



The National Organizations Responding to AIDS Principles for the Reauthorization of the Ryan White CARE Act - 2005

As the National Organizations Responding to AIDS (NORA) coalition has noted in our *Fiscal Year 2005 HIV/AIDS Appropriations Recommendations*, the Ryan White CARE Act is the largest discretionary investment solely devoted to the care of people living with HIV/AIDS in the U.S. The CARE Act serves as a payer of last resort by funding primary medical care and support services for people with HIV/AIDS who lack insurance and/or other financial resources and would otherwise be unable to access medical care. Each year, CARE Act programs reach more than 533,000 individuals living with or at risk for HIV in all 50 states the District of Columbia, Puerto Rico, and the U.S. territories. The CARE Act is scheduled for reauthorization by Congress by September, 2005.

Ryan White CARE Act services have significant impact on health outcomes. A study by HRSA-funded researchers at Columbia University examining the impact of CARE Act funded services in New York City found that among people with HIV/AIDS:

- Those receiving primary medical from a CARE Act-funded provider were *60-70 percent more likely to report appropriate medical care and 40-50 percent more likely to report being on key anti-HIV medications* than those who received their primary medical care from a non-CARE-Act-funded provider.
- Those receiving case management and/or client advocacy from a CARE Act-funded provider were *80-90 percent more likely to report appropriate medical care and 70 percent more likely to be on anti-retroviral therapy* than those who received case management and/or client advocacy from a non-CARE-Act-funded provider; and
- Those who received *primary medical care from a non-CARE-Act-funded provider were half as likely* as clients of CARE Act providers to report care that met minimum HIV practice guidelines.

The importance of the care, treatment, and medical support services, including substance abuse, mental health and nutrition services, provided through Ryan White CARE Act to people living with HIV who would otherwise not have access to care is almost impossible to overstate. Consequently NORA has developed the following principles regarding reauthorization:

- **The Ryan White CARE Act must be reauthorized.** As NORA stated in our *Fiscal Year 2005 HIV/AIDS Appropriations Recommendations*, the United States must continue to build on successes in HIV/AIDS. The nation's investment in HIV/AIDS prevention, research, and care has reaped huge dividends. Thousands of people are living longer, healthier lives because the Ryan White CARE Act, and other federally funded programs, have prevented new infections and led to the development and delivery of effective medical treatments and support services.

- **The Ryan White CARE Act must be fully funded.** An estimated one million people are living with HIV in the U.S.; at the end of 2003 over 405,926 of those people were living with AIDS. Additionally, HIV is increasingly and disproportionately affecting members of a racial or ethnic minority, women, and the poor. As NORA stated in our FY 2005 *Recommendations*, \$3.1 billion is needed to fully address the existing unmet need for HIV care. With nearly one million people living with HIV in the U.S., and 500,000 of those not in HIV care, the CARE Act must be fully funded to keep pace with this emerging need. With increasing ranks of the uninsured, rapidly shrinking state healthcare budgets, and restrictions and cutbacks in state Medicaid programs, CARE Act programs are experiencing an increase in the number of people seeking services. Without additional resources these programs are increasingly unable to maintain the existing systems of care established by the CARE Act.
- **The Ryan White CARE Act must build upon the successful palliative care model and move to a focus on lifetime and life-enhancing medical care.** As the recent Institute of Medicine (IOM) report, “Public Financing and Delivery of HIV/AIDS Care; Securing the Legacy of Ryan White” notes, “the course of the [HIV] illness has changed. Individuals with HIV, are living longer and require care that is more suited to that for a chronic illness rather than an acute terminal illness.” According to the IOM, in 1996 Highly Active Anti-Retroviral Therapy (HAART) became (and remains) the standard of care for HIV. To receive the optimal benefits of HAART individuals must achieve adherence rates of 90 percent or higher. In addition, the IOM states, “HIV is a complex, multi-system illness that is heavily influenced by other aspects of the individual; ” thus, in addition to medical treatment supportive services such as substance abuse, mental health and nutrition services are increasingly needed as patients live longer and require chronic care. The NORA coalition notes that with treatment now possible, it is now time to achieve a more enduring model of HIV care and services.
- **The Ryan White CARE Act must ensure that the currently working HIV health and care systems remain stable.** It has been estimated that approximately 40,000 individuals are newly infected with HIV each year and that between 15,000 and 16,000 people die from AIDS each year. Consequently, the total number of individuals infected with HIV is rapidly growing by about 25,000 people per year. In addition, as noted above, the development of HAART is enabling people to better manage the disease, living longer and healthier lives. However once HIV positive people begin HAART they must stay on the medication to ensure that they do not develop resistance to the drugs. In order to do so, individuals living with HIV must have access to appropriate medical care and support services and eventually to medications prescribed through HAART; these systems of care are supported by the CARE Act. Despite the increase of the numbers of people infected and consequently the number of people who need access to treatment and care, the Ryan White CARE Act has been level funded since 2000 (and with the across the board funding rescissions imposed by Congress the CARE Act has actually received less funding than in prior years). One consequence of the scarcity of new resources is that ultimately it will lead to the erosion of the healthcare systems of states and localities which are already committed to providing care. NORA supports ensuring the stability of mature HIV care systems through the CARE Act.

- **The Ryan White CARE Act must begin to address disparities in the system by providing more funding to geographic regions and populations with growing HIV incidence.** According to the IOM report, “Public Financing and Delivery of HIV/AIDS Care; Securing the Legacy of Ryan White,” systems of HIV care suffer from disparities in access to services across geographic borders and between different populations. As the payer of last resort, the CARE Act is designed to fill gaps left by Medicaid, Medicare and other insurance programs. The IOM found that access to Highly Active Anti-Retroviral Therapy (HAART) and primary care varies significantly by geographic location and population, in part due to varying income eligibility requirements for the AIDS Drug Assistance Program (ADAP) under Title II of the CARE Act and in part due to the varying resource allocation decisions made by locality. In an era of level or receding funding, regional funding issues have grown acute; this continues to be an issue throughout the United States. As previously noted, where there is currently existing need, systems must be maintained, in addition where there is new need, disparities must be addressed as new systems are developed.
- **The Ryan White CARE Act must continue to fund supportive services to ensure that people living with HIV are connecting to regular and on-going HIV related medical care.** As noted in the introduction, the CARE Act is particularly successful in ensuring that individuals receive access to care. The well being of CARE Act clients is directly related to their ability not only to access the primary medical care for HIV but also to their ability to ensure their adherence to their medical protocol, which includes ensuring medical support services such as substance abuse, mental health and nutrition services on a daily basis. The CARE Act currently provides patients with access to case management, early intervention, outreach, counseling and testing, referral services, transportation, risk reduction counseling on prevention, antibody testing, nutritional services, protection against opportunistic infections, oral health, psychosocial services, alcohol and substance abuse services, and other care services. Each of these services and others that may not be mentioned are necessary to continue the CARE Act’s record of success

The National Organizations Responding to AIDS coalition is comprised of over 175 health, labor, religious, professional and advocacy groups representing a broad consensus on HIV- and AIDS-related policy, legislation and funding.