strengthening the circle of care

The Case for Ryan White CARE Act Reauthorization, 2005
**About CAEAR Coalition**

Communities Advocating Emergency AIDS Relief (CAEAR) Coalition represents more than 400 grantees under Title I and Title III of the Ryan White CARE Act, including the 51 major metropolitan areas most adversely affected by the HIV/AIDS epidemic, as well as providers and consumers of CARE Act services. CAEAR Coalition also advocates for adequate funding for the AIDS Drug Assistance Program (ADAP) in Title II of the CARE Act. As a leading voice in Washington, DC, for HIV/AIDS care and treatment, CAEAR Coalition takes a leading role in the annual federal appropriation advocacy effort for CARE Act Title I and Title III.

CAEAR Coalition was formed in the early 1990’s by representatives of the initial sixteen CARE Act Title I cities, including Atlanta, Boston, Chicago, Los Angeles, New York, San Francisco, and Washington. In 1997, CAEAR Coalition and the National Title III Coalition joined forces to provide coordinated national advocacy for Title I and Title III resources. CAEAR Coalition incorporated in 1999 and is tax-exempt under section 501(c)(4) of the Internal Revenue Service code.

**About AIDS Action**

AIDS Action is a national organization that advocates on behalf of people living with HIV and AIDS and those who serve them. AIDS Action is dedicated to the development, analysis, cultivation, and encouragement of sound policies and programs in response to the HIV epidemic. AIDS Action seeks to organize the HIV service community, engage the U.S. government in the ever increasing challenges of the HIV epidemic, rethink the policies and social dynamics that drive the HIV epidemic and educate all those who seek to respond to it.

AIDS Action has been instrumental in the development and implementation of major public health policies to improve the quality of life for more than one million Americans who are HIV positive. AIDS Action collaborates with the greater public health community to enhance HIV prevention programs and care and treatment services; and to secure comprehensive resources to address community needs until the epidemic is over.
Continuing Crisis Demands that Reauthorization Be a Top Priority

“Neither individuals, nor society, nor government can afford to be complacent, and we will not relent against the battle of AIDS here in America.”
— President George W. Bush, 2004

The Ryan White Comprehensive AIDS Resources Emergency Act (CARE) is the heart of the nation’s response to the domestic HIV/AIDS epidemic. Each year, Ryan White CARE Act-funded programs serve over 500,000 people in all 50 states, the District of Columbia, Puerto Rico, and the U.S. territories, providing lifesaving anti-HIV medications and the medical care and support services people living with HIV/AIDS need to access and benefit from these powerful drugs.¹

Congress first passed the Ryan White CARE Act in 1990 to respond to the growing crises in communities hit hardest by the epidemic. President George W. Bush called for reauthorization of the Ryan White CARE Act in his 2005 State of the Union address and previously called it “our nation’s most important AIDS legislation, [and it] has done a lot of good, a lot of good over the years.”² The program continues to address the HIV/AIDS state of emergency in urban and rural communities alike, providing a much-needed safety net for uninsured and underinsured people living with HIV/AIDS.

The power of the Ryan White CARE Act to reach those most in need was echoed by the U.S. Government Accountability Office, which found that “CARE Act funds appear to be reaching groups of infected individuals that have generally been found to be underserved, including the uninsured and the poor.”³

“[The Ryan White CARE Reauthorization Act] is also about caring and the American tradition of reaching out to people who are suffering and in need of help. Ryan White would be proud of what is happening in his name. His example, and the tireless commitment of so many others, are bringing help and hope to our American family living with AIDS.”
— Senator Edward Kennedy (D-MA), 1996

The Case for Ryan White CARE Act Reauthorization
The Ryan White CARE Act’s authorization expires on September 30, 2005. With nearly one million Americans living with HIV, including over 405,000 living with AIDS—more than at any other time in the epidemic—and hundreds of thousands still not receiving HIV-related health care and medications, reauthorization of the Ryan White CARE Act must be a top priority for the nation’s leaders.4,5,6

CAEAR Coalition and AIDS Action stand ready to work with Congress, President Bush and the Administration, and our community partners to reauthorize the Ryan White CARE Act with enhancements that will strengthen the program’s ability to serve people living with HIV/AIDS in need.

Following are:

• An overview of the U.S. HIV/AIDS epidemic and
• An explanation of the crucial role that Ryan White CARE Act services play in helping people living with HIV/AIDS access HIV care and treatment and related support services.

The HIV/AIDS Epidemic in the United States

Well into its third decade, the AIDS epidemic in the United States continues to exploit economic and health care disparities, entrenched stigma, and the nation’s inadequate commitment to HIV prevention. According to the Institute of Medicine, “HIV has continued its march into the most vulnerable populations in society: the uninsured, racial/ethnic minorities, those with substance use disorders and mental illness, homeless persons, and unsupervised youth.”

The Centers for Disease Control and Prevention (CDC) estimates that there were 850,000 to 950,000 Americans living with HIV in 2000 and that number has likely risen. In 2003, more than 405,000 people were living with AIDS, the most advanced form of HIV disease. There are now more people living with AIDS in the U.S. than at any other time in the epidemic. The CDC predicts that more than 40,000 individuals in the U.S. are newly infected each year with HIV, the virus that causes AIDS.

While significant advances in HIV treatment have substantially reduced AIDS-related illnesses and deaths, an estimated 42 to 59 percent of all people living with HIV/AIDS in the U.S. do not receive regular HIV care.
Although people of color represent only 33 percent of the U.S. population, they represent 64 percent of people living with AIDS and 71 percent of new AIDS cases in 2003. Women of color accounted for 84 percent of new AIDS cases among women in 2003. The AIDS case rate for African American men in 2003 (103.8 cases per 100,000) was the highest of any subgroup and was eight times the rate for white men (12.8) while the rate for Latino men (40.3) was more than three times the rate for white men. The AIDS case rate for African American women (50.2) was 25 times higher than the rate for white women (2.0) and the rate for Latino women (12.4) was more than six times the rate for white women.

In 2003, almost twice as many African Americans with AIDS died compared with whites, a gap that has been increasing since 1996. Researchers say the reasons include late diagnoses and inferior care, along with complications because African Americans are more likely than whites to suffer from other illnesses. Several studies have found that African Americans are less likely to receive antiretroviral medications, including one that found that African Americans and Hispanics were 24 percent less likely to receive key anti-HIV medications than whites at their initial assessment. The study also found that African Americans waited 13.5 months to receive these medications, as opposed to 10.6 months for whites.
Nearly Half a Million People with HIV in the U.S. Receive No HIV Care

The CDC estimates that 250,000 to 300,000 individuals diagnosed with HIV infection still receive no HIV-related medical treatment. Another 180,000–240,000 do not even know they are infected, meaning that there are at least 430,000 people living with HIV in the U.S. who are not receiving HIV-related medical care.21

According to CDC Director Dr. Julie Gerberding, CDC’s Advancing HIV Prevention (AHP) initiative aims “to open up the door to [HIV] testing so that people can learn their status and get the appropriate treatment and prevention services that they deserve and need.”22 Many, if not most, of the estimated 200,000 people living with HIV in the U.S. whose HIV status is diagnosed through the CDC AHP initiative will turn to health care providers funded through the Ryan White CARE Act for their HIV-related care.

High Rates of Comorbid Infections

Many people living with HIV/AIDS also suffer from other very serious, often life-threatening conditions. The most common medical comorbidities associated with HIV are sexually transmitted diseases, hepatitis C virus (HCV) and tuberculosis (TB). Additionally, HIV disease is frequently co-occurring with alcohol and other drug use and mental illness. About 25 percent of all people living with HIV are estimated also to be infected with HCV and the rate of HIV and HCV coinfections among injection drug users is estimated to range from 50-90 percent. Coinfection with HIV is associated with swifter progression of HCV-related liver disease and cirrhosis, which may lead to limited tolerance for anti-HIV medications. If infected with TB, people living with HIV are 100 times more likely to progress to active TB than those not infected with HIV.23

“The area my clinic’s in is essentially a suburb of the third world. It’s a shame no one seems to know that the problem in Africa looks like the problem in inner-city Houston, Chicago and New York.”

Dr. Joseph C. Gathe Jr., Clinical instructor, Baylor College of Medicine; Medical Director, Donald R. Watkins Memorial Foundation, Houston

“I have to travel 250 miles just to see a doctor. It’s a long trip for me. We don’t have doctors around here. It is pretty hard without doctors.”

Laura, woman living with HIV/AIDS, Piney Woods, TX

The Case for Ryan White CARE Act Reauthorization
Ryan White CARE Act Services Integral to Delivering Comprehensive HIV/AIDS Care in the U.S.

"It is now clear that management of this very complex disease is much more difficult than just taking pills, particularly for my African-American patients who often have very difficult life challenges. So now when I go to these international AIDS meetings and hear that the problem is solved here, I get incredibly angry. This epidemic is out of control in the black community. There is no magic bullet."

— Dr. Valerie E. Stone, a physician at Massachusetts General Hospital who has treated HIV/AIDS patients for the past two decades, Boston

**Lifesaving Drugs Also Present Tremendous Challenges**

The advent of Highly Active Antiretroviral Therapy (HAART) to treat HIV has dramatically altered the HIV/AIDS landscape by significantly decreasing HIV-related illnesses and deaths in some populations—between 1995 and 2002, the age-adjusted HIV death rate declined by 70 percent, though those rates now appear to be stabilizing.24

In an effort to standardize the use of these powerful drugs, the U.S. Department of Health and Human Services convenes an ongoing panel of experts that originally developed and regularly updates national HIV treatment guidelines. These guidelines call for early access to medical care and treatment, including HAART. Sadly, approximately 40 percent of HIV-infected people in the U.S. begin antiretroviral treatment later than recommended by the guidelines.25

For those who initiate treatment, the central challenge of HAART is adherence to treatment regimens. For many, the drugs cause serious side effects and adverse reactions, while the lack of basic necessities, such as housing, food, and transportation, and an inadequate support system, provide obstacles to beginning or adhering to HAART treatment regimens.26
Adherence is crucial for the individual and for the larger public health. Fully successful suppression of HIV in an individual’s bloodstream requires high levels of adherence of up to 95 percent, while poor adherence can contribute to development of drug-resistant strains of the virus that can then be transmitted to others. Drug resistance can also lead to individual treatment failure and resistance to an entire class of drugs.27

**CARE Act Titles Work Together to Provide Comprehensive Network of Medical Care and Support Services Necessary for Effective HIV/AIDS Care**

The Ryan White CARE Act’s multi-title structure was designed to provide the comprehensive medical care and enhancing support services necessary for the complex treatment of HIV/AIDS and has adapted well to the integration of HAART into HIV/AIDS care. Care and treatment offered through Ryan White CARE Act-funded providers and the AIDS Drug Assistance Program (ADAP) in Title II help people living with HIV/AIDS determine and access the most appropriate drug regimens. Of course, the administration of drugs does not by itself result in successful treatment and Title I and Title III programs also provide the appropriate level of medical and support services needed to manage these complex drug regimens.

**PEOPLE LIVING WITH HIV/AIDS EXPRESS SATISFACTION WITH RYAN WHITE CARE ACT SERVICES**

Focus groups conducted with 135 people living with HIV/AIDS in ten cities found that over 75 percent felt that the current structure and provisions of the Ryan White CARE Act were working well and they were satisfied with the quality of the Ryan White CARE Act-funded services they received. The majority of those reporting problems cited lack of access to key services, including housing assistance, transportation, mental health services, dental services and lack of sufficient non-HIV specific medications on formulary.


“Sometimes it's hard for me to stay on the medications, because I feel better when I'm off the drugs. I've had stomach pain so bad that I couldn't get out of bed and I could eat only baby food. I know that the drugs are working, and I don't mean to sound ungrateful. But it is a struggle to stay on them because of how it affects your quality of life.”

Success of Drug Therapies Requires Extensive Medical Services

HAART and other components of HIV/AIDS care require continuous monitoring and follow-up by medical professionals. The selection and initiation of an antiretroviral regimen are critical elements of successful treatment of HIV infection. The programs supported by Title I and Title III provide the infrastructure in which people living with HIV/AIDS can take an anti-HIV/AIDS drug regimen under proper ongoing medical supervision, including costly laboratory testing. Without the experience and expertise of these medical professionals, the powerful drugs used to manage HIV/AIDS could easily be misused or insufficiently managed and result in serious consequences such as:

- viral resistance;
- complications, including increased risk of heart disease, high cholesterol, anemia, diabetes, kidney and pancreatic and liver dysfunction; and
- treatment failure.

RYAN WHITE CARE ACT SERVICES HAVE POSITIVE 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 living with HIV/AIDS:

- those receiving primary medical care 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 provider not covered by the CARE Act;
- 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 antiretroviral therapy than those who received case management and/or client advocacy from a provider not funded by the CARE Act; 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 distribution of drugs to patients not under the direct care of a medical professional is ineffective and dangerous. For individuals served by the Ryan White CARE Act, Title I and Title III programs provide access to the medical supervision necessary for successful treatment.

The clinical management of HIV/AIDS, particularly the use of HAART, is the central focus of training by the AIDS Education and Training Centers (AETCs), which train approximately 60,000 physicians, nurses, physician assistants, dentists and pharmacists each year.

### Lack of Appropriate Support Services Can Be a Significant Barrier to Care

Competing needs, such as food, nutrition services, and housing, and barriers to care, such as lack of transportation or childcare, limit access to HIV health care services. One study found that more than one-third of people living with HIV in care postponed or went without care during a six-month period because of these competing needs and barriers. These barriers were also associated with significantly greater odds for never receiving antiretroviral treatment. Others went without food, housing, and clothes in order to pay for their care.28 While the majority of Ryan White CARE Act Title I and Title III funds support HIV treatment, a portion of Title I funds provide key support services, such as food and transportation, as well as case management services to link people living with HIV/AIDS to medical care and support services.

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“*When others hear that people are doing well on their medications they give the medications a second chance.*”

**Support group coordinator, CARE Act-funded agency, Phoenix, AZ**

“*Twenty-five percent of the client population is “transient.” They move around for work, school, life. Adherence work makes it easier for clients to come back to the clinic.*”

**Clinical case manager, CARE Act-funded agency, Anchorage, AK**
**Type of Services Used by CARE Act Clients, 2002**

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case management: HIV-positive clients</td>
<td>332,377</td>
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<tr>
<td>Ambulatory/outpatient care</td>
<td>319,295</td>
</tr>
<tr>
<td>Mental health</td>
<td>81,437</td>
</tr>
<tr>
<td>Oral health</td>
<td>71,504</td>
</tr>
<tr>
<td>Substance abuse: outpatient</td>
<td>36,081</td>
</tr>
<tr>
<td>Case management: HIV-affected clients</td>
<td>23,854</td>
</tr>
<tr>
<td>Home health: paraprofessional care</td>
<td>3,865</td>
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<tr>
<td>Substance abuse: residential</td>
<td>3,292</td>
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<tr>
<td>Home health: professional</td>
<td>2,998</td>
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<tr>
<td>Rehabilitation</td>
<td>1,300</td>
</tr>
<tr>
<td>Home health: specialized care</td>
<td>858</td>
</tr>
</tbody>
</table>

**Gender**

- Female: 31.3%
- Male: 67.6%
- Unknown/Unreported: 0.7%
- Transgender: 0.5%

**Ethnicity**

- Non-Hispanic: 74.7%
- Hispanic: 19.8%
- Unknown/Unreported: 0.5%

**Race**

- White: 35.4%
- African American: 46%
- Pacific Islander: 0.01%
- American Indian/Alaska Native: 0.7%
- Unknown/Unreported: 13.2%
- Multiracial: 3.6%
- Asian: 0.9%

**Age**

- 25-44 years: 59.7%
- 45-64 years: 31.6%
- <2 years: 0.4%
- 65+ years: 1.3%
- Unreported: 1.3%
- 2-12 years: 1.6%

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Ryan White’s Legacy of Compassion

“I think this bill is a fitting tribute to Ryan White, although it is not nearly what he deserves. But it is one of the finest pieces of legislation to come out of this body.”

Senator Orrin Hatch (R-UT), 1990

The Ryan White CARE Act is named in honor of Ryan White, who was diagnosed with AIDS in 1984 at age 13 and gained international notoriety fighting for his right to attend school. In the process, he opened the hearts and minds of millions of people. He was, as Ted Koppel described him on Nightline, “an extraordinary young man; brave, tolerant, and wise beyond his years.”

During the time between his diagnosis and his death in 1990, Ryan spoke out often and eloquently about the challenges he faced and the need for greater compassion towards people with HIV and AIDS. Despite the ravages of the illness to his body and the discrimination he faced, Ryan remained a positive, healing force throughout his life.

Though constantly surprised by the notoriety he received because of his seemingly simple wish just to go to school, Ryan nevertheless recognized the value of the spotlight and seized the opportunities he was given. Throughout all of his appearances, he gave voice to the desires of thousands of people with HIV/AIDS who wanted only to be treated with respect and compassion and given the opportunity to live as normal a life as possible. His visibility and outspokenness were especially crucial in the early days of the AIDS epidemic and the programs and services supported through the Ryan White CARE Act are a lasting tribute to his legacy.