally assist with the deductible and co-pays. Often, insurance policies are purchased from a state high-risk insurance pool. Notable among states with insurance purchasing programs are Minnesota, Oregon, and Indiana. In some cases, individuals may be eligible for both an insurance continuity/purchasing program and ADAP benefits; in these cases, the ADAP will cover the costs of medicines during coverage waiting periods and after the private insurance benefit has been temporarily exhausted.

States may use Ryan White base Title II funds and, in some cases, state funds to purchase insurance policies for low income individuals with HIV/AIDS. However, there is some question as to whether states may use their federal ADAP earmarked funds for services, such as insurance continuity programs, that facilitate access to treatment. Additionally, some states have legal restrictions on the use of federal and/or state funds for the purchase of insurance. These administrative and legal barriers have prohibited some state AIDS agencies (e.g., Florida, Mississippi) from initiating or expanding cost-effective insurance purchasing programs.

States were asked to briefly describe their efforts to enhance access to private insurance coverage through insurance continuity/purchasing programs. Thirty-seven states (71%) indicated that they administer some type of insurance continuity/purchasing program. Nine states indicated that they do not administer insurance continuity/purchasing programs and five states did not respond to this survey question. North Carolina reported that the establishment of an insurance continuity program in the state is currently under study.

The size, structure, eligibility criteria, and scope of these programs vary greatly from state to state. A comprehensive review of all of the various state insurance continuity/purchasing

programs is beyond the scope of this report. However, profiles of selected state initiatives are presented below in order to provide a sense of the variability and scope of these programs.

Connecticut: The Connecticut Insurance Assistance Program for AIDS Patients (CIAPAP) pays insurance premiums for eligible individuals who leave employment and qualify for COBRA coverage. Eligibility for the program is an AIDS or AIDS-related diagnosis, monthly income below 200% of FPL and assets of less than $10,000 (excluding an automobile). The program makes COBRA payments on behalf of qualified individuals for at least 18 months, and for 29 months for those individuals who are qualified as disabled by the Social Security Administration.

Illinois: The state Continuation of Health Insurance Coverage (CHIC) Program is funded with Ryan White CARE Act Title II dollars and assists individuals with an AIDS diagnosis, or individuals who are disabled due to HIV, have discontinued working, and who will continue to receive health insurance benefits through COBRA or other group health insurance plans. An eligible client must have an income less than 200% of FPL and less than $10,000 in assets (although the state is currently considering expanding these criteria to allow for greater access). CHIC will pay up to $300 per month for a client's insurance premium. In some cases, CHIC will pay more for an insurance premium (up to a maximum of $1,500 more per year) if the insurance policy provides family coverage or is deemed to be extremely cost-effective. The program currently serves approximately 200 clients per month.

Minnesota: The state of Minnesota allocated approximately $1.5 million in 1997 to support the purchase/continuation of insurance for people with HIV. Individuals eligible for this program must have an income of less than 300% of FPL and meet a state-determined standard of disability due to HIV. The state also uses Ryan White Title I and II funds (approximately $150,000 this fiscal year) to provide insurance purchasing/continuity for non-disabled individuals with HIV. All insurance plans must provide at least 50% drug coverage within six months of payment of premiums by the state. Currently, over ninety percent (90%) of Minnesota ADAP clients have health insurance that covers prescription drugs.

New Mexico: The state's HIV/AIDS Services Program's Insurance Assistance Program (IAP) is designed to assist eligible individuals with HIV/AIDS to maintain/continue health insurance coverage. Eligible clients must have a gross monthly income less than or equal to 200% of FPL. The IAP will pay a client's existing insurance premium, up to $400 per month.

Oregon: Beginning January 1997, Oregon began moving many of its ADAP clients onto private insurance through an insurance purchasing program. The state AIDS office assists clients with signing up for the state high risk insurance pool, helps clients through insurance transitions (e.g., from employer policy to COBRA) and pays clients' premiums, deductibles and co-pays. In January 1997, the state was paying over sixty percent (60%) of ADAP client prescriptions at 100%; in November 1997, the state was paying less than forty percent (40%) of prescriptions at 100%, due to the increase in the number of clients who had private health insurance. The state reports significant cost-savings in its ADAP through this process, and has been able to significantly expand the ADAP formulary.

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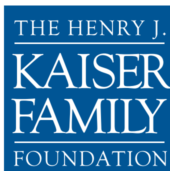

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