until it's over
AIDS ACTION

**"Streamlining and Modernizing
the AIDS Drug Assistance Program (ADAP) of the Ryan White CARE Act"**

Recommendations at a Glance:

1. Structure of the Program

Recommendation #1:
The AIDS Drug Assistance Program must continue to be funded in the Ryan White CARE Act and run by the states, but should be removed from Title II and placed into a separate title—Title V— to allow greater Congressional oversight and supervision of the program.

2. Managed Growth

Recommendation #2:
AIDS Action recommends the implementation of a treatment focused program of managed growth for ADAP consisting of the creation of regional and state consistency and portability, and the adoption of a consistent drug formulary. State ADAPs must receive enough federal funding to create flexible programs that meet minimum reporting goals and levels of success. This proposal requires federal assistance to manage growth, beginning with $1.5 billion in FY 2006 and increasing the base by $100 million each year to $2.0 billion in 2011, the fiscal year after the next reauthorization. This program of streamlining and managing growth will ensure that jurisdictional and state funding that is potentially being allocated to purchase medications will remain within the jurisdiction to fund needed improvements or maintenance of the local public health infrastructure responding to HIV. AIDS Action further recommends that this proposal be implemented only upon assurance that sufficient funds are appropriated; these funds are necessary to ensure that the proposal can be carried out without additional mandatory costs to the states.

3. Enhancing Access to Medications and Creating Portability

Standards of Care

Recommendation #3a:
Revise the U.S. Department of Health and Human Services' Public Health Service HIV/AIDS Clinical Practice Guidelines for the Use of AIDS Drugs to ensure that all HIV care is consistent with the treatment guidelines. AIDS Action recommends that the Department of Health and Human Services establish a "PHS Guidelines Panel to Integrate Guidelines w/ADAP,"

composed of doctors, nurses, and pharmacists, as well as HIV positive patients. Such a panel will help ensure that there is scientific and clinical expertise to review the PHS and ADAPs on an ongoing basis. Such a panel will also help to answer questions arising at the state level about best practices in treatment. Panel members will monitor and ensure 100% compliance with PHS Guidelines. Additionally, it is recommended that a Clinical Advisory Panel be established to allow professional clinical review of the guidelines by doctors, nurses, and public health professionals.

Recommendation #3b:
Ensure consistency between formulary guidelines and Medicaid guidelines. Depending on the state, medications available through ADAP may vary greatly from medications available through the Medicaid program. AIDS Action recommends that the Center for Medicare and Medicaid Services (CMS), the Health Resources Services Administration (HRSA), and relevant individuals, agencies, and organizations (with HIV expertise) create an ongoing structure to ensure coordination and consistency.

Recommendation #3c:
Require the Secretary of Health and Human Services to report to Congress about the implementation of this initiative to integrate state and national standards of care and on consistency of Medicaid and ADAP formulary guidelines by 2008.

Portability

Recommendation #3d:
ADAP should enhance portability among state programs. Creating portability among the states will, of necessity, begin to end regional differences in care, ensure consistency and high quality of treatment of HIV, and allow people living with HIV the freedom to move to maintain work, to be closer to families, or to be closer to care and treatment. Program specifics:

- *When an ADAP client moves to another state, the client should become eligible for services through the new state ADAP within 30 days of arrival to the new home state.*
- *The new enrollee should be transferred from the old home state to the new home state after 30 consecutive days enrolled in the new state's program.*
- *To facilitate record keeping, compliance, monitoring, program participation, and reimbursements, each ADAP participant should be issued an "ADAP participant card" which can be "bar-coded" for monitoring purposes. The goal of the portability program is to ensure the ongoing and consistent treatment of HIV without interruptions.*
- *Such tracking will improve accountability and enhance the reporting of health outcomes, including medical/clinical indicators such as viral load, tolerability, patient visits and more.*

4. Ensuring Consistency in Formularies and Eligibility

Eligibility

Recommendation #4a:
Given that 38 states and territories already match or exceed eligibility standards set at 300% of the federal poverty level, AIDS Action recommends setting a minimum eligibility requirement of 350% for all states and territories—states and territories should be encouraged to exceed this standard. Such a requirement is reachable by all states and territories and will help to ensure that regional and state variability is diminished while also removing one of the main obstacles to portability.

Formularies

Recommendation #4b:
To ensure state consistency and enhance portability, ADAP must establish a baseline HIV/AIDS drug formulary which will allow individuals to move between states. The best option therefore is an open formulary, since it will include all of the medications required to treat HIV infection. Such a formulary must include all FDA-approved anti-retroviral therapeutics, all FDA-approved prophylaxes and therapeutics for opportunistic infections, all medications to treat side effects and major psychiatric disorders associated with HIV. Such a baseline formulary has the advantage of correlating state programs and aiding portability. Furthermore, it will allow individuals living with HIV more treatment options and efficacy.

Recommendation #4c:
AIDS Action recommends that states and territories discontinue burdensome rebate programs. Given the relative expense of HIV drugs and the large number of individuals served under the state ADAPs, AIDS Action recommends that the CARE Act ensure that state ADAPs are able to purchase drugs at the lowest possible federal price. If necessary, AIDS Action recommends that purchase should be negotiated through a single federal agency (most likely the Public Health Service) at the Federal Ceiling Price (FCP).

5. Ensuring the Continuing Strength of State and Territorial Managed ADAP Programs

Recommendation #5a:
States must be encouraged to exceed the minimum eligibility and formulary standards set out in the CARE Act. For the proposed ADAP streamlining and modernization program to succeed, states currently contributing to ADAPs must continue to contribute, and other states are encouraged to contribute. AIDS Action recommends creating incentives for state contributions. Part of the proposed new funding should be set aside as a match in some form for states that contribute to ADAP. In order to be of greatest use, the state match should be flexible, allowing states to move the match to ADAP-related services, but it should not require states to place the funds directly into ADAP. State contributions and matches may be used flexibly for publicly funded HIV health care programs—e.g. funds might be used to improve access to public health system programs responding to HIV.

Recommendation #5b:
AIDS Action feels strongly that states must be required to ensure or have open enrollment and to eliminate waiting lists, lotteries, and other limits on ADAP eligibility. States must allow individuals who are eligible for ADAP Services to receive these services.

State Flexibility and Reporting

Recommendation #5c:
States that have the legal ability to purchase insurance policies with ADAP funds are encouraged to do so, provided they meet the eligibility criteria created by the CARE Act. States with laws prohibiting purchase of insurance policies with state or federal funds are encouraged to consider creating an exception for ADAP.

Recommendation #5d:
States may use a percentage of ADAP funds to create flexible ways to expand treatment and medical support services to ensure adherence and full program participation. States must be allowed to use ADAP funds flexibly to permit not only the provision of medications but also the provision of a mixture of treatment and care, laboratory work, insurance payments, follow-up care, monitoring, and counseling.

Recommendation #5e:
A small part of the increase should be set aside to provide technical assistance to states to ensure that they meet eligibility and formulary requirements.

Recommendation #5f:
States shall be required to submit a statewide plan for the coordination of medical, medical support, and therapeutic services with ADAP.

Recommendation #5g:
The Secretary of Health and Human Services shall issue guidelines providing his/her recommendations for ADAP therapeutics which should be included in the formularies that are maintained by the states for purposes of this section.

Recommendation #5h:
The Secretary of Health and Human Services shall submit to the Congress a report each fiscal year that specifies the amount the Secretary expects to obligate during such year for the purpose of sponsoring conferences or seminars regarding matters within the jurisdiction of the Public Health Service, and the amount that the Secretary obligated for such purpose during the preceding fiscal year.

The report shall include for each state:
1. The number of patients who have requested therapeutics described in sub-section (a) from the program as carried out in the state, but are on a waiting list because such program does not have the capacity to serve the patients.

2. The sources from which the patients are obtaining the therapeutics, if the patients on the waiting list are receiving such therapeutics.
3. The estimated cost to provide the amount of therapeutics that would be necessary to serve all patients on the waiting list and thereby eliminate the wait in the state.
4. Information regarding the actions being taken by states with such waiting lists to reduce the number of patients on the lists, including any restrictions imposed by such states on the number or quantity of therapeutics made available under the program.
5. Each source of funds that, in addition to funds under this part, is used by the State to provide therapeutics under the program.
6. A listing of each State whose formulary does not meet the recommendations of the Secretary.
7. A listing of any other cost cutting or cost containment measures in place with regards to ADAP.

Recommendation #5i:
States must collect aggregate data on health status of state ADAP clients. Data reports should be collected by HRSA every 6 months. HRSA shall report these data to Congress on an annual basis. Outcome data gathered must show Congress how states are doing with their ADAPs. At a minimum, such data should include CD4 counts, viral load and the results of resistance testing, and analysis that can be compared between states about the effect of ADAP on these statistics. States should also report information about Hepatitis C, Tuberculosis, and other co-infections.