NATIONAL POLICY AGENDA

2002 - 2004

1. Support and Improvement of the Ryan White CARE Act

The Ryan White Comprehensive AIDS Relief Emergency (CARE) Act is the largest source of federal funding solely focused on domestic HIV care, treatment, and medical support services. Adopted by Congress in 1990, it is reauthorized every five years and funded through annual appropriations; the current authorization is scheduled to expire on September 30, 2005 and must be reauthorized by Congress. The CARE Act was created as a safety net that has now become the foundation of service delivery for HIV care.

Since its first authorization and the rapid development of its programs, there have been concerns regarding gaps in service delivery, inconsistent funding, and unmet needs. Both legislators and community advocates have expressed interest in amending the CARE Act to address these concerns. However, significant changes could dismantle the health care system created for people with HIV, putting them at risk for possible life-threatening health conditions. AIDS Action will work with its members, Congress, the Administration, and coalition partners to support the reauthorization, expansion, and full funding of the Ryan White CARE Act.

2. Access to Care

Access to early medical care and treatment remains elusive for many people in the United States including those who are of low income and uninsured. Current treatments are expensive, effective only for some, and associated with debilitating side effects. According to the Department of Health and Human Services, one half to two thirds of people living with HIV are not currently in care. Barriers in accessing quality care result in disparities in health outcomes, which are most often, experienced by people with low income, women, minority populations, and Lesbian, Gay, Bisexual, Transgender (LGBT) populations.

The quality of HIV clinical management has a direct effect on the outcome of the epidemic. Standards must therefore be implemented in HIV care to ensure that people living with HIV get the highest quality of care, thus enjoy the best health outcomes possible. As HIV disease progresses, treating it becomes more complex. Over time, HIV can be compounded by life-threatening infections and severe conditions caused by antiretroviral use that must be accurately diagnosed and quickly treated. Thus, it is essential for all people living with HIV to have access to qualified and experienced HIV health care providers, who can successfully address the complex needs of their HIV positive patients. AIDS Action will work with its members, Congress, the Administration, and coalition partners to support access to quality care for all people living with HIV.

3. Access to HIV related medications and treatment options

Current treatment for HIV infection is based on the utilization of antiretroviral therapies and other medications to treat opportunistic infections. Access to these medications must be assured for all people to improve overall health outcomes and quality of life. While certain private insurance programs cover HIV related medications, severe limitations exist in accessing life-prolonging medications. To establish an emergency safety net providing access to medications, the federal government created the AIDS Drug Assistance Program (ADAP) under the Ryan White CARE Act and, under Medicaid, allows states to provide optional prescription drug benefits. Currently, ADAP is facing a budget crisis; Medicaid requires an AIDS defining diagnosis before access; and Medicare's outpatient medication benefit will not be fully implemented until 2006. AIDS Action will work with its members, Congress, the Administration, coalition partners, and the private sector to support access to life saving medication for all people living with HIV.

4. Improved Surveillance Systems through Reporting and Notification

People are living longer without developing a clinical AIDS diagnosis; therefore, an epidemiological surveillance based on AIDS cases alone no longer provides an accurate reflection of the epidemic.

The Ryan White CARE Act Reauthorization of 2000 directed the U.S. Department of Health and Human Services to examine whether HIV reporting and surveillance could be used to restructure its funding formulas by 2007. HIV surveillance data must be standardized across the nation, while individual states

may implement HIV surveillance systems that report names or other unique identifiers. The U.S. will never have a true picture of the epidemic without accurate and uniform HIV surveillance from every state in the country. Further, reliable data on HIV infection would permit rapid response and long-term planning by local, state, and federal bodies to impact HIV prevention and care efforts. AIDS Action will work with its members, Congress, the Administration, and coalition partners to support the development of an HIV surveillance system that accurately reflects the U.S. epidemic.

5. HIV and the Faith Community

The American faith community is a trusted and established institution that has been providing information, support, and services to its constituencies since the beginning of the HIV epidemic. The diversity of religions, beliefs, and practices that make up the faith community offers a wide and far reaching network to distribute prevention messages and offer care and support services to communities that may be in need of these resources. When offering HIV prevention, care, and support services, faith-based organizations that utilize scientifically evaluated programs and non-discriminatory models will be well equipped to meet the needs of their communities. As the federal government continues to implement its faith-based initiative, new monies must be provided in order to support the initiative's additional programs and services. AIDS Action will work with its members, coalition partners, and the Administration to encourage the participation of communities of faith in HIV prevention, care and support services.

6. Improved Testing and Counseling

Everyone should be aware of their HIV serostatus in order to make decisions about health care and their behaviors that could decrease the number of new infections. Yet according to the Centers for Disease Control and Prevention, between 250,000 and 350,000 people in the United States are HIV positive and do not know it.

There are multiple and complex reasons why people do not learn their HIV status. Many people are unaware of their risk and see no need for testing. Testing programs may have locations, hours, or costs that make them inconvenient or inaccessible. Further, not all health care providers are equipped or prepared to offer counseling and testing services. Fear and concerns about privacy, stigma, and discrimination are still significant obstacles to testing. Additionally, the waiting period between the time of testing and receiving the results discourages many people from returning.

Advances in testing, including the approval of a rapid HIV test by the Food and Drug Administration, provide an opportunity to receive fast, accurate results and expand both testing availability and use in non-clinical settings. HIV testing and counseling should be bundled with testing for other sexually transmitted diseases. AIDS Action will work with its members, coalition partners, and the Administration to support improved voluntary testing and counseling programs that encourage all individuals to know their HIV status.

7. Effective Prevention Messages

There is no cure for HIV infection, yet it is 100 percent preventable. Adhering to effective prevention strategies is the only way to avoid HIV infection. Factual, culturally relevant, and comprehensive health information is essential to the development of effective HIV prevention strategies. HIV prevention messages are most useful when integrated into broader health promotion efforts such as those found in educational institutions, correctional facilities, or as a part of substance abuse and mental health treatment. The U.S. government does not mandate a systematic, population-wide education program to teach children and adults about HIV transmission and how to avoid risks for infection. This lack of information has had serious consequences, even for our youngest citizens. At least 50 percent of new infections in the U.S. occur among young people under the age of 25. AIDS Action will work with its members, Congress, the Administration, and coalition partners to advocate for factual, comprehensive, culturally relevant, and scientifically evaluated prevention models to be developed and implemented across the United States.

8. Research Needs of People Living with HIV

As we understand more about the human immunodeficiency virus (HIV), the evolution of infection, and how clinical management affects patients, new issues arise around treatment interventions and quality of life. It is therefore important for scientists and researchers to examine the new questions and challenges that surface for people living with HIV. Research initiatives must explore the following subjects: side effects and chronic conditions caused by long-term use of antiretrovirals, drug resistance and viral mutations, adherence and treatment interruption, primary infection and transmission risk, and body mass and physiologyical changes. AIDS Action will work with its members, Congress, the Administration, coalition partners, and the private sector, to support the expansion of research efforts dedicated to examining these and other long-term health issues and the related needs of people living with HIV.