Overview of Ryan White CARE Act Titles

THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT was first enacted in 1990 and has been reauthorized twice—first in 1996 and again in 2000; its authorization expires in September 2005. The Ryan White CARE Act is divided into four titles. Each title, along with several other more specialized programs, is designed to address a specific component or aspect of the HIV/AIDS epidemic.

Title I (Part A)
Provides emergency relief through funding for health care and support services to the 51 U.S. eligible metropolitan areas (EMAs) disproportionately affected by HIV/AIDS.

Title II (Part B)
Assists states and territories in improving the quality, availability, and organization of health care and support services for individuals and families with HIV disease, and provides access to pharmaceuticals through the AIDS Drug Assistance Program (ADAP).

Title III (Part C)
Provides support directly to community-based providers for early intervention and primary care services for people living with HIV/AIDS.

Title IV (Part D)
Enhances access to comprehensive care and research of potential clinical benefit for children, youth, women, and their families with or at risk for HIV.

Special Projects National Significance (SPNS)
Supports the development of innovative HIV/AIDS service delivery models that have potential for replication in other areas.

HIV/AIDS Education and Training Centers (Part F)
Supports training for health care providers to identify, counsel, diagnose, treat, and manage individuals with HIV infection and to help prevent high-risk behaviors that lead to infection.

Dental Reimbursement Program (Part F)
Provides support to dental schools, postdoctoral dental education programs, and dental hygiene programs for non-reimbursed care provided to persons with HIV/AIDS.
Effective HIV/AIDS Care Requires Comprehensive Network of Medical Care and Support Services

CARE Act Title I and Title III Services Integral to Delivering Comprehensive HIV/AIDS Care in the U.S.

**CARE Act Titles Work Together to Ensure Broad Safety Net**

The 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. An important component of care to HIV/AIDS patients is to identify and ensure access to the appropriate drug regimen. However, the administration of drugs does not by itself result in the successful treatment of HIV/AIDS. Title I and Title III programs ensure the appropriate level of support needed to manage complex drug regimens.

**Success of Drug Therapies Requires Extensive Medical Services**

Managing HIV/AIDS is complex and requires continuous monitoring and follow-up by trained medical professionals. Recent studies show resoundingly that the choice and timing of antiretroviral regimen are critical elements of successful treatment of HIV infection. The programs supported by CARE Act 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 medical supervision, including costly laboratory testing.

Without the experience and expertise of medical professionals, the powerful drugs used to manage HIV/AIDS could be misused or insufficiently managed resulting 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.

The appropriate use of effective combination antiviral medications is an essential part of HIV care. The assembly-line distribution of drugs to patients not under the direct care of a medical professional is ineffective, if not dangerous. For individuals served by the CARE Act, Title I and Title III programs provide access to the medical supervision necessary for successful treatment.

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

Competing needs, such as food and housing, and barriers to care, such as lack of transportation or childcare, limit access to 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, which 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.

While the majority of CARE Act Title I and Title III funds support HIV treatment, a significant portion of Title I funds provide key support services, such as food and transportation, as well as case management services to link people with HIV/AIDS to medical care and support services.
Ryan White CARE Act Title I

Supporting Medical Care and Support Services In Communities — Eligible Metropolitan Areas (EMAs) — Hardest Hit by HIV/AIDS

The Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was first enacted in 1990 and has been reauthorized twice—first in 1996 and again in 2000; its authorization expires in September 2005. The Ryan White CARE Act is divided into four titles. Each title is designed to address a specific component or aspect of the HIV/AIDS epidemic.

Title I Basics

Title I of the Ryan White CARE Act funds health care and support services for uninsured and underinsured persons living with HIV and AIDS in 51 U.S. urban areas most adversely affected by the HIV/AIDS epidemic, known as Eligible Metropolitan Areas or “EMAs.” Title I serves an estimated 200,000 people living with HIV/AIDS each year, providing nearly three million health-care-related visits. Approximately two-thirds of Title I clients are people of color and 30 percent are women. More than 70 percent of people with HIV/AIDS live in a metropolitan area served by Title I.

“...The CARE Act supports a system of care. It extends way beyond the prescription—it extends to a total commitment to providing comprehensive care that addresses many patient needs in order to achieve optimal outcomes.”

— Marla J. Gold, M.D., Professor and Dean, Drexel University School of Public Health in testimony before the House Labor/HHS Appropriations Subcommittee.

A Continuum of Care

Communities use Title I funds to provide outpatient health services, including medical and dental care, and support services, including the medical care and laboratory testing required for those taking anti-HIV medications.

EMAs have used Title I funds to build community-based care systems that include desperately needed services for those living with HIV/AIDS, such as mental health treatment, drug adherence programs, clinical case management, substance abuse treatment, nutrition services, housing and transportation assistance, home care, and emergency assistance. The guiding philosophy behind this integrated, comprehensive system of care is that people living with HIV/AIDS can best manage their illness and reap the benefits of HIV treatments when the full set of care and related needs are met.

(Over)
Responding to Local Needs

Realizing that each community has different service needs and gaps in care, Congress structured Title I of the Ryan White CARE Act so that local communities play a central role in determining how funds should be used to meet the needs of people living with HIV/AIDS in their areas.

The Ryan White CARE Act requires the establishment of a planning council in each EMA. Planning council membership must be reflective of the local epidemic and is comprised of local public health officials, community-based service providers, people living with HIV/AIDS, community leaders, and others; at least one-third of planning council membership must be consumers of CARE Act services. The planning councils develop needs assessments and funding priorities for use of Title I funds within parameters set by the authorizing statute.

Distribution of Title I Funds

The HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) distributes Title I funds to the chief executive of the lead city or county in each EMA. The grantee then distributes funds to local service providers based on the priorities developed by the planning council.

There are 51 eligible metropolitan areas (EMAs) in 21 states, Puerto Rico, and the District of Columbia that receive Title I funding. In order to qualify as a Title I EMA, an urban area must have a population of at least 500,000 and more than 2,000 cumulative AIDS cases reported during the past five years. Title I funding includes formula and supplemental components, as well as Minority AIDS Initiative (MAI) funds targeted for services to minority populations. Formula grants are based on the estimated number of living cases of AIDS over the most recent 10-year period. HRSA awards supplemental grants competitively based on demonstration of severe need and other criteria.

51 CARE Act Title I EMAs

- Atlanta, GA
- Austin, TX
- Baltimore, MD
- Bergen-Passaic, NJ
- Boston, MA and NH
- Caguas, PR
- Chicago, IL
- Cleveland, OH
- Dallas, TX
- Denver, CO
- Detroit, MI
- Dutchess County, NY
- Ft. Lauderdale, FL
- Ft. Worth, TX
- Hartford, CT
- Houston, TX
- Jacksonville, FL
- Jersey City, NJ
- Kansas City, MO
- Las Vegas, NV
- Los Angeles, CA
- Miami, FL
- Middlesex-Somerset-Hunterdon, NJ
- Minneapolis-St. Paul, MN
- Nassau-Suffolk, NY
- New Haven, CT
- New Orleans, LA
- New York, NY
- Newark, NJ
- Norfolk, VA
- Oakland, CA
- Orange County, CA
- Orlando, FL
- Philadelphia, PA
- Phoenix, AZ
- Ponce, PR
- Portland, OR
- Riverside-San Bernardino, CA
- Sacramento, CA
- San Antonio, TX
- San Diego, CA
- San Francisco, CA
- San Jose, CA
- San Juan, PR
- Santa Rosa/Petaluma, CA
- Seattle, WA
- St. Louis, MO
- Tampa-St. Petersburg, FL
- Vineland-Millville-Bridgeton, NJ
- Washington, DC - MD and VA
- West Palm Beach, FL
Ryan White CARE Act Title III
Providing Health Care to People with Living with HIV/AIDS
In Underserved Communities

The Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was first enacted in 1990 and has been reauthorized twice—first in 1996 and again in 2000; its authorization expires in September 2005. The Ryan White CARE Act is divided into four titles. Each title is designed to address a specific component or aspect of the HIV/AIDS epidemic.

Title III Basics

Title III of the Ryan White CARE Act provides direct grants to over 360 community-based primary health clinics and public health providers in 49 states, Puerto Rico, the District of Columbia, and the US Virgin Islands.

Title III is the primary means for targeting HIV medical services to underserved and uninsured people living with HIV/AIDS in the nation’s rural and urban communities. Title III programs target the most vulnerable communities, including people of color, women, and low-income populations. The program also funds capacity building and planning grants to help organizations strengthen their ability to deliver care to people living with HIV/AIDS. Title III-funded services reach more than 150,000 people with HIV/AIDS per year, including more than 35,000 new patients. Two-thirds of those served are people of color and 30 percent are female. In addition, Title III clinics are central to the nation’s HIV testing initiatives, providing HIV counseling and testing to more than 415,000 people each year.

Most new patients at Title III-funded clinics are classified as moderately to severely ill and require extensive and costly medical services. Forty-two percent have no health insurance and 72 percent have incomes at or below the federal poverty level.*

*Source: HRSA, Ryan White CARE Act Title III 2001 Data Report

Medical Care for the Underserved

Title III clinics provide a range of health care services designed to help people with HIV learn their HIV status and then access appropriate medical care and services in a community health center/clinic. Specific medical and support services include:

- medical assessment and on-going medical care;
- laboratory testing related to antiretroviral therapies;
- antiretroviral therapies and adherence support;
- prevention and treatment of HIV-related opportunistic infections;
- mental health services;
- substance abuse treatment;
- oral health care;
- care for other health problems that occur frequently with HIV infection, including tuberculosis and Hepatitis B and C;
- case management to ensure access to services and continuity of care for HIV-infected clients;
- nutritional and psychosocial services;
- risk-reduction counseling to prevent HIV transmission; and
- HIV counseling and testing.
Planning and Capacity Building Grants

Planning and capacity building grants are critical tools for communities to explore the financial and program implications of starting or expanding primary health services. Planning grants are limited to one year and provide organizations with resources to plan for the provision of new, high quality comprehensive HIV primary health care services in rural or urban underserved areas and communities of color. Intended for a fixed period of one to three years, capacity building grants support efforts to strengthen organizational infrastructure and enhance capacity to develop, improve or expand high quality HIV primary health care services.

Title III is the primary method for delivering HIV care to rural areas. Approximately half of Title III providers serve rural communities. Frequently, Title III providers are the only means by which many persons receive HIV testing and care.

Funding Mechanism

The HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) distributes Title III funds directly to service providers through competitive grants in three categories: early intervention services, planning, and capacity building. The following types of organizations are eligible for Title III grants:

- Community Health Centers, Migrant Health Centers, and Health Care for the Homeless sites funded under Section 330 of the Public Health Service (PHS) Act;
- Family planning grantees (other than states) funded under Section 1001 of the PHS Act;
- Comprehensive Hemophilia Diagnostic and Treatment Centers;
- Federally qualified health centers funded under Section 1905(1)(2)(b) of the Social Security Act; and
- City and county health departments providing primary care;
- Out-patient primary care programs at community hospitals and medical centers; and
- Current public or private not-for-profit providers of comprehensive primary care for populations at risk for HIV.

Title III Grantees 2001

*Source: HRSA, Ryan White CARE Act Title III 2001 Data Report*
Ryan White CARE Act AIDS Drug Assistance Programs (ADAP)

Providing Access to HIV Medications for Those in Greatest Need

The Ryan White CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was first enacted in 1990 and has been reauthorized twice—first in 1996 and again in 2000; its authorization expires in September 2005. The Ryan White CARE Act is divided into four titles. Each title is designed to address a specific component or aspect of the HIV/AIDS epidemic.

ADAP Basics

The AIDS Drug Assistance Programs (ADAPs) are a component of Ryan White CARE Act Title II, which provides funds to all 50 states, DC, Puerto Rico, and the U.S. territories to provide HIV/AIDS care. ADAPs provide FDA-approved prescription medications for people with HIV/AIDS with limited or no prescription drug coverage. ADAP funds also may be used to purchase health insurance for eligible clients or to pay for services that enhance access, adherence, and monitoring of drug treatments. In 2002, ADAPs served approximately 136,000 people with HIV/AIDS, representing approximately 30 percent of those with HIV/AIDS who are receiving care in the U.S. More than 60 percent of those served by ADAPs are people of color.

Individual ADAPs operate in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, Commonwealth of the Northern Mariana Islands, and the Republic of the Marshall Islands.

Eligibility

The ADAP in each state or territory determines the eligibility criteria for its participants. All ADAPs require that individuals document their HIV status. Nine programs require a CD4 count of 500 or less—a marker of disease progression. Fifteen states have income eligibility at 200 percent or less of the Federal Poverty Level (FPL). Nationally, more than 80 percent of ADAP clients have incomes at 200 percent or less of the FPL.

Waiting Lists and Other Cost Containment Measures Hamper Access

Due to increasing demand and limited funds, as of June 2004, 15 ADAPs had cost containment measures in place, including closed enrollment (12), reduced formularies (2), per capita expenditure limits (2), lowered income eligibility criteria (1), and increased client cost-sharing (1). Eleven of the states with capped enrollments had waiting lists with a total of 1,629 people living with HIV/AIDS identified as waiting for services.
Formularies and Distribution Vary by Program

The ADAP in each state or territory also determines which medications will be included in its formulary and how those drugs will be distributed. The majority of ADAPs cover all FDA-approved antiretrovirals, but 16 do not. Only 17 ADAPs provide all 14 drugs recommended by the U.S. Public Health Service/Infectious Diseases Society of America (IDSA) for prevention and treatment of HIV-related opportunistic infections, while 39 provide 10 or more.

Many states and territories provide medications through a pharmacy reimbursement model, while others use pharmacies located within public health clinics or purchase drugs and mail them to clients directly.

Funding Mechanism

Congress “earmarks” a portion of its annual Ryan White CARE Act Title II appropriation for ADAPs. Although the ADAP “earmark” is by far the fastest growing component of CARE Act appropriations, current funding levels do not match the increasing need. A formula based on AIDS prevalence is used to award ADAP funds to states and territories. ADAPs also receive money from their respective states, other CARE Act programs in the state/territory, and cost-savings strategies, such as participation in the 340B Drug Discount program. In FY 2003, the earmark totaled 73 percent of total ADAP spending.

Need for Ryan White CARE Act Services Has Never Been Greater

HIV/AIDS Epidemic Remains A Public Health Emergency in the U.S.

■ More People Then Ever are Living With AIDS
The Centers for Disease Control and Prevention (CDC) estimated that 850,000 to 950,000 Americans were living with HIV and AIDS in 2000 and that number has likely risen. The CDC also estimates that over 405,000 people were living with AIDS, the most advanced form of HIV disease, in 2003—more people are now living with AIDS in the U.S. than at any other time in the epidemic.

■ 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 know even know they are infected, meaning that there are at least 430,000 people with HIV in the U.S. who are not receiving HIV-related medical care.

■ CDC Initiative Aims to Bring Thousands into Care
According to CDC Director Dr. Julie Gerberding, CDC’s “Advancing HIV Prevention” 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.” Many, if not most, of the estimated 200,000 people living with HIV in the U.S. who are currently unaware of their HIV status and are diagnosed with HIV under the new CDC initiative will turn to health care providers funded through the CARE Act for their HIV-related care. The Health Resources and Services Administration, which administers the CARE Act, estimates that between 7,700 and 15,300 people living with HIV/AIDS have or will enter the health care system in 2004 and 2005 as a result of this new initiative alone.

(Continued on next page.)
HIV/AIDS in the U.S. Increasingly Affects Communities of Color, As Well As Economically-Depressed and Other Underserved Communities

African Americans account for up to 54 percent of new HIV infections and Latinos account for 19 percent of new infections, though they account for only approximately 12 percent and 13 percent of the U.S. population, respectively. Hispanic and African American women account for 82 percent of new infections among females in the U.S. Approximately one in 50 African American males and one in 160 African American females is infected with HIV.

Almost Half of All People with HIV Start Treatment Too Late

According to a recent study, 40 percent of HIV-infected people in the U.S. begin antiretroviral treatment later than is recommended by the U.S. Public Health Service. Ryan White CARE Act programs have been proven to maximize cost effective services. Unfortunately, many programs are now reporting the need to limit, delay or restrict live saving treatments because of insufficient funding.

Public Programs are Key to Health Care Access

According to the Kaiser Family Foundation, one in five people—20 percent— with HIV receiving HIV-related care is uninsured and a total of 68 to 83 percent either rely on public-sector insurance programs or are uninsured.

Effective Treatments and Related Care are Expensive

While new treatments have helped extend the lives of some people with HIV/AIDS, these drugs are very expensive and difficult to take. Those taking the drugs require extensive medical monitoring and support services. According to a recent report by the Kaiser Family Foundation, the cost of HIV treatment and services averages $20,000 a year.

HIV/AIDS Treatment Requires Ongoing Clinical Management And Monitoring

Recent findings suggest that a significant number of people face the possibility that their HIV infections may become more difficult to treat due to opportunistic or co-morbid diseases, including hepatitis, and resistance to anti-HIV drugs.