



Principles for Reauthorization of the Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was originally signed into law on August 18, 1990 as a federal program designed to improve the quality and availability of care for persons with HIV/AIDS and their families. The Act was subsequently amended and reauthorized in 1996 and again in 2000. The current act is scheduled to expire and requires reauthorization at the end of September 2005. The CARE Act reaches over 500,000 individuals each year, making it the federal government's largest program specifically for people living with HIV disease.

Like many health problems, HIV disease disproportionately strikes people in poverty, racial/ethnic populations, and others who are underserved by healthcare and prevention systems. CARE Act funded programs are the "payer of last resort." They fill gaps in care not covered by other resources. Most likely users of CARE Act services include low income, uninsured or underinsured individuals who have no other source of healthcare. In order to fill these gaps in care while maximizing limited available CARE Act resources, states are entrusted with ensuring collaboration among other CARE Act grantees and programs within the state to reduce duplication of services. States are the only CARE Act grantees that have this legal responsibility within the United States public health system to ensure the delivery of effective public health programs in their respective jurisdictions. The role of states, therefore, is unique among CARE Act grantees and must be affirmed in CARE Act legislation to reflect this responsibility.

Scheduled reauthorization of the CARE Act presents NASTAD and its member states and jurisdictions a timely opportunity to re-evaluate the extent to which the goals and objectives of the CARE Act continue to be met. The goal in 2005, as it was in 1990, is to assure all persons living with HIV/AIDS equitable access to state-of-the-art care and treatment by eliminating barriers to care imposed by income, age, race, ethnicity, place of residence, or gender and sexual orientation. The epidemic today can be characterized somewhat differently than the epidemic 20 years ago. Today's infected population is more likely to include persons of color, women, and youth. The CDC estimates that over 40,000 new HIV infections occur each year; of these new infections, over half are among persons from communities of color, about 70% are among men and 30% are among women. Between 1985 and 2001, the proportion of adult/adolescents AIDS cases reported in the U.S. among women increased from 7% to 25.8%. Furthermore, in August of 2004, there were over 1,500 persons on waiting lists for the AIDS Drug Assistance Program (ADAP), a figure which will likely continue to increase as funding levels fall behind demand and need for the program. There should be no wait for medical care or medications for those in need. Access to medications, as well as to other essential health care and supportive services, varies from one state to another throughout the nation.

Ongoing principles for CARE Act programs include:

- Assuring that all persons with HIV/AIDS have access to appropriate and high-quality health, medical care, and other related and required support services.
- Coordinating CARE Act services with other health care delivery systems, thus ensuring that available resources are expended in a manner such that efficiency, effectiveness, and accountability are optimized, both within the CARE Act and across other delivery systems.
- Revising care systems as needed to meet emerging needs.
- Evaluating the impact of CARE Act funds and making improvements as needed.

These principles must guide current reevaluation in light of the changes noted. Evaluation is particularly pertinent in the face of fiscal tensions in states throughout the nation that relate to medical assistance programs and the ability of the states to provide care and services for populations at risk. For those who have no other source of or access to health care, the role and responsibility of CARE Act programs is paramount.

NASTAD proposes that the CARE Act be evaluated in a manner that seeks to achieve the following goals and objectives through subsequent proposals for change:

- ✓ Assure equitable access to state of the art care and treatment for all persons with HIV/AIDS.
- ✓ Assure that all individuals, regardless of income, racial or ethnic group, age, gender and sexual orientation, or place of residence have equitable access to care.
- ✓ Ensure that the role of the states is emphasized and is meaningful and enforceable. As the only CARE Act grantees that have legal authority within the United States public health system to ensure the delivery of effective and coordinated public health programs in their respective jurisdictions, the role of states is important and unique to other grantees.
- ✓ Ensure coordination of all publicly financed health and medical care programs, including CARE Act programs, Medicare and Medicaid, Veterans Administration programs, State Children's Health Insurance Programs (SCHIP), state Pharmacy Assistance Programs, as well as other federal, state and local programs.
- ✓ Maximize simplicity, minimize administrative requirements, and maintain maximum state flexibility in terms of program design and implementation.
- ✓ Ensure there is little to no disruption in service delivery or major changes to infrastructure that impact service delivery.
- ✓ Emphasize the federal government's role and responsibility in assuring equitable access to care while incorporating, where possible, mechanisms to maximize utilization of state resources.

These goals and ongoing principles will provide the guidance and direction for all reauthorization analyses and NASTAD's subsequent program recommendations.