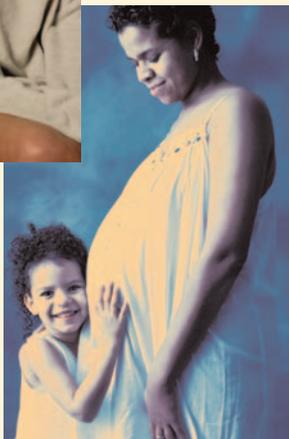
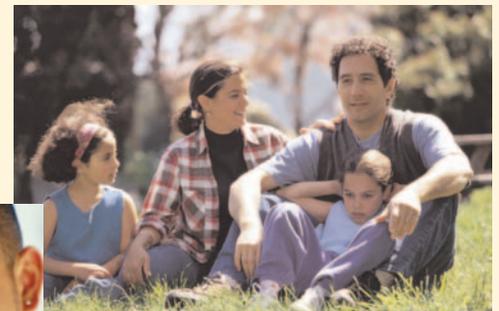




strengthening the circle of care

Policy Recommendations for Reauthorization of the Ryan White CARE Act, 2005



COMMUNITIES ADVOCATING
EMERGENCY AIDS RELIEF

CAEAR
COALITION

until it's over
AIDS ACTION

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 the 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.

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February 2005

Dear Colleagues:

The reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is crucial to the health and well-being of people living with HIV/AIDS in the United States. It must be a top priority for Congress, President Bush and his Administration, and the HIV/AIDS community in 2005.

CAEAR Coalition and AIDS Action developed our joint *Policy Recommendations for the Reauthorization of the Ryan White CARE Act, 2005*, to demonstrate our resolve to work together to ensure swift passage of a reauthorized bill that enhances an already strong and effective program. The majority of our recommendations relate to Title I, Title III, and Part F of the Ryan White CARE Act—the programs with which our members are mostly actively involved.

The Ryan White CARE Act's ability to reach those in greatest need is demonstrated everyday in urban and rural communities across the country and was echoed by the Government Accountability Office in their review of the program. Indeed, the Ryan White CARE Act is a model for the effective use of federal resources to address ongoing and emerging public health crises.

The recommendations outlined in the following pages will allow the Ryan White CARE Act to continue adapting to changes in the epidemiology and treatment of HIV, while insuring that communities maintain the ability to use these resources to best meet the needs of people living with HIV/AIDS.

Since its inception, the Ryan White CARE Act has enjoyed strong bipartisan support. We stand eager and committed to working with members of Congress, the Administration and our allies in the HIV/AIDS community on the 2005 reauthorization.

Sincerely,



Patricia Bass

Chair

CAEAR Coalition



Craig E. Thompson

Chair

AIDS Action Council

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 Programs (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 and funds community-based partnerships.



Ryan White CARE Act Title I

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

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 (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 living with HIV/AIDS live in a metropolitan area served by Title I.



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.

“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.



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 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 II

Providing Outpatient Care and Support Services at the State Level

Title II Basics

Title II of the Ryan White CARE Act provides grants to all 50 states, the District of Columbia, Puerto Rico and the U.S. territories for a wide-range of services for people living with HIV/AIDS, including outpatient medical care, dental care, developmental and rehabilitative services, home- and community-based services, continuation of health insurance coverage, prescription drugs, HIV care consortia, and supportive services. Title II includes the AIDS Drug Assistance Program (ADAP), which supports the provision of HIV medications and related services in all 50 states. (See page 5.)

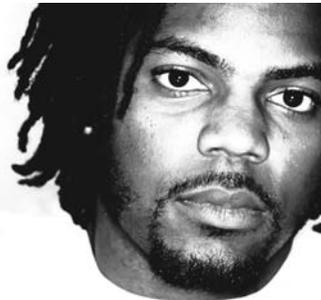
Emerging Communities

The Title II supplemental grants for emerging communities distribute funds to cities that do not qualify as Title I Eligible Metropolitan Areas (EMAs), but are experiencing growing rates of HIV infection, though with lower proportions of AIDS cases than the EMAs. Supplemental funding is provided to two categories of cities: 1,000-1,999 AIDS cases reported over the last five years and 500-999 AIDS cases reported over the last five years.

Funding Mechanisms

Funds are distributed based on a formula that estimates the number of people with AIDS in each state (80 percent) and the estimated number of people living with AIDS outside of a state's EMAs (20 percent). A state's allocation cannot decrease by more than one percent per year. States with more than one percent of the total U.S. AIDS cases reported during the previous two years must contribute a match with their own resources, according to a formula outlined in the Ryan White CARE Act.

Most states provide some services directly, while others work through subcontracts with Title II HIV Care Consortia. A consortium is an association of public and nonprofit health care and support service providers and community-based organizations that plans, develops, and delivers services for people living with HIV/AIDS. Emerging communities apply for supplemental funding through a grant application.



Ryan White CARE Act Title II AIDS Drug Assistance Programs (ADAP)

Providing Access to HIV Medications for Those in Greatest Need

ADAP Basics

The AIDS Drug Assistance Programs (ADAPs) are a component of Ryan White CARE Act Title II. ADAPs provide FDA-approved prescription medications for people living 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 living 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

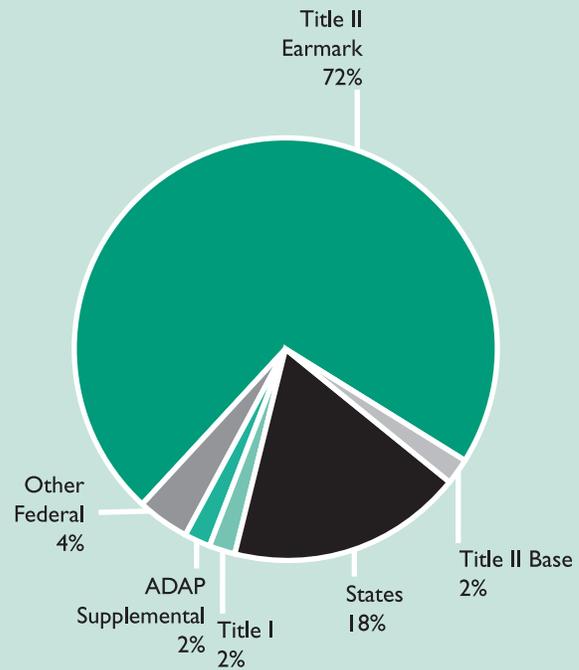
The ADAP in each state or territory also determines which medications will be included in its formulary and how those drugs will be distributed. The majority of ADAPs cover all FDA-approved antiretrovirals, but 16 do not. Only 17 ADAPs provide all 14 drugs recommended by the U.S. Public Health Service/Infectious 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 directly to clients.

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 72 percent of total ADAP spending.

National ADAP Budget by Source, FY 2003



Source: Kaiser Family Foundation, *AIDS Drug Assistance Program*, May 2004.



Ryan White CARE Act Title III

Providing Health Care to People with Living with HIV/AIDS In Underserved Communities

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 U.S. 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

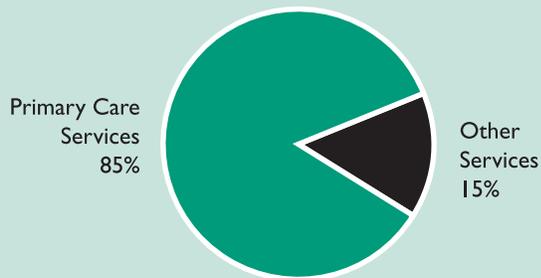
Medical Care for the Underserved

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 an 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.



Title III Expenditures by Service Category



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

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 fix 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.



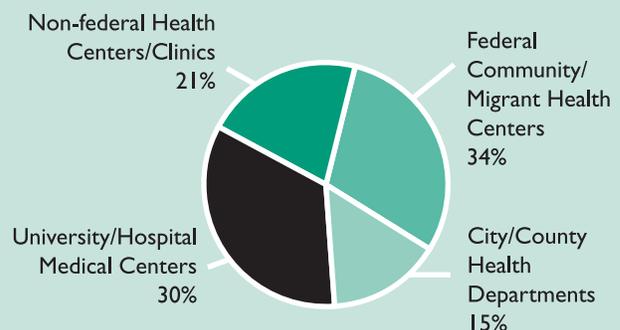
Title III is the primary method for delivering HIV care to rural areas. Approximately half of Title III providers serve rural communities. Frequently, Title III providers are the only means by which many persons receive HIV testing and care.

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;
- 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 2000



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

Ryan White CARE Act Title IV

Specialized Networks of Care for Women, Infants, Children, Youth and Affected Family Members

Title IV Basics

Title IV of the Ryan White CARE Act serves uninsured and underinsured women, children, and youth infected with or affected by HIV/AIDS through the provision of comprehensive, family-centered health care services, including primary medical services, case management and related social services, and access to research.

Preventing Mother-to-Child Transmission of HIV

A special focus of Title IV is to help identify pregnant women living with HIV and connect them with care that can improve their health and prevent perinatal transmission. The program has been instrumental in reducing the rates of perinatal HIV transmission in the U.S. In some localities, the rate has been reduced to zero.



Services

Title IV grantees build a comprehensive care system for women, children, and youth, providing access to:

- Primary and HIV specialty care
- Neonatal and pediatric specialty care
- Substance abuse and mental health services
- Case management
- Transportation, child care and housing assistance
- Education about and access to clinical trials and clinical research.

Funding Mechanism

Title IV grants are administered in a three-year cycle. Title IV currently supports 91 grantees in 34 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. The grantees provide or arrange direct HIV services at more than 300 clinical sites. Seventy-five of the current grants target all Title IV populations and 16 are a part of the Youth Initiative addressing the unique barriers to care faced by youth living with HIV/AIDS.



Ryan White CARE Act Part F: AIDS Education and Training Centers (AETCs)

AETC Basics

The AETC program provides multi-disciplinary HIV education and training for health care providers treating people living with HIV/AIDS. The program is currently composed of a network of 11 regional centers, with more than 130 associated sites and four national centers that support and complement the regional centers. The centers serve all 50 states, the District of Columbia, the U.S. Virgin Islands, Puerto Rico, and the U.S. Pacific Jurisdictions.

AETC education and training services are provided to physicians (including psychiatrists and other medical subspecialists), nurses, physician assistants, advanced practice nurses, pharmacists, oral health professionals, and health professionals and other members of the HIV treatment team who assist people living with HIV/AIDS adhere to treatment recommendations.

The AETCs work to maintain and increase the number of health care providers who are competent and willing to counsel, diagnose, treat, and medically manage people living with HIV/AIDS, and to help prevent high-risk

behaviors that lead to HIV transmission. They link HIV expertise from academic and highly skilled community HIV clinicians and medical institutions to community health care practitioners, correctional health providers, and other front line HIV clinical care providers who serve minority and disproportionately affected populations. AETC resources are prioritized to provide training and education to remote, underserved areas within their region with a need for training, but without sufficient, alternate training resources. AETCs also support the ability of health professionals to stay abreast of changing and complex drug treatment options for patients with HIV, the emergence of drug resistance, and access to early treatment and care.

Training Techniques

AETCs provide training, education, consultation, and other clinical decision support focused on teaching methods likely to result in behavior changes of clinicians managing patients. Education is provided in a variety of formats including skills-building workshops, hands-on preceptorships and mini-residencies, on-site training, and technical assistance. Clinical faculty also provides clinical consultation in person, or via the telephone or internet. Based in leading academic centers across the country, the AETCs use nationally recognized faculty and HIV researchers in the development, implementation, and evaluation of the education and training offered.

Training is culturally appropriate and supportive of the cultural and ethnic diversity among both trainees and patients in the training service area. Training focuses on diagnosis and treatment of HIV and related health



conditions. Special attention is given to the Department of Health and Human Services HIV Treatment Guidelines, prevention of HIV transmission by people living with HIV/AIDS, early diagnosis and referral to HIV/AIDS care and services, pharmacological management of HIV patients, prenatal care for at-risk or HIV-infected women, prevention of perinatal transmission and prevention and treatment of opportunistic infections, including Hepatitis C and tuberculosis.

Educating Providers in Communities of Color

The AETC programs emphasize training of health care professionals who will provide treatment for minority individuals and other high risk individuals. The program places a special emphasis on clinical providers who have less experience in diagnosis, treatment or management of the disease in Ryan White CARE Act-funded programs, and in areas with increasing rates of HIV infection. These providers have the potential to increase the capacity of HIV clinical care at the community level. Approximately 20 percent of regional AETC funding comes from Minority AIDS Initiative funds including programs that:

- expand HIV care and training for minority clinics in urban and rural areas and along the US-Mexico border;
- offer targeted training for minority providers and those who serve minorities; and
- develop training programs in concert with community-based programs to build capacity in medically underserved areas.

AETC Services Nationwide

Regional Centers

Delta Region AETC (Arkansas, Louisiana, Mississippi), Louisiana State University, Health Services Center, New Orleans

Florida/Caribbean AETC (Florida, Puerto Rico, Virgin Islands), University of South Florida, Tampa

Midwest AETC (Illinois, Indiana, Iowa, Michigan, Minnesota, Missouri, Wisconsin), University of Illinois at Chicago

Mountain-Plains AETC (North Dakota, South Dakota, Utah, Colorado, New Mexico, Nebraska, Kansas, Wyoming), University of Colorado, Denver

New England AETC (Connecticut, Maine, Vermont, New Hampshire, Massachusetts, Rhode Island), University of Massachusetts, Boston

New York/New Jersey AETC (New York, New Jersey), Columbia University, New York

Northwest AETC (Washington, Alaska, Montana, Idaho, Oregon), University of Washington, Seattle

Pacific AETC (California, Arizona, Nevada, Hawaii, 6 US Affiliated Pacific Jurisdictions), University of California, San Francisco

Pennsylvania/Mid-Atlantic AETC (Delaware, District of Columbia, Maryland, Ohio, Pennsylvania, Virginia, West Virginia), University of Pittsburgh

Southeast AETC (Alabama, Georgia, Kentucky, North Carolina, South Carolina, Tennessee) Emory University, Atlanta

Texas/Oklahoma AETC (Texas, Oklahoma) Parkland Health and Hospital System, Dallas

National Centers

National Clinician Consultation Center, University of California at San Francisco

National Evaluation Center, Columbia University, New York

National Minority AETC, Howard University, Washington, DC

National Resource Center, University of Medicine & Dentistry of New Jersey, Newark

Ryan White CARE Act Part F: Dental Programs

Dental Reimbursement Program Basics

The HIV/AIDS Dental Reimbursement provides access to oral health care for people living with HIV/AIDS by reimbursing dental education programs for the non-reimbursed costs they incur providing such care. By offsetting the costs of non-reimbursed HIV care in dental education institutions, the Dental Reimbursement Program improves access to oral health care for people living with HIV/AIDS and trains dental and dental hygiene students and dental residents to provide oral health care services to people living with HIV/AIDS.

The care provided through the program includes a full-range of diagnostic, preventive, and treatment services, including oral surgery, as well as oral health education and health promotion.

The Community-Based Dental Partnership Program Basics

The partnership program supports collaborations between dental education programs and community-based partners to deliver oral health services in community settings while training students and residents enrolled in accredited dental educations programs.

Funding Mechanism

Dental schools, post-doctoral dental education programs, and dental hygiene education programs accredited by the Commission on Dental Accreditation that have documented non-reimbursed costs for providing oral health care to people living with HIV are eligible to apply for reimbursement. Funds are then distributed to eligible organizations taking into account the number of people served and the cost of providing care. In 2003, the program provided reimbursements to 64 institutions in 23 states, the District of Columbia, and Puerto Rico.

The partnership program provides grants for a period of up to three years to selected institutions. The program supported 12 dental education programs in FY 2003.



Minority AIDS Initiative

Responding to a State of Emergency

MAI Basics

In 1998, as the result of the HIV/AIDS state of emergency declared by African American community leaders and championed by the Congressional Black Caucus (CBC), President Clinton announced and Congress funded an initiative to address this crisis through increased funding and outreach. In Fiscal Year 1999, the initiative targeted African American and Hispanic communities and provided \$165.5 million in new and redirected resources within the HHS budget. In Fiscal Year 2000, the Minority AIDS Initiative (MAI) was expanded to include all communities of color and the funding level now reaches almost \$400 million per year.

MAI funds target HIV/AIDS programs that directly benefit racial and ethnic minority communities in three broad funding categories:

- technical assistance and infrastructure support,
- increasing access to prevention and care, and
- building stronger community linkages to address the HIV prevention and health care needs of specific populations.



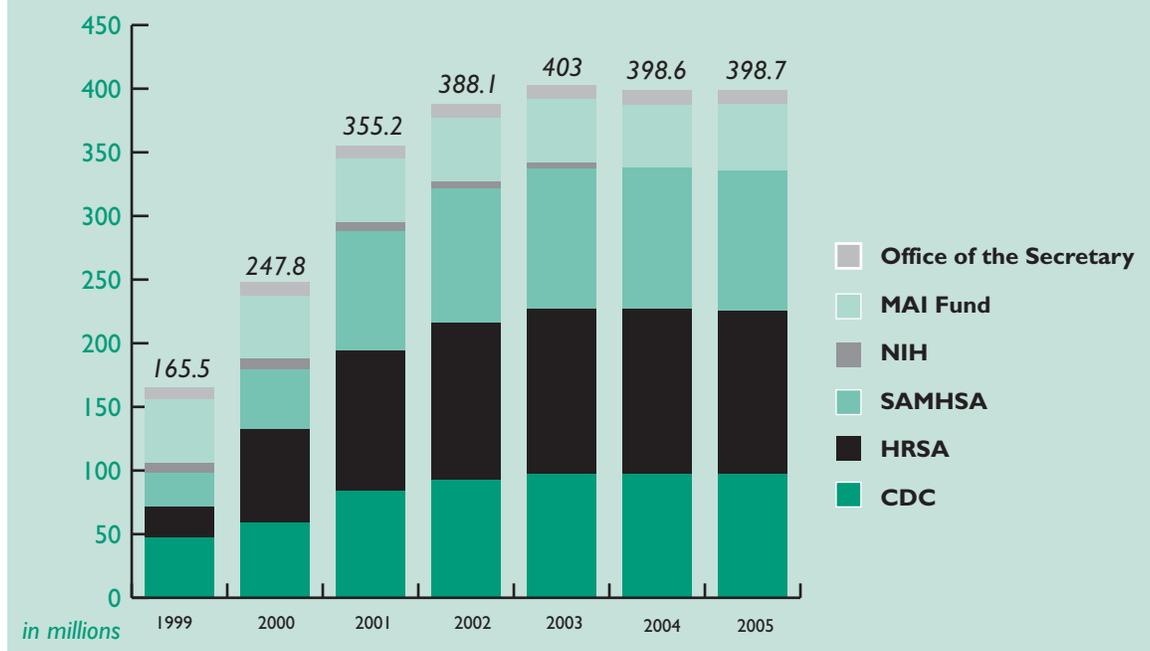
The MAI is not a part of the Ryan White CARE Act authorizing legislation, but provides directed resources to some Ryan White CARE Act programs, as it does to other Public Health Service HIV/AIDS programs (see chart on next page).

THE MAI in the Ryan White CARE Act

The MAI expands and strengthens the capacity of minority community-based organizations (MCBOs) to deliver high-quality HIV health care and supportive services to historically underserved groups and mount an effective response to the epidemic within their own communities. The MAI addresses HIV-related health disparities among racial and ethnic minorities by providing targeted funding to:

- create and improve HIV service capacity in minority communities to provide HIV prevention interventions, support services and case-finding, health care, treatment, and supportive services;
- expand services in historically underserved minority communities to complement existing HIV prevention and health care services and ensure sustainability by providing a bridge to enable MCBOs to access broader federal HIV/AIDS funding; and
- reduce persistent health disparities by enabling MCBOs to deliver culturally competent and linguistically appropriate health care and treatment services, as well as substance abuse, mental health, prevention, and other supportive services.¹

Minority AIDS Initiative Funding by Agency



MAI funds are directed to all four Ryan White CARE Act Titles and Part F. In Fiscal Year 2003, seven percent of Title I funds (\$43.8 million) were MAI funds¹, while 25 percent (\$49.4 million) of Title III funds were MAI funds.² A study by the CAEAR Coalition Foundation indicates that the four service categories that received the majority of Title I MAI dollars in Fiscal Year 2001 were ambulatory/outpatient medical care (39 percent), outreach (19 percent), case management (13 percent), and support services (17 percent).³ Between 2000 and 2001, the number of clients served by MAI Title I funds doubled from 38,032 to 77,051. In 2001, African Americans utilized 64.5 percent of Title I MAI funds while Latinos represented 28.7 percent of those utilizing MAI-funded Title I services.⁴

Funding Mechanism

MAI funds are distributed to five HHS agencies (see chart), and the majority of those funds are then distributed to outside organizations through competitive processes.

1 CAEAR Coalition Foundation, *The Minority AIDS Initiative in CARE Act Title I Communities*, 2003 (Figure 1).

2 National Minority AIDS Council, *Extending the Reach of the Ryan White CARE Act: The Minority AIDS Initiative*, 2003 (Table 1).

3 CAEAR Coalition Foundation (Figure 4).

4 CAEAR Coalition Foundation (Figure 5).

Policy Recommendations for Reauthorization of the Ryan White CARE Act

Summary of Recommendations

Full text of the Recommendations is available on pages 19-37.

Emergency Designation

Recommendation #1: Continue to fund the Ryan White CARE Act as an AIDS Emergency Relief Act.

Title I Resource Allocation

Recommendation #2a: Base Title I formula allocations on the number of persons reported to be living with AIDS adjusted for reporting delays within an Eligible Metropolitan Area (EMA), instead of the current “ten-year weighted AIDS case band.” Require the Centers for Disease Control and Prevention (CDC) to develop a national HIV/AIDS case data set from name- and non-name-based reporting systems and inclusive of all reported living HIV cases and, starting in FY 2007, base Title I formula awards on the number of persons reported to be living with HIV and AIDS adjusted for reporting delays. Maintain the protection-period provision for Title I formula allocations, applying percentages of 96, 92, 88, 84, and 79 over the course of five consecutive years of need beginning in the first year the protection period applies.

Recommendation #2b: Change the Title I EMA eligibility criteria from 2000 AIDS cases over the past five years to 1,500 estimated living AIDS cases adjusted for reporting delays. Starting in FY 2007, base EMA eligibility on living HIV and AIDS cases adjusted for reporting delays at a threshold determined to be equivalent to the 1,500 living AIDS case threshold.

Changing the EMA threshold will result in two to four new Title I jurisdictions previously funded through the top tier of the Title II Emerging Communities program. Accordingly, eliminate the top tier and transfer its \$5 million allocation to the Title I appropriated line item. Provide additional new funding for Title I to minimize potential funding reductions to continuing EMAs and support the addition of the new EMAs.

Recommendation #2c: Revise Title I EMA boundaries to be consistent with the most recent Combined Statistical Area (CSA), Metropolitan Statistical Area (MSA) or Metropolitan District (MD) boundaries, using whichever one most closely approximates the boundary of the existing EMA.

Recommendation #2d: Establish, by the end of FY 2006, objective, comparable, measurable and weighted indices to determine severity of HIV need for use in determining Title I supplemental allocations.

**Unduplicated
Service Data**

Recommendation #3: Make it a goal of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau to develop a national, unduplicated, client-level data system.

Core Services

Recommendation #4a: Continue support of jurisdictional level flexibility and accountability to determine the appropriate mix of HIV health care and supportive services, taking into account the local assessment of unmet and continuing needs and the availability of other resources.

Recommendation #4b: Maintain the current list of allowable services as described in the Ryan White CARE Act.

Recommendation #4c: Do not include a mandated set of Title I services, percentage set-asides for specific services, or limitations on the amount of funding that can be allocated at the jurisdictional level for an eligible service.

**Title I HIV
Health Services
Planning Council**

Recommendation #5: Maintain the requirement that at least 33 percent of planning council members be persons living with HIV/AIDS and consumers of Title I services. Allow non-aligned consumers to retain their status for the remainder of the year if they become aligned to a funded entity by employment or board affiliation. Require planning councils to report annually on the demographic status of their memberships and ensure compliance with HRSA HIV/AIDS Bureau guidance.

**Improving
Accountability
for Evaluation
and Technical
Assistance
Funds at HRSA**

Recommendation #6: Require the HRSA HIV/AIDS Bureau to provide an annual report on the uses of the two percent evaluation tap and one percent technical assistance tap.

**Title III
Consumer Input**

Recommendation #7: Require Title III grantees to demonstrate that they have a mechanism for documented consumer input by documenting the process, the recommendations provided, and the outcomes of these recommendations.

**Enhancing Federal
Coordination**

Recommendation #8a: Provide a mechanism to rapidly resolve conflicting practices between federal agencies or departments coordinating with the HRSA HIV/AIDS Bureau.

Recommendation #8b: Require HRSA HIV/AIDS Bureau and Centers for Medicare & Medicaid Services (CMS) leadership to assess the coordination of Ryan White CARE Act programs and state Medicaid programs.

Recommendation #8c: Do not penalize a Title EMA in its grant if its HIV health services planning council has been unable to fulfill its obligation to include the State Medicaid Agency and the agency administering the program under part B, but has shown documented due diligence in its attempt to fulfill this obligation.

Recommendation #8d: Maintain existing parameters for Early Intervention Services and other collaborations outlined in the Ryan White CARE Act.

Recommendation #8e: Expand existing language to direct biennial consultation between the Departments of Health and Human Services and Veterans Affairs. Encourage Title I HIV health services planning councils to include representation from the local VA facilities in their membership and maintain VA facilities' eligibility for Ryan White CARE Act funds.

AIDS Education and Training Centers

Recommendation #9: Reauthorize and continue funding the AIDS Education and Training Centers.

Oral Health Services

Recommendation #10a: Reauthorize the HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnership Program as separately funded programs.

Recommendation #10b: Maintain current eligibility criteria for grantees in the HIV/AIDS Dental Reimbursement Program.

Recommendation #10c: Maintain the retrospective reimbursement system in the HIV/AIDS Dental Reimbursement Program with a requirement that providers document that clients served are living with HIV disease.

Recommendation #10d: If additional funding is appropriated, additional accredited dental schools should be encouraged to apply for community-based partnership grants, while communities that lack an accredited dental school should be eligible to apply for these grants independently.

Recommendation #10e: Permit HIV/AIDS Dental Reimbursement Program grantees to utilize Ryan White CARE Act funds to participate in Ryan White CARE Act grantee meetings.

Price of Pharmaceuticals

Recommendation #11: Direct the Secretary of Health and Human Services to ensure that Ryan White CARE Act programs receive the lowest price available to the federal government for pharmaceutical products, unless otherwise negotiated at a lower rate.

Infrastructure and Capacity Expansion Program

Recommendation #12: Expand Part F to include the “Infrastructure and Capacity Expansion Program” to be funded through a new appropriation line item with such sums as may be necessary. This program should be used expressly to provide resources to help organizations and jurisdictions serving medically underserved minority, rural, and urban communities build the infrastructure and capacity they need to improve HIV/AIDS care in underserved communities.

The following recommendations do not require legislative changes to the Ryan White CARE Act, but do require administrative action or Congressional action in other areas.

Title III

Recommendation #13a: Establish a formal plan to ensure that HIV/AIDS care is identified as a core component of health care services to be provided by 330 Clinics and other Federally Qualified Health Centers. Establish greater collaboration between the HRSA HIV/AIDS Bureau and the Bureau of Primary Health Care to reduce barriers that prevent community-based HIV service providers from successfully competing to become 330 Clinics and Federally Qualified Health Centers.

Recommendation #13b: Instruct the HRSA HIV/AIDS Bureau to be flexible in their initial agency capacity assessment to determine which capacity building grant category an agency is best suited to apply for based on their developmental stage.

Recommendation #13c: Make widely known the availability of technical assistance from Title III programs and HRSA in the development of unique, effective service delivery models.

Recommendation #13d: Strengthen the HIV care infrastructure of Title III programs by directly funding existing and new Title III projects in rural and medically underserved areas, and those in smaller communities.

Recommendation #13e: Direct HRSA to work collaboratively with the CDC to implement CDC's Advancing HIV Prevention Initiative.

Recommendation #13f: Support continued use of Minority AIDS Initiative (MAI) resources to expand the number of planning and capacity building grants, as well as early intervention services grants, targeted to culturally competent organizations with a history of serving minority communities.

Recommendation #13g: Establish a process to inform Title III grantees when organizations within their respective states are awarded planning and capacity building grants.

Minority AIDS Initiative

Recommendation #14: Preserve the MAI to address the development, implementation and provision of high quality care to underserved populations. Maintain the existing MAI structure, increase appropriations to the MAI, and maintain MAI allocations through existing Ryan White CARE Act Titles. Do not use MAI funds to supplant other HIV/AIDS resources at the local level.

Federal Coordination

Recommendation #15: Encourage direct collaboration between local care and prevention planning bodies and require care planning bodies to work with their local prevention counterpart to conduct a joint assessment of the merits and challenges of collaboration and establish a plan for future coordination.

Policy Recommendations for Reauthorization of the Ryan White CARE Act

Purpose and Structure of the CARE Act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, first authorized in 1990 and due for reauthorization by September 30, 2005, has been tremendously successful in fulfilling its mission to provide medical care and support services for people living with HIV/AIDS without access to private insurance or other public programs and it must continue to perform that role. Key to the success of the Ryan White CARE Act are the four Titles and Part F, which continue to provide Congress, the Administration and Ryan White CARE Act grantees the ability to target policies and resources to diverse populations impacted by the HIV/AIDS epidemic.

1. Emergency Designation

As defined in the original Ryan White CARE Act and both subsequent reauthorizations, it is the purpose of the legislation “to provide emergency assistance to localities disproportionately affected by the Human Immunodeficiency Virus epidemic.”

Recommendation #1: The Ryan White CARE Act should continue to be funded as an AIDS Emergency Relief Act, as the HIV/AIDS epidemic in the United States continues to be an emergency for affected communities, especially for communities of color and in rural areas where there are not sufficient health care services.

2. Title I Resource Allocation

Title I of the Ryan White CARE Act is a central component in the nation’s response to providing access to care and treatment to people living with HIV/AIDS. Over 70 percent of reported cases of people living with AIDS live within the 51 eligible metropolitan areas (EMAs) receiving Title I funds, where many must depend on lifesaving primary medical care, prescription drugs and supportive services supported by the Ryan White CARE Act. CAEAR Coalition and AIDS Action emphasize at the outset that no Title I community receives adequate federal resources to fully meet the needs of people living with HIV/AIDS. In response to widespread evidence of continuing unmet need, CAEAR Coalition and AIDS Action will continue advocating increases in Title I resources to more adequately address the escalating needs of people living with HIV/AIDS receiving Title I services and those eligible for services, but not yet enrolled.

2a. Title I Formula Grants

The intent of the Title I formula grants to the EMAs is to fairly distribute resources to address the burden of unmet need among areas highly impacted by the HIV/AIDS epidemic while protecting existing systems of care from destabilization. The current distribution formula is based on the number of AIDS cases diagnosed in the preceding ten-year period, using a weighted formula that assigns a lower value to each additional year that has elapsed since the diagnosis. This formula, known as the “ten-year weighted case band,” has been an imperfect but useful mechanism for providing resources to communities endeavoring to develop comprehensive systems of medical care and supportive services for uninsured and underinsured people living with HIV/AIDS.

The ten-year weighted case band was included in the Ryan White CARE Act amendments of 1996 and was designed to more accurately reflect the number of people living with AIDS who might require services through the Ryan White CARE Act. Since that time, the Centers for Disease Control and Prevention (CDC) has established data sets that provide more accurate estimates of the number of people living with AIDS.

One drawback to the ten-year weighted case band is that individuals living with HIV infection require medical care, diagnostic testing and supportive services long before their illness progresses to an AIDS diagnosis. Indeed, it is the goal of quality HIV care to prevent progression to AIDS, and a growing number of people with HIV are living longer before developing AIDS. The 2003 study by the Institute of Medicine (IOM), *Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*, evaluated the feasibility of using HIV case data instead of AIDS cases to allocate Ryan White CARE Act resources. The IOM concluded that reporting of HIV cases is not yet developed or consistent enough across states to provide an effective or accurate measure of HIV infection nationally. CAEAR Coalition and AIDS Action support this finding. The Ryan White CARE Act amendments of 2000 required the Secretary of Health and Human Services to make a determination not later than July 1, 2004, regarding the availability of accurate and reliable HIV case reporting as an element in formula determinations. In June 2004, the Secretary determined that the national HIV case data set remains incomplete and cannot be used as an accurate mechanism for funding distribution at this time.

The 1996 amendments also included a protection-period provision in the Title I formula to phase-in potential funding reductions as AIDS caseloads decreased in some jurisdictions in proportion to other localities, in order to prevent the rapid destabilization of existing health care systems while concurrently expanding resources to areas with emerging HIV/AIDS epidemics. The phased-in protection-period funding reductions were revised in the 2000 amendments to guarantee that no Title I community would lose more than a total of 15 percent of its formula funding relative to Fiscal Year 2000 and those reductions are spaced out over the five-year authorization period.

Over the course of the next reauthorization cycle, any movement to transition the basis for Title I formula grants to HIV cases, as recommended below, will dramatically impact individual EMA formula awards. Therefore, continuation of a protection-period provision will be essential to maintain stable systems of care for people living with HIV/AIDS.

Recommendation #2a: The Secretary of Health and Human Services should be required to follow the recommendations in the 2003 IOM report (*Measuring What Matters: Allocation, Planning and Quality Assessment for the Ryan White CARE Act*) and direct the CDC to establish a process to be completed no later than December 2006, by which state and other eligible area HIV data from name- and non-name-based reporting systems is accurately merged to produce a national HIV/AIDS case data set inclusive of all reported living HIV cases. This newly established data set would be used for formula distribution for the first Fiscal Year subsequent to a determination by the Secretary that the HIV/AIDS data set is complete. Until such time, the Secretary shall adopt, as the determinant for Title I formula allocations, the number of persons reported to be living with AIDS adjusted for reporting delays.

When and after the Secretary determines the HIV/AIDS data set to be complete by December 2006, then, beginning in Fiscal Year 2007, Title I formula awards shall be determined by the number of persons reported to be living with HIV and AIDS adjusted for reporting delays. An ongoing challenge for Congress, the Administration and Ryan White CARE Act advocates is determining how to best direct resources to jurisdictions where the epidemic is emerging while sustaining resources and service delivery in areas with significant disease burden. Ensuring that Ryan White CARE Act service systems among jurisdictions are better able to appropriately address the medical, treatment and supportive service needs of people living with HIV/AIDS is a shared goal of CAEAR Coalition and AIDS Action. The position endorsed by the CAEAR Coalition and AIDS Action regarding the protection-period provision in Title I, as outlined below, is among a group of positions and provisions in the Ryan White CARE Act intended to achieve a balance among multiple, competing and legitimate priorities of maintaining existing systems of care, directing resources to areas of greatest or emerging need for services, and progressing towards greater equity of funding distribution.

A number of changes to Title I are being recommended that would occur concurrently. Because the overall impact of the implementation of these changes is anticipated but unknown, and to be consistent with the past commitment to stabilize systems of HIV care and to direct funds to areas of emerging need, CAEAR Coalition and AIDS Action recommend the continuance and maintenance of the protection-period provision for Title I formula allocations. The following percentages shall apply over the course of five consecutive years of need beginning in the first year that the protection period applies: 96, 92, 88, 84, 79; this is also known as percentage reductions of 4, 4, 4, 4, 5 from the first consecutive year of need. The protection period shall continue to apply for each consecutive year until it is no longer required.

2b. Title I EMA Definition

Title I EMAs are currently defined both by the overall population of the metropolitan statistical area (500,000) and the number diagnosed cases of AIDS over the past five years (2,000). As more accurate models for determining the HIV/AIDS disease burden within communities are developed, it is important that the criteria for determining EMAs also evolve. As the criteria change to more accurately reflect current disease burden, the number of EMAs will increase and additional resources must be available in the Title I appropriation to address the HIV care needs of these communities as they enter the Title I program.

Recommendation #2b: The Secretary of Health and Human Services should adopt the number of persons reported to be living with AIDS adjusted for reporting delays as the eligibility criteria for determining which metropolitan statistical areas qualify as a Title I EMA. In order to initially attain EMA status, a jurisdiction must have at least 500,000 total residents and have at least 1,500 estimated living AIDS cases adjusted for reporting delays in the most recent available CDC data.

The Secretary should follow the IOM report recommendations to use existing state and other eligible area HIV reporting systems to produce, by December 2006, nationwide HIV/AIDS case data inclusive of living HIV cases. If the Secretary determines that the national HIV/AIDS case data set exists and is accurate, then in Fiscal Year 2007, the EMA eligibility criteria should be based on living HIV and AIDS cases adjusted for reporting delays. The threshold should be set at a point determined by the Secretary to be equivalent to the 1,500 living AIDS case threshold. The intent is to maintain the threshold at a consistent point for eligible EMAs while making the change to a more inclusive data set. With the eligibility criteria change to living AIDS cases and then living HIV/AIDS cases, all existing EMAs would maintain their EMA status even if their caseloads do not reach the new thresholds.

One result of lowering the EMA threshold will likely be the addition of two to four new Title I jurisdictions, which were previously funded through the top-tier of the Emerging Communities provision in Title II of the Ryan White CARE Act. CAEAR Coalition and AIDS Action propose that the top tier of the Title II emerging communities be eliminated, that the \$5 million allocation for those top-tier communities be retained and transferred to the Title I appropriated line item, and that new funding for Title I be authorized and appropriated to minimize potential funding reductions to continuing EMAs and support the addition of those EMAs. CAEAR Coalition and AIDS Action recognize the important transitional role of emerging communities. At the same time, it is clear that slight alterations in the levels of HIV/AIDS cases may run the risk of destabilizing care systems by forcing these communities to change categories. Therefore CAEAR Coalition and AIDS Action note that the EMA levels are intended to be at a low enough level to bring most or all of the top-tier emerging communities into Title I as EMAs.

Proposed Changes to Title I Formula and EMA Definition

Issue	Current	Proposed – AIDS <i>(until certification of national HIV/AIDS data)</i>	Proposed – HIV/AIDS <i>(after certification of national HIV/AIDS data)</i>
Minimum size of metropolitan area	At least 500,000, with grandfathered exceptions	Same	Same
Case criteria	New AIDS cases diagnosed in the last five years	Total living AIDS cases, adjusted for reporting delays	Total living HIV/AIDS cases, adjusted for reporting delays
Threshold number of cases	2,000	1,500	To be determined by the Secretary of Health and Human Services
Formula allocation criteria	Estimated Living Cases (ELC) – ten-year weighted case band	Total living AIDS cases, adjusted for reporting delays	Total living HIV/AIDS cases, adjusted for reporting delays

2c. Title I EMA Boundaries

To avoid resource and planning disruptions, the boundaries for Ryan White CARE Act Title I EMAs have remained constant since the last revision in 1994. The 2000 Census, however, produced demographic data that has resulted in significant changes to the boundaries of some of the Metropolitan Statistical Areas (MSAs) that are the basis for the EMAs. As a part of this process, the Office of Management and Budget also created two new statistical areas—Combined Statistical Areas (CSAs) and Metropolitan Districts (MDs)—which reflect the boundaries of several existing EMAs.

Recommendation#2c: In an effort to ensure that Ryan White CARE Act resources are accurately targeted to those areas where people living with HIV/AIDS reside, CAEAR Coalition and AIDS Action believe that recent revisions to the MSA boundaries and the creation of CSAs and MDs should inform revisions to existing EMA boundaries. To ensure that Ryan White CARE service planning is responsive to local needs, the revised EMA boundaries should be consistent with the most recent CSA, MSA or MD boundaries issued by the Office of Management and Budget, whichever most closely approximates the boundaries of existing EMAs. (See Appendix A.)

2d. *Title I Supplemental Grants*

The supplemental portion of Title I funding has historically served two purposes: (1) encouraging accountability in carrying out the mandates of the Title I formula awards and (2) addressing the complexity of providing services among increasingly poor and marginalized populations heavily impacted by HIV/AIDS. Across the country, the HIV/AIDS epidemic has progressively come to be regarded as a disease of poverty, disproportionately affecting disenfranchised populations, including minorities, injection drug users, the homeless and those living in poverty. These vulnerable groups are also heavily affected by high rates of sexually transmitted diseases, tuberculosis, and mental illness. The supplemental grants have recognized the many challenges of delivering HIV treatment and care to these populations by including severity of need criteria as part of the grant application process.

Congress requested that the IOM provide guidance to the Congress and the Department of Health and Human Services (HHS) regarding methods to improve the criteria for measuring resource needs and refining and improving assessment of severity of need. The IOM offered recommendations to HRSA to enhance both direct and indirect indicators of resource needs in the report noted above. CAEAR Coalition and AIDS Action support the IOM recommendations on strengthening quantitative data measures to reflect severity of need as an element in the allocation of supplemental awards.

Recommendation #2d: The Ryan White CARE Act should require that the Secretary of Health and Human Services convene an HHS process that establishes a series of objective, comparable and measurable indices to determine severity of HIV need. The goal would be to ensure that the Title I supplemental funding process has maximum transparency and that limited resources are targeted to areas with the most severe unmet needs that impact the HIV health status of people living with HIV/AIDS. The indices should be weighted by the degree to which they impact on the HIV health status of people living with HIV/AIDS. The process should be completed within Fiscal Year 2006 and the indicators should be available to determine supplemental awards by Fiscal Year 2007.

3. *Unduplicated Service Data*

Unduplicated client-level service data provides the most accurate information on the number and demographics of people living with or at-risk for HIV/AIDS served by the Ryan White CARE Act. Such data assures that each person served by the Ryan White CARE Act system is only counted once, even if they receive services from multiple providers. Currently only four of 51 Title I EMAs collect unduplicated data.

Unduplicated data helps service planners and providers more accurately target services and measure their impact. It also provides Ryan White CARE Act grantees and federal policymakers with clear information about the impact of Ryan White CARE Act

programs on people living with HIV/AIDS. Moving to data collection systems with the capacity to gather unduplicated data, however, often requires significant financial and human resources at all levels of the care continuum.

Recommendation #3: It should be a goal of the HRSA HIV/AIDS Bureau to develop a national unduplicated client-level data system for Ryan White CARE Act programs. The goal of an unduplicated client-level data set is to maximize the efficient and effective use of Ryan White CARE Act resources at the local, state and federal levels. We expect that more accurate data will produce efficiencies in service planning that will enable Ryan White CARE Act grantees to expand access to critical HIV services. To that end, all Ryan White CARE Act grantees should be encouraged and supported to develop data collection systems to gather unduplicated client service data. The HRSA HIV/AIDS Bureau should investigate the possibility of adapting its existing data collection software and provide technical assistance and support to assist grantees with the transition to collect and report unduplicated client-level data. The HIV/AIDS Bureau should not impose requirements on grantees to develop unduplicated data without providing additional adequate resources to support those systems. New client-level data systems must continue to comply with the Health Insurance Portability and Accountability Act (HIPAA), respect the confidentiality of client health records and conform to federal and/or state confidentiality statutes, whichever is more stringent.

4. *Core Services*

The Ryan White CARE Act provides a vital continuum of care for people living with HIV/AIDS. Services supported through the Ryan White CARE Act are intended to help people living with HIV/AIDS to enter and remain in systems of ongoing care and treatment, thereby improving health outcomes for these individuals. The Ryan White CARE Act also includes an emphasis on identifying unknown HIV infections among people living with HIV, bringing these individuals into care, and preventing new HIV infections by focusing prevention messages on those living with HIV. Altogether, Ryan White CARE Act programs focus on improving health outcomes through essential medical care and those supportive services that assist individuals to both access and benefit from this care. The term “core services” has been used to describe the range of services that contribute to documented improvements in health outcomes. These include primary medical care, medications, clinical and laboratory monitoring, oral health services, case management, and mental health and substance abuse treatment. In addition to these health services, supportive services such as nutritional services, housing, and other critical services are often necessary to enable individuals to access and remain in the health care system and adhere to medication regimens. Individuals who are tested and become aware of their HIV status must be connected to appropriate and regular medical and supportive services. Outcome data has shown a direct relationship between Ryan White CARE Act-funded core services and improved health outcomes.

Title I EMAs and Title III grantees have long reflected a strong commitment to expanding access to HIV primary medical care, medications and case management services in order to improve health outcomes of people living with HIV/AIDS.

The appropriate mix of specific services funded with Ryan White CARE Act resources should be defined locally as a result of local planning, based on assessment of unmet local needs. Defining a limited list of core services or prescribing a minimum percent of funding for specific services at the federal level may adversely affect the ability of grantees to identify and retain people living with HIV/AIDS in care. Local variations in services supported by other funding streams, such as State Medicaid programs, substance abuse treatment, or mental health services for persons with multiple diagnoses, require flexibility in Ryan White CARE Act-funded programs. All services supported with Ryan White CARE Act funds should be linked with improvements in health outcomes related to access and appropriate utilization of health services by people living with HIV/AIDS.

Recommendation #4a: CAEAR Coalition and AIDS Action support flexibility and accountability at the jurisdictional level to determine the appropriate mix of health care and supportive services for people living with HIV/AIDS, with the goal of improving access to, engagement with, maintenance in, and appropriate utilization of care. The mix of services must be based on the jurisdictional local assessment of unmet and continuing needs and take into account other available resources.

Recommendation #4b: The current list of allowable services as described in the Ryan White CARE Act should be maintained.

Recommendation #4c: The Ryan White CARE Act should not include a mandated set of Title I services, percentage set-asides for specific services, or limitations on the amount of funding that can be allocated at the jurisdictional level for an eligible service.

5. Title I HIV Health Services Planning Council Membership

The Ryan White CARE Act has always required that Title I HIV health services planning councils include “affected communities, including individuals (changed to ‘people’ in 1996) with HIV disease” in their membership. In the 2000 amendments, a new provision was added to strengthen this requirement; it mandates that 33 percent of the council members be individuals who are receiving services funded by Title I and who are not officers, employees or consultants to any entity that receives Title I funds (non-aligned). The goal of this provision is to insure that individuals with firsthand experience as consumers of Title I services and without conflicts of interest have an appropriate role in fulfilling the councils’ crucial planning and priority-setting mandates. Some people living

with HIV/AIDS who join councils as non-aligned members are recruited as staff or officers of funded agencies because of their demonstrated expertise and commitment. Allowing non-aligned members to keep their status for the remainder of the year even if they do accept a job or officer position will promote stability in the councils, encourage the participation of interested consumers, and reduce unnecessary administrative burdens on Title I grantees.

Recommendation #5: Maintain the requirement that at least 33 percent of planning council members be persons living with HIV/AIDS and consumers of Title I services. If a person living with HIV/AIDS is appointed as a non-aligned member of a planning council but subsequently becomes aligned, by employment or Board affiliation to a funded entity, he or she may retain their non-aligned status for the remainder of the year of their status change. Planning councils should be required to report annually on the demographic status of their memberships and be responsible as necessary for annual adjustments to the status of individual planning council members to ensure compliance with HRSA HIV/AIDS Bureau guidance. Local jurisdictions will continue to determine the length of planning council member appointments.

6. Improving Accountability for Evaluation and Technical Assistance Funds at HRSA

Congress affirmed the importance of data collection, analysis and evaluation at the federal program level when it stipulated that two percent of the annual Ryan White CARE Act appropriation be used for these purposes. Opportunities to prove program effectiveness and to continually refine program activities and planning are anchored by timely evaluation studies both at the grantee and federal levels. Extensive data reports are provided to the HRSA HIV/AIDS Bureau by grantees, providing a wealth of information for evaluation activities that could demonstrate the efficacy of Ryan White CARE Act programs if analyzed in aggregate or arrayed to inform specific questions. The CAEAR Coalition and AIDS Action are concerned that HHS does not utilize the technical assistance and evaluation funds tapped from the Ryan White CARE Act for technical assistance and evaluation activities at the HRSA HIV/AIDS Bureau, thereby limiting opportunities at hand to benefit from program experience and more fully document the impact of the Ryan White CARE Act on the health outcomes of people living with HIV/AIDS. Indeed, there is no transparency on how the resources tapped from the Ryan White CARE Act are used once transferred to the Office of the Secretary of Health and Human Services.

There are significant ongoing needs for technical assistance and evaluation as Ryan White CARE Act programs respond to new trends in the HIV/AIDS epidemic and changing environments affecting the delivery of health care services. Activities to define unmet

need, measure program and health outcomes, and strengthen links between HIV prevention and care are recent examples of program elements creating technical assistance and evaluation demands. The Ryan White CARE Act targets one percent of the annual appropriation for technical assistance activities. However, in light of ongoing and unmet needs for technical assistance at the program level, there is inadequate information to assess how effectively these resources are being directed.

Recommendation #6: The Secretary of Health and Human Services should be directed to require HRSA to provide an annual report on the uses of the two percent evaluation tap and one percent technical assistance tap to increase HRSA's accountability for how these resources benefit people living with HIV/AIDS, Ryan White CARE Act consumers and Ryan White CARE Act programs.

7. *Title III Consumer Input*

Title III of the Ryan White CARE Act funds public and other private non-profit entities to develop, organize, coordinate and operate health systems for the delivery of health care and support services to medically underserved individuals and families affected by HIV disease. Title III allows clients to receive a comprehensive continuum of HIV primary care from the same community-based organizations that provide them with related medical care and support services, providing for the creation of innovative systems of care. Building HIV primary care capacity within existing community health and medical care programs is both cost-effective and an efficient use of available resources. CAEAR Coalition and AIDS Action continue to believe that this is a comprehensive model for public health programs of the future.

As in all Ryan White CARE Act programs, Title III grantees benefit significantly from the input of the people living with and at-risk for HIV/AIDS that they serve. In order to ensure that such input is given appropriate weight, it should be gathered, responded to and integrated appropriately through a formal, documented process.

Recommendation #7: Title III grantees should be required to demonstrate that they have a mechanism for documented consumer input by documenting the process, the recommendations provided, and the outcomes of these recommendations.

8. *Enhancing Federal Coordination*

The response of the federal government to the HIV/AIDS epidemic involves multiple and concurrent program initiatives located in diverse federal departments and their agencies. These efforts include medical research (National Institutes of Health), HIV prevention and education (CDC), health care services and treatment (HRSA), substance abuse and mental health (Substance Abuse and Mental Health Services Administration), housing

(Department of Housing and Urban Development), among others such as the Department of Veterans Affairs (VA) and the Indian Health Service.

During the 1996 and 2000 reauthorizations of the Ryan White CARE Act, special emphasis was placed on the need for collaboration between Ryan White CARE Act programs at the HRSA HIV/AIDS Bureau and other federal agencies providing services to the same populations. Although signs of progress are evident, there continues to be a significant need for greater coordination and collaboration among departments and agencies implementing programs addressing the HIV epidemic. In an environment of more restrictive federal domestic budgets, CAEAR Coalition and AIDS Action believe that better integration of federal prevention, health care, supportive services and housing programs are vital to ensuring that these limited federal resources are used effectively. Integration can eliminate duplication of services, while also fostering collaborations to achieve the best possible health outcomes for people living with HIV/AIDS, including ensuring that the nation reaches its goal of reducing the national annual HIV infection rate by half in the next five years.

The Ryan White CARE Act should ensure that individuals who become aware that they are infected with HIV have access to medical and supportive care either through the Ryan White CARE Act or through another system of care.

There remain specific examples of conflicting institutional practices and authorizing legislation regarding programs and services for people living with HIV/AIDS. One example of a concern to CAEAR Coalition and AIDS Action was the eligibility of veterans for medical care under the Ryan White CARE Act and the responsibility of the VA for their care. Some had argued that Ryan White CARE Act grantees, as the payors of last resort, should not serve veterans. In a December 2004 policy notice, the HRSA HIV/AIDS Bureau clarified veterans' eligibility for Ryan White CARE Act-funded services and outlined the requirement that Ryan White CARE Act grantees coordinate services with local VA providers. The resolution of these issues reflects the type of coordination that needs to occur more broadly and expediently across all federal programs providing HIV/AIDS-related care and services. A mechanism is needed to rapidly resolve conflicting practices and perceptions in order to mitigate confusion among persons seeking care.

Recommendation #8a: The Ryan White CARE Act should continue developing better coordination among federal programs and funding streams, and should take measures to enhance this coordination. Further, the Ryan White CARE Act should provide a mechanism that will rapidly resolve any conflicting practices between federal agencies or departments coordinating with the HRSA HIV/AIDS Bureau, including the VA, CDC, Medicaid, SAMHSA, Centers for Medicare & Medicaid Services and HUD.

The Medicaid and Medicare programs, along with the Ryan White CARE Act, are the major payors for services for HIV/AIDS care, according to the HIV Cost and Services Utilization Study (HCSUS). Closer coordination has the potential to result in improved services for clients and better program management.

Recommendation #8b: Amend Section 2675(b) to read: The Secretary shall commission a report from the Associate Director of HRSA, HIV/AIDS Bureau and the CMS Director of Medicaid and State Operations to assess the coordination of CARE Act programs and state Medicaid programs, and to report what barriers to coordination of CMS and HRSA HIV programs exist and what successes have been achieved at the local, state and federal levels.

The Ryan White CARE Act requires Title I HIV health services planning councils to include a representative of the state Medicaid program on each of the councils. There is no corresponding requirement on the Medicaid program. CAEAR Coalition and AIDS Action believe a measure of flexibility is necessary for the Title I grantee where the state Medicaid program is unable or unwilling to send a representative.

Recommendation #8c: Amend Section 2602(b)(2)(i) as follows: (I) State government (including the State Medicaid Agency and the agency administering the program under part B). If a HIV health services planning council has not been able to fulfill this obligation, and has shown documentation of due diligence in its attempt to fulfill this obligation, the Eligible Metropolitan Area shall not be penalized in its grant.

Moreover, HRSA will make every attempt to work with CMS Medicaid and State Operation to facilitate a response from the state Medicaid program that has been negligent in fulfilling this request.

CAEAR Coalition and AIDS Action are supportive of allowing Early Intervention Services to be provided with Title I funds under specific circumstances in order to better link people living with HIV to care.

Recommendation #8d: The Ryan White CARE Act should maintain the existing set of parameters for Early Intervention Services, and all other collaborations outlined in the 2000 reauthorization.

CAEAR Coalition and AIDS Action acknowledge the major role of the VA as the single largest direct provider of HIV care and services in the nation. CAEAR Coalition and AIDS Action recommend regular consultations between the Secretary of Health and Human Services and the Secretary of Veterans Affairs to facilitate coordination at the highest level, as well as promoting local representation of VA entities on Title I planning councils to enhance program awareness and facilitate coordination. CAEAR Coalition and AIDS Action also support the eligibility of select VA facilities for Ryan White CARE Act funds in those locations where these facilities are determined to be the best possible source of care for non-veterans.

Recommendation #8e: Expand existing language to direct the Secretary of Health and Human Services to consult with the Department of Veterans Affairs at least biennially. Further, in order to facilitate collaboration and coordination at the local level, Title I HIV health services planning councils should be encouraged to include representation from the local VA in their membership. Furthermore, VA facilities providing HIV-related health services should be maintained as eligible entities to receive Ryan White CARE Act funds.

9. *AIDS Education & Training Centers*

HIV and AIDS prevention and treatment continue to increase in scope and complexity. Maintaining a well-educated and trained health professional workforce is essential in the effort to improve access to quality HIV treatment, care and prevention, reduce disparities, and enhance clinical capacity building.

Recommendation #9: CAEAR Coalition and AIDS Action support the continued reauthorization and funding of the AIDS Education and Training Centers to meet the education and training needs of health care professionals involved in HIV/AIDS prevention, treatment, and capacity building.

10. *Oral Health Services*

The Ryan White CARE Act addresses the unmet oral health needs of people living with HIV/AIDS through two programs, (1) the HIV/AIDS Dental Reimbursement Program and (2) the Community-Based Dental Partnership Program.

The HIV/AIDS Dental Reimbursement Program trains dental students and residents in the oral health complications associated with HIV and dental treatment considerations necessary to manage medically complex patients. This program provides partial reimbursement to academic dental institutions in recognition of the financial burden they incur in providing uncompensated care to people living with HIV/AIDS—often a population with significant oral health needs.

The Community-Based Dental Partnership Program was created by the Ryan White CARE Act Amendments of 2000. It supports and encourages partnerships between dental schools and communities for the primary purpose of increasing access to oral health care for people living HIV/AIDS and residing in areas lacking dental institutions. A secondary benefit of these partnerships is increasing the professional experience of dental students and residents in treating patients with HIV infection in community-based settings.

Each program fills a specific need in promoting access to oral and dental health care for people living with HIV/AIDS. The HIV/AIDS Dental Reimbursement Program addresses the need for skilled professionals to be knowledgeable in the care of people living with

HIV/AIDS, and the investment that academic dental institutions make in providing services to poor or indigent patients as a part of clinical training. The Community-Based Dental Partnership Program recognizes the reality that many communities lack dental educational facilities, and partnerships between communities and these institutions may be needed to address the unmet needs of patients in these communities. These complementary programs should be separately authorized and appropriated at such sums as necessary.

Recommendation #10a: Reauthorize the HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnership Program separately, at “such sums as necessary” through 2010.

Current eligible grantees in the HIV/AIDS Dental Reimbursement Program include dental schools, dental residency programs, and dental hygiene programs accredited by the Commission on Dental Accreditation.

Recommendation #10b: Maintain current eligibility criteria for grantees in the HIV/AIDS Dental Reimbursement Program.

Applications that document unreimbursed costs for oral health care provided to HIV/AIDS patients may be submitted annually by eligible grantees. Technical assistance should also be made available to eligible grantees to assist in applying for reimbursement for oral and dental care.

Recommendation #10c: Maintain retrospective reimbursement system in the HIV/AIDS Dental Reimbursement Program with a requirement that providers document to HRSA that clients served through the program are living with HIV. Provide technical assistance to help grantees in applying for reimbursement for oral and dental care provided to HIV/AIDS patients. Such reimbursement does present a challenge in trying to plan for the level of additional dental care needed within a state or EMA. Funded institutions must work closely with other entities in their jurisdictions in the planning process to help determine local service needs.

Recommendation #10d: If additional funding is appropriated, additional accredited dental schools should be encouraged to apply for community-based partnership grants, particularly those in areas of high need, while communities that lack an accredited dental school should be eligible to apply for these grants independent of a partnership with a dental school.

Participation of HIV/AIDS Dental Reimbursement Program grantees in Ryan White CARE Act all-Titles meetings facilitates better integration of systems of care and training of dental professionals as part of the comprehensive health care required by people living with HIV/AIDS and supported through the Ryan White CARE Act.

Recommendation #10e: Permit HIV/AIDS Dental Reimbursement Program grantees to utilize Ryan White CARE Act funds to participate in Ryan White CARE Act grantee meetings and other activities that foster participation and expansion of existing programs.

11. Price of Pharmaceuticals

The state AIDS Drug Assistance Programs (ADAPs), authorized and funded through Title II of the Ryan White CARE Act, serve approximately 30 percent of people living with HIV/AIDS and receiving care. Administered and designed by the states, ADAPs operate in 57 jurisdictions (all 50 states plus the District of Columbia, Puerto Rico, the U.S. Virgin Islands, the three Pacific Territories and an Associated Jurisdiction) and vary in terms of eligibility criteria and medications provided. The ADAP programs in many jurisdictions are unable to serve all who qualify. A survey of waiting lists for ADAP services found that between July 2002 and November 2004 the number of people on waiting lists ranged from a low of 537 to a high of 1629. Over this time period, 18 states had waiting lists. In addition to waiting lists, states have been forced to limit access through eligibility requirements, limited formularies, and other measures. One of the major factors in limiting access to ADAPs is the high cost of HIV medications. Unfortunately, state ADAPs do not receive the same low prices available to some federal programs, even though these programs are funded primarily with federal dollars.

Recommendation #11: The Secretary of Health and Human Services should be directed to ensure that Ryan White CARE Act programs receive the lowest prices for pharmaceuticals available to the federal government, currently the Departments of Defense and Veterans Affairs prices, unless otherwise negotiated at a lower rate.

12. Infrastructure and Capacity Expansion Program

There are numerous communities where people living with HIV/AIDS do not have access to high quality and culturally competent HIV care due to a lack of organizations with the commitment and/or the expertise to provide that care. In addition, both the CDC and HRSA expect to identify many more people living with HIV/AIDS who do not currently know their HIV status or individuals who have been tested and are aware of their HIV status but are not in care. The Ryan White CARE Act must connect such individuals to appropriate and regular medical and supportive services. In some communities there exist community health centers or other outpatient medical facilities without specialized HIV expertise. In others, there are organizations with the energy and commitment to respond to HIV/AIDS, but without the organizational and programmatic capacity to

deliver services effectively. There have been previous efforts within the Ryan White CARE Act to address these gaps with capacity building and planning grant funding. However, with rapidly growing service needs and flat funding over the past few appropriations cycles, these initiatives have received minimal investment. Building organizations to reach those in underserved communities requires a dedicated pool of funds that can only be used for infrastructure and capacity development.

Recommendation #12: The “Infrastructure and Capacity Expansion Program” should be added to Part F of the Ryan White CARE Act to be funded through a new appropriation line item with such sums as may be necessary. This program should be used expressly to provide resources to help organizations and jurisdictions serving medically underserved minority, rural, and urban communities build the infrastructure and capacity they need to improve access to, engagement with, maintenance in, and appropriate utilization of HIV/AIDS care in underserved communities where such care is difficult to access. The Ryan White CARE Act must ensure that individuals who learn of their HIV infection are connected to appropriate care and treatment. This infrastructure and service capacity expansion support must be of adequate scope and duration to ensure that funded entities have sufficient time and resources to develop the infrastructure necessary to sustain high quality programs. As a condition of award, funded programs must demonstrate their relevance to existing local, regional or state plans for HIV services.

Program Recommendations

The following recommendations do not require legislative changes to the Ryan White CARE Act, but do require administrative action or Congressional action in other areas.

13. Title III

Ryan White CARE Act Title III directly funds public and other private non-profit entities to develop, organize, coordinate and operate health systems for the delivery of health care and support services to medically underserved individuals and families affected by HIV/AIDS. Title III-funded programs provide clients with a comprehensive continuum of HIV primary care from the same community-based organizations that provide them with other kinds of medical care and support services, and allows for the creation of innovative systems of care. Building HIV primary care capacity within existing community health and medical service programs is both cost-effective and an efficient use of available resources. We continue to believe that this is a model for public health programs of the future.

By providing grants directly to community providers, Title III ensures a rapid clinical response to ever-changing treatment practices and addresses inadequacies in primary care and supportive services to poor areas, smaller cities, and rural communities. Grants reach geographically isolated communities in rural areas that lack HIV/AIDS primary medical care capacity as well as urban areas that continue to be confronted with increasing case loads and remain the sole source of culturally competent quality HIV/AIDS services for tens of thousands of people living with HIV/AIDS. Approximately 47 percent of Title III providers are located in rural and geographically isolated communities outside Title I areas and approximately 23 percent are the only outpatient HIV health care program available in their area.

Title III planning and capacity building grants are a critical tool for communities to explore the financial and program implications of starting or expanding primary health services. The expansion of services or development of new service delivery sites within existing community networks merits attention from members of that community. As coordination needs take on higher priorities, it is important that existing network participants are informed and, where appropriate, actively involved in the process from its initiation.

Recommendation #13a: The Secretary should direct the Administrator of HRSA to establish a formal plan to ensure that HIV/AIDS care is identified as a core component of health care services to be provided by 330 clinics and other Federally Qualified Health Centers administered by the HRSA Bureau of Primary Health Care. Additionally, steps should be taken to establish collaboration between the HRSA HIV/AIDS Bureau and the Bureau of Primary Health Care that reduces barriers that prevent community-based HIV service providers from successfully competing to become 330 clinics and Federally Qualified Health Centers. Training programs and technical assistance from Title III community health clinics and AIDS Education and Training Centers (AETCs) with significant HIV expertise to strategically located Community Health Centers (CHCs) where HIV health care is in short supply should be developed. As a part of their training, CHCs should develop cultural competency to go along with HIV competence.

Recommendation #13b: HRSA HIV/AIDS Bureau be instructed to be flexible in their initial agency capacity assessment to determine which capacity building grant category an agency is best suited to apply for based on its developmental stage.

Recommendation #13c: HRSA should make widely known the availability of technical assistance, both from currently funded Title III programs and from HRSA itself, in the development of unique and effective service delivery models that meet the needs of those in rural and medically underserved areas, and in smaller communities.

Recommendation #13d: Strengthen the HIV care infrastructure of Title III programs by directly funding existing and new Title III projects in rural and medically underserved areas, and those in smaller communities.

Recommendation #13e: The Secretary should direct HRSA to work collaboratively with the CDC to implement CDC's Advancing HIV Prevention initiative.

Recommendation #13f: Support continued use of resources provided through the MAI to expand the number of planning and capacity building grants, as well as Early Intervention Services grants targeted to culturally competent organizations that have a history of serving minority communities and ensure that people living with HIV/AIDS who are aware of their HIV status are able to access medical and supportive care.

Recommendation #13g: The HRSA HIV/AIDS Bureau should establish a process that will inform Title III grantees when organizations within their respective states are awarded planning and capacity building grants.

14. *Minority AIDS Initiative (MAI)*

The Minority AIDS Initiative expands and strengthens the capacity of minority community-based organizations (MCBOs) to deliver high-quality HIV health care and supportive services to historically underserved groups. The MAI addresses HIV-related health disparities faced by racial and ethnic minorities by providing targeted funding to:

- create and improve HIV service capacity in minority communities
- expand services in historically underserved minority communities and ensure sustainability, and
- reduce persistent health disparities.

The MAI was created in 1998 in an effort to provide funding and services targeted to African American communities as a result of the state of emergency declared by the Congressional Black Caucus (CBC) for the alarming rates of HIV/AIDS in this community. In 2000, the MAI included the Congressional Hispanic Caucus, the Asian Pacific American Caucus and Native American Caucus to address the rampant impact of HIV/AIDS through all communities of color. While the MAI is not a component of the Ryan White CARE Act, it provides additional, targeted resources for Ryan White CARE Act programs, as well as other HIV/AIDS programs in HHS. The initiative allows for (1) the creation and improvement of HIV service capacity in communities of color and (2) for the expansion of services in historically underserved minority communities and to ensure these services remain intact. These targeted capacity building and service dollars are allocated across HHS agencies, including HRSA, as well as the CDC, Office of Minority Health, SAMHSA, NIH and the Office of the Secretary.

CAEAR Coalition and AIDS Action support the goals of the MAI to expand the infrastructure of community-based organizations and HIV service delivery to people of color living with HIV/AIDS. CAEAR Coalition and AIDS Action support the allocation of targeted resources to address the development, implementation and provision of high quality care to underserved communities of color. In addition, CAEAR Coalition and AIDS Action maintain that the MAI should continue to increase allocations through existing Ryan White CARE Act Titles and that these funds should not be used to supplant other HIV/AIDS resources.

Recommendation #14: There continues to be a need for targeted federal appropriations serving hard-to-reach populations of color disproportionately affected by the HIV/AIDS epidemic. CAEAR Coalition and AIDS Action recommend that:

- The MAI be preserved to address the development, implementation and provision of high quality care to underserved populations.
- Appropriations to the MAI should be increased.
- The MAI maintain funding allocations through existing Ryan White CARE Act Titles.

- MAI funds are not used to supplant other HIV/AIDS resources at the local level.
- Local conditions are recognized.
- The current MAI structure remains the same as per the previous recommendations.

15. Federal Coordination

Coordination between HRSA and CDC has increased at the federal level, with the merging of their respective HIV/AIDS advisory committees into one. CAEAR Coalition and AIDS Action believe that enhanced coordination of prevention and care planning at the local level will further facilitate the goals of increasing identification of prevalent HIV infections, ensuring that people living with HIV/AIDS are able to access medical and supportive care, and delivering targeted prevention education.

Recommendation #15: Direct collaboration between local care and prevention planning bodies should be encouraged, and a requirement developed that care planning bodies conduct a joint assessment with their local prevention counterpart to study the merits and challenges of collaboration and to establish a plan for future coordination.

Appendix A: Proposed Changes In EMA Boundaries Based on OMB Classifications

Current EMA	Member counties/Jurisdictions	New CSA, MSA or MD	Member counties/Jurisdictions	Difference (+/-)
Atlanta, GA	Barrow County, Bartow County, Carroll County, Cherokee County, Clayton County, Cobb County, Coweta County, DeKalb County, Douglas County, Fayette County, Forsyth County, Fulton County, Gwinnett County, Henry County, Newton County, Paulding County, Pickens County, Rockdale County, Spalding County, Walton County	Atlanta-Sandy Springs-Marietta, GA MSA	Barrow County, Bartow County, Butts County, Carroll County, Cherokee County, Clayton County, Cobb County, Coweta County, Dawson County, DeKalb County, Douglas County, Fayette County, Forsyth County, Fulton County, Gwinnett County, Haralson County, Heard County, Henry County, Jasper County, Lamar County, Meriwether County, Newton County, Paulding County, Pickens County, Pike County, Rockdale County, Spalding County, Walton County	Add: Butts, Dawson, Haralson, Heard, Jasper, Lamar, Meriwether, and Pike counties
Austin, TX	Bastrop County, Caldwell County, Hays County, Travis County, Williamson County	Austin-Round Rock, TX MSA	Bastrop County, Caldwell County, Hays County, Travis County, Williamson County	None
Baltimore, MD	Anne Arundel County, Baltimore City, Baltimore County, Carroll County, Harford County, Howard County, Queen Anne's County	Baltimore-Towson, MD MSA	Anne Arundel County, Baltimore County, Carroll County, Harford County, Howard County, Queen Anne's County, Baltimore city	None
Bergen-Passaic, NJ	Bergen County, Passaic County	A part of the New York-Wayne-White Plains, NY-NJ MD		No longer exists as an MSA or MD
Boston, MA	Bristol County, MA; Essex County, MA; Middlesex County, MA; Norfolk County, MA; Plymouth County, MA; Suffolk County, MA; Worcester County, MA; Hillsborough County, NH; Rockingham County, NH; Strafford County, NH.	Boston-Worcester-Manchester, MA-NH Combined Statistical Area	<p>BOSTON-CAMBRIDGE-QUINCY, MA-NH METROPOLITAN STATISTICAL AREA</p> <p>Essex County, Middlesex County, Norfolk County, Plymouth County, and Suffolk County, MA; Rockingham County and Strafford County, NH</p> <p>CONCORD, NH MICROPOLITAN STATISTICAL AREA</p> <p>Merrimack County</p> <p>LACONIA, NH MICROPOLITAN STATISTICAL AREA</p> <p>Belknap County</p> <p>MANCHESTER-NASHUA, NH METROPOLITAN STATISTICAL AREA</p> <p>Hillsborough County</p> <p>WORCESTER, MA METROPOLITAN STATISTICAL AREA</p> <p>Worcester County</p>	<p>Add: Belknap and Merrimack counties, NH</p> <p>Lose: Bristol County, MA</p>
Caguas	Caguas Municipio, Cayey Municipio, Cidra Municipio, Gurabo Municipio, San Lorenzo Municipio	A part of the San Juan MSA		No longer exists as an MSA or MD
Chicago, IL	Cook County, DeKalb County, DuPage County, Grundy County, Kane County, Kendall County, Lake County, McHenry County, Will County	Chicago-Naperville-Joliet, IL-IN-WI MSA	<p>CHICAGO-NAPERVILLE-JOLIET, IL METROPOLITAN DIVISION:</p> <p>Cook County, DeKalb County, DuPage County, Grundy County, Kane County, Kendall County, McHenry County, Will County</p> <p>GARY, IN METROPOLITAN DIVISION:</p> <p>Jasper County, Lake County, Newton County, Porter County</p> <p>LAKE COUNTY-KENOSHA COUNTY, IL-WI METROPOLITAN DIVISION:</p> <p>Lake County, IL; Kenosha County, WI</p>	Add: Jasper, Lake, Newton, and Porter counties, IN, and Kenosha County, WI
Cleveland, OH	Ashtabula County, Cuyahoga County, Geauga County, Lake County, Lorain County, Medina County	Cleveland-Elyria-Mentor, OH MSA	Cuyahoga County, Geauga County, Lake County, Lorain County, Medina County	Lose: Ashtabula County

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Current EMA	Member counties/Jurisdictions	New CSA, MSA or MD	Member counties/Jurisdictions	Difference (+/-)
Dallas, TX	Collin County, Dallas County, Denton County, Ellis County, Henderson County, Hunt County, Kaufman County, Rockwall County	Dallas-Plano-Irving, TX MD	Collin County, Dallas County, Delta County, Denton County, Ellis County, Hunt County, Kaufman County, Rockwall County	Add: Delta County Lose: Henderson County.
Denver, CO	Adams County, Arapahoe County, Denver County, Douglas County, Jefferson County	Denver-Aurora, CO MSA	Adams County, Arapahoe County, Broomfield County *, Clear Creek County, Denver County, Douglas County, Elbert County, Gilpin County, Jefferson County, Park County	Add: Broomfield, Clear Creek, Elbert, Gilpin, and Park counties
Detroit, MI	Lapeer County, Macomb County, Monroe County, Oakland County, St. Clair County, Wayne County	Detroit-Warren-Livonia, MI MSA	DETROIT-LIVONIA-DEARBORN, MI METROPOLITAN DIVISION: Wayne County WARREN-FARMINGTON HILLS-TROY, MI METROPOLITAN DIVISION: Lapeer County, Livingston County, Macomb County, Oakland County, St. Clair County	Add: Livingston County Lose: Monroe County
Dutchess County, NY	Dutchess County	Poughkeepsie-Newburgh-Middleton, NY MSA	Dutchess County, Orange County	Add: Orange County
Ft. Lauderdale, FL	Broward County	Fort Lauderdale-Pompano Beach-Deerfield Beach, FL MD	Broward County	None
Ft. Worth, TX	Hood County, Johnson County, Parker County, Tarrant County	Fort Worth-Arlington, TX MD	Johnson County, Parker County, Tarrant County, Wise County	Add: Wise County Lose: Hood County
Hartford, CT	Hartford County, Middlesex County, Tolland County	Hartford-West Hartford-East Hartford, CT MSA	Hartford County, Middlesex County, Tolland County	None
Houston, TX	Chambers County, Fort Bend County, Harris County, Liberty County, Montgomery County, Waller County	Houston-Baytown-Sugar Land, TX MSA	Austin County, Brazoria County, Chambers County, Fort Bend County, Galveston County, Harris County, Liberty County, Montgomery County, San Jacinto County, Waller County	Add: Austin, Brazoria, Galveston, San Jacinto counties
Jacksonville, FL	Clay County, Duval County, Nassau County, St. Johns County	Jacksonville, FL MSA	Baker County, Clay County, Duval County, Nassau County, St. Johns County	Add: Baker County
Jersey City, NJ	Hudson County	A part of the New York-Wayne-White Plains, NY-NJ MD		No longer exists as an MSA or MD
Kansas City, MO	Johnson County, Leavenworth County, Miami County, Wyandotte County, Cass County, Clay County, Clinton County, Jackson County, Lafayette County, Platte County, Ray County	Kansas City, MO-KS MSA	Franklin County, KS; Johnson County, KS; Leavenworth County, KS; Linn County, KS; Miami County, KS; Wyandotte County, KS; Bates County, MO; Caldwell County, MO; Cass County, MO; Clay County, MO; Clinton County, MO; Jackson County, MO; Lafayette County, MO; Platte County, MO; Ray County, MO	Add: Franklin and Linn counties, KS, and Bates and Caldwell counties, MO
Las Vegas, NV	Mohave County, Clark County, Nye County	Las Vegas-Paradise, NV MSA	Clark County	Lose: Mohave and Nye counties
Los Angeles, CA	Los Angeles County	Los Angeles-Long Beach-Glendale, CA MD	Los Angeles County	None
Miami, FL	Miami-Dade County	Miami-Miami Beach-Kendall, FL MD	Miami-Dade County	None
Middlesex-Somerset-Hunterdon, NJ	Hunterdon County, Middlesex County, Somerset County	Edison, NJ MD	Middlesex County, Monmouth County, Ocean County, Somerset County	Add: Monmouth, Ocean counties Lose: Hunterdon (now in Newark-Union, NJ-PA MD)
Minneapolis-St. Paul, MN	Anoka County, MN; Carver County, MN; Chisago County, MN; Dakota County, MN; Hennepin County, MN; Isanti County, MN; Ramsey County, MN; Scott County, MN; Sherburne County, MN; Washington County, MN; Wright County, MN; Pierce County, WI; St. Croix County, WI	Minneapolis-St Paul-Bloomington, MN-WI MSA	Anoka County, MN; Carver County, MN; Chisago County, MN; Dakota County, MN; Hennepin County, MN; Isanti County, MN; Ramsey County, MN; Scott County, MN; Sherburne County, MN; Washington County, MN; Wright County, MN; Pierce County, WI; St. Croix County, WI	None

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Current EMA	Member counties/Jurisdictions	New CSA, MSA or MD	Member counties/Jurisdictions	Difference (+/-)
Nassau-Suffolk, NY	Nassau County, Suffolk County	Nassau-Suffolk, NY MD	Nassau County, Suffolk County	None
New Haven, CT	Fairfield County, New Haven County	New Haven-Milford, CT MSA	New Haven County	Lose: Fairfield County
New Orleans, LA	Jefferson Parish, Orleans Parish, Plaquemines Parish, St. Bernard Parish, St. Charles Parish, St. James Parish, St. John the Baptist Parish, St. Tammany Parish	New Orleans-Metairie-Kenner, LA MSA	Jefferson Parish, Orleans Parish, Plaquemines Parish, St. Bernard Parish, St. Charles Parish, St. John the Baptist Parish, St. Tammany Parish	Lose: St. James Parish
New York, NY	Bronx County, NY; Kings County, NY; New York County, NY; Putnam County, NY; Queens County, NY; Richmond County, NY; Rockland County, NY; Westchester County, NY	New York-Wayne-White Plains, NY-NJ MD	Bergen County, NJ; Hudson County, NJ; Passaic County, NJ; Bronx County, NY; Kings County, NY; New York County, NY; Putnam County, NY; Queens County, NY; Richmond County, NY; Rockland County, NY; Westchester County, NY	Add: Bergen, Hudson and Passaic counties, NJ
Newark, NJ	Essex County, Morris County, Sussex County, Union County, Warren County	Newark-Union, NJ-PA MD	Essex County, NJ; Hunterdon County, NJ; Morris County, NJ; Sussex County, NJ; Union County, NJ; Pike County, PA	Add: Hunterdon County (formerly in the Middlesex EMA)
Norfolk, VA	Currituck County, NC; Gloucester County, VA; Isle of Wight County, VA; James City County, VA; Mathews County, VA; York County, VA; Chesapeake city, VA; Hampton city, VA; Newport News city, VA; Norfolk city, VA; Poquoson city, VA; Portsmouth city, VA; Suffolk city, VA; Virginia Beach city, VA; Williamsburg city, VA	Virginia Beach-Norfolk-Newport News, VA-NC MSA	Currituck County, NC; Gloucester County, VA; Isle of Wight County, VA; James City County, VA; Mathews County, VA; Surry County, VA; York County, VA; Chesapeake city, VA; Hampton city, VA; Newport News city, VA; Norfolk city, VA; Poquoson city, VA; Portsmouth city, VA; Suffolk city, VA; Virginia Beach city, VA; Williamsburg city, VA	Add: Surry County, VA
Oakland, CA	Alameda County, Contra Costa County	Oakland-Fremont-Hayward, CA MD	Alameda County, Contra Costa County	None
Orange County, CA	Orange County	Santa Ana-Anaheim-Irvine, CA MD	Orange County	None
Orlando, FL	Lake County, Orange County, Osceola County, Seminole County	Orlando, FL MSA	Lake County, Orange County, Osceola County, Seminole County	None
Philadelphia, PA	Burlington County, NJ; Camden County, NJ; Gloucester County, NJ; Salem County, NJ; Bucks County, PA; Chester County, PA; Delaware County, PA; Montgomery County, PA; Philadelphia County, PA	Philadelphia-Camden-Wilmington, PA-NJ-DE-MD MSA	CAMDEN, NJ METROPOLITAN DIVISION: Burlington County, Camden County, Gloucester County PHILADELPHIA, PA METROPOLITAN DIVISION: Bucks County, Chester County, Delaware County, Montgomery County, Philadelphia County WILMINGTON, DE-MD-NJ METROPOLITAN DIVISION: New Castle County, DE; Cecil County, MD; Salem County, NJ	Add: New Castle County, DE, and Cecil County, MD
Phoenix, AZ	Maricopa County, Pinal County	Phoenix-Mesa-Scottsdale MSA	Maricopa County, Pinal County	None
Ponce, PR	Guayanilla Municipio, Juan Diaz Municipio, Penuelas Municipio, Ponce Municipio, Villalba Municipio, Yauco Municipio	Ponce, PR MSA	Juana Díaz Municipio, Ponce Municipio, Villalba Municipio	Lose: Guayanilla, Penuelas, and Yauco Municipio
Portland, OR	Clackamas County, OR; Columbia County, OR; Multnomah County, OR; Washington County, OR; Yamhill County, OR; Clark County, WA	Portland-Vancouver-Beaverton, OR-WA MSA	Clackamas County, OR; Columbia County, OR; Multnomah County, OR; Washington County, OR; Yamhill County, OR; Clark County, WA; Skamania County, WA	Add: Skamania County, WA
Riverside-San Bernardino, CA	Riverside County, San Bernardino County	Riverside-San Bernardino-Ontario, CA MSA	Riverside County, San Bernardino County	None
Sacramento, CA	El Dorado County, Placer County, Sacramento County	Sacramento—Arden-Arcade—Roseville MSA	El Dorado County, Placer County, Sacramento County, Yolo County	Add: Yolo County
San Antonio, TX	Bexar County, Comal County, Guadalupe County, Wilson County	San Antonio, TX, MSA	Atascosa County, Bandera County, Bexar County, Comal County, Guadalupe County, Kendall County, Medina County, Wilson County	Add: Atascosa, Bandera, Kendall, Medina counties

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Current EMA	Member counties/Jurisdictions	New CSA, MSA or MD	Member counties/Jurisdictions	Difference (+/-)
San Diego, CA	San Diego County	San Diego-Carlsbad-San Marcos, CA MSA	San Diego County	None
San Francisco, CA	Marin County, San Francisco County, San Mateo County	San Francisco-San Mateo-Redwood City, CA MD	Marin County, San Francisco County, San Mateo County	None
San Jose, CA	Santa Clara County	San Jose-Sunnyvale-Santa Clara, CA MSA	San Benito County, Santa Clara County	Add: San Benito County
San Juan, PR	Aguas Buenas Municipio, Barceloneta Municipio, Bayamon Municipio, Canovanas Municipio, Carolina Municipio, Catano Municipio, Ceiba Municipio, Comerio Municipio, Corozal Municipio, Dorado Municipio, Fajardo Municipio, Florida Municipio, Guaynabo Municipio, Humacao Municipio, Juncos Municipio, Las Piedras Municipio, Loiza Municipio, Luquillo Municipio, Manati Municipio, Morovis Municipio, Naguabo Municipio, Naranjito Municipio, Rio Grande Municipio, San Juan Municipio, Toa Alto Municipio, Toa Baja Municipio, Trujillo Alto Municipio, Vega Alta Municipio, Vega Baja Municipio, Yabucoa Municipio	San Juan-Caugus-Guaynabo, PR, MSA	Aguas Buenas Municipio, Aibonito Municipio, Arecibo Municipio, Barceloneta Municipio, Barranquitas Municipio, Bayamón Municipio, Caguas Municipio, Camuy Municipio, Canóvanas Municipio, Carolina Municipio, Cataño Municipio, Cayey Municipio, Ciales Municipio, Cidra Municipio, Comerio Municipio, Corozal Municipio, Dorado Municipio, Florida Municipio, Guaynabo Municipio, Gurabo Municipio, Hatillo Municipio, Humacao Municipio, Juncos Municipio, Las Piedras Municipio, Loiza Municipio, Manatí Municipio, Maunabo Municipio, Morovis Municipio, Naguabo Municipio, Naranjito Municipio, Orocovis Municipio, Quebradillas Municipio, Río Grande Municipio, San Juan Municipio, San LorenzoMunicipio, Toa Alta Municipio, Toa Baja Municipio, Trujillo Alto Municipio, Vega Alta Municipio, Vega Baja Municipio, Yabucoa Municipio	Add: Aibonito, Arecibo, Barranquitas, Caguas, Camuy, Cayey, Ciales, Cidra, Gurabo, Hatillo, Maunabo, Orocovis, Quebradillas, San Lorenzo Municipios Lose: Ceiba, Fajardo, Luquillo Municipios
Santa Rosa, CA	Sonoma County	Santa Rosa-Petaluma, CA MSA	Sonoma County	None
Seattle, WA	Island County, King County, Snohomish County	Seattle-Tacoma-Bellevue, WA MSA	SEATTLE-BELLEVUE-EVERETT, WA METROPOLITAN DIVISION: King County, Snohomish County TACOMA, WA METROPOLITAN DIVISION: Pierce County	Add: Pierce County Lose: Island County
St. Louis, MO	Clinton County, IL; Jersey County, IL; Madison County, IL; Monroe County, IL; St. Clair County, IL; Franklin County, MO; Jefferson County, MO; Lincoln County, MO; St. Charles County, MO; St. Louis County, MO; Warren County, MO; St. Louis city, MO	St Louis, MO-IL MSA	Bond County, IL; Calhoun County, IL; Clinton County, IL; Jersey County, IL; Macoupin County, IL; Madison County, IL; Monroe County, IL; St. Clair County, IL; Crawford County, MO (part—Sullivan city); Franklin County, MO; Jefferson County, MO; Lincoln County, MO; St. Charles County, MO; St. Louis County, MO; Warren County, MO; Washington County, MO; St. Louis city, MO	Add: Bond, Calhoun, and Macoupin counties, IL; Crawford County, MO; Washington County, MO
Tampa-St. Petersburg, FL	Hernando County, Hillsborough County, Pasco County, Pinellas County	Tampa-St Petersburg-Clearwater, FL MSA	Hernando County, Hillsborough County, Pasco County, Pinellas County	None
Vineland-Millville-Bridgeton, NJ	Cumberland County	Vineland-Millville-Bridgeton, NJ MSA	Cumberland County	None
Washington, DC	District of Columbia, DC; Calvert County, MD; Charles County, MD; Frederick County, MD; Montgomery County, MD; Prince George's County, MD; Arlington County, VA; Clarke County, VA; Culpeper County, VA; Fairfax County, VA; Fauquier County, VA; King George County, VA; Loudoun County, VA; Prince William County, VA; Spotsylvania County, VA; Stafford County, VA; Warren County, VA; Alexandria city, VA; Fairfax city, VA; Falls Church city, VA; Fredericksburg city, VA; Manassas city, VA; Manassas Park city, VA; Berkeley County, WV; Jefferson County, WV	Washington-Arlington-Alexandria, DC-VA-MD-WV MSA	BETHESDA-FREDERICK-GAITHERSBURG, MD METROPOLITAN DIVISION: Frederick County, Montgomery County WASHINGTON-ARLINGTON-ALEXANDRIA, DC-VA-MD-WV METROPOLITAN DIVISION: District of Columbia, DC; Calvert County, MD; Charles County, MD; Prince George's County, MD; Arlington County, VA; Clarke County, VA; Fairfax County, VA; Fauquier County, VA; Loudoun County, VA; Prince William County, VA; Spotsylvania County, VA; Stafford County, VA; Warren County, VA; Alexandria city, VA; Fairfax city, VA; Falls Church city, VA; Fredericksburg city, VA; Manassas city, VA; Manassas Park city, VA; Jefferson County, WV	Lose: Culpepper and King George counties, VA and Berkeley County, WV
West Palm Beach, FL	Palm Beach County	West Palm Beach-Boca Raton-Boynton Beach, FL MD	Palm Beach County	None

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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.

COMMUNITIES ADVOCATING
EMERGENCY AIDS RELIEF

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until it's over

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