Waiting for AIDS Medications in the United States:  
An Analysis of ADAP Waiting Lists

Introduction
Waiting lists are a reality of state AIDS Drug Assistance Programs (ADAPs), which rely on specific federal appropriations, or capped funding, each year. Capped funding determines an ADAP’s income eligibility criteria, the number of drugs on its formulary, and the number of people who can be served. 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. In recognition of ADAP funding shortfalls and the waiting lists that result, President Bush announced the availability of an additional $20 million in FY 2004, for medications in 10 states with ADAP waiting lists in place in June 2004. The Initiative began distributing medications to eligible individuals in October 2004.

This fact sheet provides an overview of ADAP waiting lists based on analysis of data collected by the National ADAP Monitoring Project between July 2002 and November 2004, which includes the implementation of the $20 million ADAP Initiative. States were surveyed on a regular basis over the period, for a total of 18 times, to assess the status of waiting lists and other cost containment measures.

Background
ADAPs, part of the federal Ryan White CARE Act, provide HIV-related prescription drugs to people with HIV/AIDS who have limited or no prescription drug coverage. ADAPs reach approximately 30% of those estimated to be living with HIV/AIDS and receiving care in the U.S. each year. Administered and designed by the states, they operate in 57 jurisdictions including all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, three U.S. Pacific Territories and one Associated Jurisdiction.

ADAPs are discretionary grant-funded programs, with “capped” funding each year. Unlike entitlement programs, ADAPs receive a fixed amount of federal funding from Congress each year and funding does not necessarily correspond to the number of people who need services or the costs of those services. Although ADAPs may also receive some state and other funding, these are highly variable and limited. At the same time, demand for ADAP services has increased over time due to several factors: a growing number of people living with HIV/AIDS; rising costs of prescription drugs; and increasing complexity of HIV-related treatment regimens requiring multiple drugs. Changes in the larger fiscal environment may also affect demand for ADAPs; if other programs, particularly Medicaid, face tighter fiscal times, they may reduce program access, thereby increasing demand for ADAP services. As a result of these factors, access to ADAPs varies across the country.

Within these constraints, ADAPs have only a limited set of cost containment “tools” available for managing their programs, many of which may compromise access and result in unmet need. Waiting lists are perhaps the most visible example of unmet need. Those on ADAP waiting lists cannot get medications through ADAP, even though they meet all eligibility criteria. These individuals may go without medications at all, or they may be able to access a state- or manufacturer-operated pharmaceutical assistance program (PAP). However, only a handful of states operate PAPs for the non-elderly disabled and pharmaceutical manufacturer PAPs generally require people to apply as often as every month, with separate applications to the manufacturer of each medication needed, creating an extremely difficult process to navigate, especially for someone on a multiple drug regimen. Some states may not have waiting lists in place, but may have other program restrictions or limitations. Other cost containment tools used by states, some of which can affect access, 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 (Title II base) for ADAPs, often at the expense of other critical services.

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?
Key Findings
ADAP Waiting List Trends: July 2002 – November 2004

- The number of people on ADAP waiting lists was 1,108 in 7 states in July 2002 and 813 in 9 states in November 2004.
- Waiting lists fluctuated significantly across states over the period:
  - The number of people on waiting lists ranged from a low of 537 to a high of 1629; the average was 862.
  - The number of states with waiting lists in any given survey period ranged from a low of 6 to a high of 11.
- Waiting lists also fluctuated significantly within states over the period:
  - The number of people on some state waiting lists often went up and down. For example, the size of the waiting list in Alabama was 250 in July 2002, 89 in August 2003, and 244 in November 2004;
  - Several states (AK, AR, IN, MT, NE, NC, SD) were able to eliminate their waiting lists at some point over the period only to reinstate them at a later date;
  - Fluctuation is hard to predict and is due to several factors such as changes in a state’s fiscal environment, client demand, and costs of medications (including the introduction of new therapies).
- A total of 18 states had a waiting list in place at some point during the period (AL, AK, AR, CO, Guam, HI, ID, IN, IA, KY, MT, NE, NC, OR, SD, UT, WV, WY).
- Most states with waiting lists had them in place for more than one survey period
  - One state had a waiting list in all 18 survey periods (AL)
  - Seven other states had waiting lists in at least 10 of the survey periods (KY, MT, NE, NC, OR, SD, WV).
- The highest number of individuals on any one state’s waiting list was 891 (NC); the lowest was 1 (AK and MT).
- North Carolina had the highest average number of people on its waiting list over the period (412), followed by Alabama (205). The lowest average was 2, in Wyoming.
- As of November 2004, 13 states had also instituted other cost containment measures (other than waiting lists)
  over the last year: 6 anticipate having to implement new or additional cost containment measures during the remainder of the fiscal year due to limited funds.
- The $20 Million ADAP Initiative has resulted in a reduction of the number of individuals on waiting lists:
  - A total of 591 individuals eligible to receive medications through the Initiative had been enrolled by November 2004 (representing 44% of those eligible);
  - Five of the 10 eligible states had eliminated their waiting lists by November 2004, 3 due directly to the Initiative (ID, KY, MT) and 2 due to additional state appropriations (CO, SD);
  - In the remaining 5 eligible states, the number of individuals on waiting lists has been reduced, with 758 eligible individuals remaining to be served.
  - Four states instituted waiting lists after June 2004 and therefore are not eligible for the Initiative (AR, HI, NE, WY). Collectively, they had 55 individuals on their waiting lists as of November 2004, bringing the total number of individuals on waiting lists in that month up to 813 (758 eligible for the Initiative, 55 not eligible).

Please see accompanying Table and Figures 1-4

Conclusion
People with HIV/AIDS continue to be placed on ADAP waiting lists despite their need for medications and otherwise meeting ADAP eligibility criteria. There is significant variation in the number of people with HIV/AIDS on ADAP waiting lists within and across states over time, making it difficult for states to predict and manage need. The $20 Million ADAP Initiative has reduced the size of the waiting lists in eligible states in FY 2004. Waiting lists in non-eligible states will not be addressed by the Initiative. It is uncertain whether this approach will continue in FY 2005 and beyond; as currently configured, the Initiative addresses the waiting list problem in a subset of states at a fixed point in time in the current fiscal year. The challenge posed by ADAP waiting lists, and variability in access to ADAPs more generally, will be a key issue in the Reauthorization of the Ryan White CARE Act in FY 2005.

References
1 The term “state” used in this fact sheet includes states, territories and associated jurisdictions.
3 NASTAD, Fact Sheet: President Bush’s $20 Million ADAP Initiative, December 2004.
7 Of those eligible at time of implementation in November 2004.

Additional copies of this publication (#7230) are available on the Kaiser Family Foundation's website at www.kff.org.

The Kaiser Family Foundation is a non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.
Figure 1: Number of States with ADAP Waiting Lists by Survey Period, July 2002-November 2004

Figure 2: Number of People with HIV/AIDS on ADAP Waiting Lists by Survey Period, July 2002-November 2004

Figure 3: Number of People with HIV/AIDS on ADAP Waiting Lists by State & Survey Period, July 2002-November 2004

Figure 4: Implementation of the Administration's $20 Million ADAP Initiative: Enrollment Status as of November 2004

|----------------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|
Additional copies of this publication (#7230) are available on the Kaiser Family Foundation's website at www.kff.org.