

The Ryan White CARE Act & Reauthorization 2005:

A Briefing for OPA/OFP HIV Prevention Projects

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Today's U.S. HIV/AIDS Epidemic

- Between 1,039,000 and 1,185,000 living with HIV disease in the U.S.
- 24-27% undiagnosed and unaware of their HIV infection.
- 40,000 new HIV infections and about 16,000 AIDS related deaths per year.

Source: CDC Surveillance Report Vol.15, 2003 and Glynn M, Rhodes P. Estimated HIV prevalence in the United States at the end of 2003. National HIV Prevention Conference; June 2005; Atlanta.

Where We Were . . . How Far We've Come

- In the 25 years since the AIDS epidemic was first recognized, the pattern and the treatment of HIV disease have shifted dramatically.
- In 1990, when the CARE Act legislation was first passed, an AIDS diagnosis was still a death sentence.
- The structures created in the CARE Act focused on later medical intervention and providing support services for individuals who became severely disabled and died in a relatively short time frame.

Where We Were . . . How Far We've Come

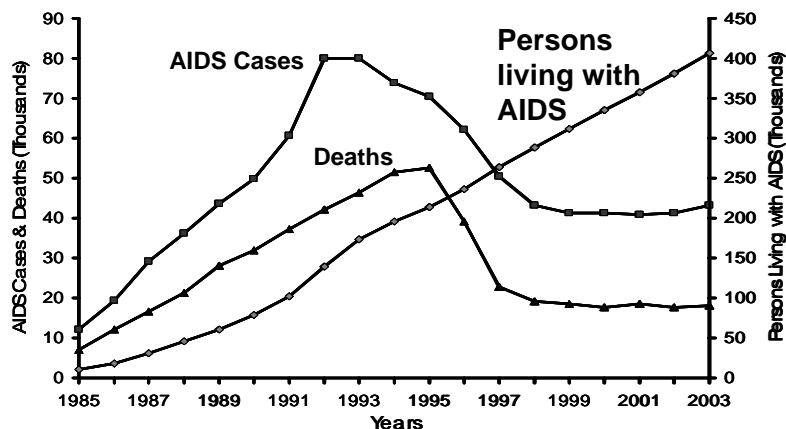
- First reauthorization in 1996 - new treatments were postponing death; prognosis for PLWH still quite grim
- 1996 reauthorization - stronger emphasis on medical services and the nationalization of the epidemic
- Late 1990s - Highly Active Anti-Retroviral Therapy (HAART) shown to be successful in slowing disease progression, disability, and death
- Today, many patients who know their status, enter and stay in continuous care over their lifetime, experiencing HIV/AIDS as a lifetime chronic disease.

Where We Were . . . How Far We've Come

- The reauthorization of 2005 will reflect an even greater emphasis on prioritizing medical care and treatment provision for a growing number of persons living with HIV/AIDS that rely on CARE Act programs.

- Greater attention to life prolonging anti-retroviral treatments and the challenges posed by these costly and complex therapies is needed.

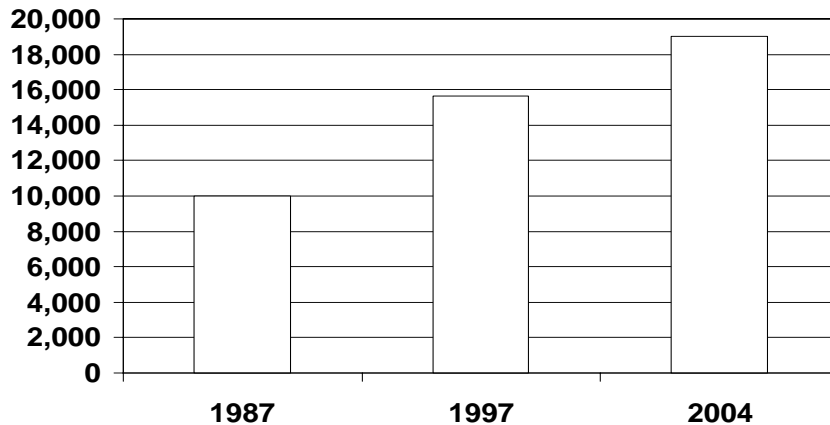
Annual Numbers of AIDS Cases, Deaths of Persons with AIDS, and Persons Living with AIDS, United States (including US Territories), 1985-2003



Source: CDC (RSJanssen – 2004) Note: Estimates are adjusted for reporting delays



Average National Annual Cost Per Patient For HIV/AIDS Care

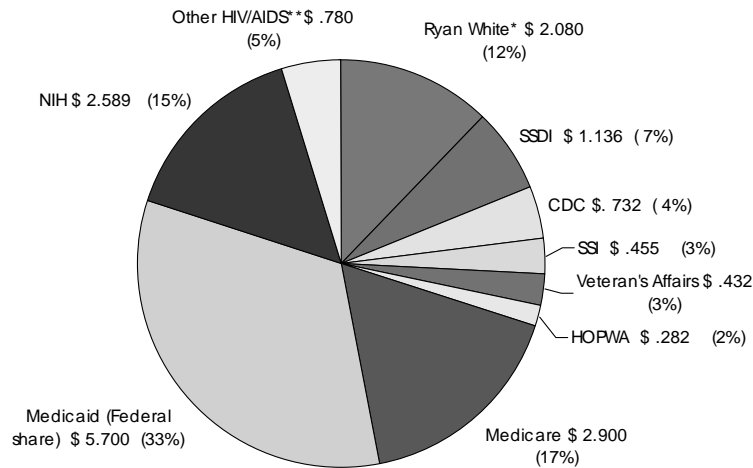


- > Source: Kaiser Family Foundation, 2004 and
- > Gebo, KA et al, "Costs of HIV Medical Care in the Era of Highly Active Antiretroviral Therapy," *AIDS* 1999, 13.



Domestic Federal Funding For HIV/AIDS – FY 2005

Total: \$17.1 billion* (in billions \$)



Source: DHHS Budget Office

*Ryan White estimates includes appropriated funds and \$25 million SPNS Evaluation Set-Aside.

**Other includes OPM, SAMHSA, FDA, DOD, DHHS/OS, BOP, etc.

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

Purpose – To fund medical care and essential support services for individuals living with HIV disease who do not have the resources to acquire services on their own.

CARE Act Programs

- Title I: Eligible Metropolitan Areas
- Title II: States and Territories
- Title III: Early Intervention Services
- Title IV: Women, children and families
- Part F:
 - Special Projects of National Significance
 - Dental Programs
 - AIDS Education and Training Centers

Title I: Eligible Metropolitan Areas (EMAs)

- There are 51 EMAs today.
- EMAs have at least 500,000 inhabitants and 2,000 reported AIDS cases in the past 5 years.
- Grants fund medical care, support services, counseling and testing.
- Planning council allocates grant to fund specific services, according to local needs.

Title II: States and Territories

- Provides formula grants to all 50 States, the District of Columbia, Puerto Rico, Guam, U.S. Virgin Islands, and five U.S. Pacific Territories and Associated Jurisdictions.
- Title II includes AIDS Drug Assistance Program and Emerging Communities.
- Grants fund medical care, home-based care, support services, outreach, counseling and testing.
- Spending decisions made at state and local level.

Title II: AIDS Drug Assistance Program

- Provides medications for the treatment of HIV disease, health insurance with a prescription drug benefit and adherence support.
- Congress “earmarks” funds which are distributed by formula.
- Grants are awarded to all 50 States, the District of Columbia, Puerto Rico, the Virgin Islands, Guam, the Marshall Islands and North Marianas Islands.
- Severe need – based on Federal Poverty Level, medical criteria, # of medications on formulary

Title III: Early Intervention Services (EIS)

- Grants are awarded directly to providers, rather than to State or local governments.
- Funds comprehensive primary care, counseling and testing and case management.
- At least 50% of EIS grants must be used for primary care.
- A comparatively small portion of funds are used for other support services.

Title III: Planning and Development Grants

- 2000 provisions modify the Title III planning grant program to create two types of grants.
- Grants that prepare organizations to provide EIS. Funding: \$50,000 maximum for one year only.
- Grants for capacity building. Funding: \$150,000 maximum over a three-year period.

Title IV: Women, Children and Families

- Grants are awarded directly to providers.
- Funds and coordinates care for the entire family. At least one family member must be HIV-positive.
- Funds primary care, counseling, testing, and case management.
- Links to research

Special Projects of National Significance (SPNS)

- Identify service delivery models that improve outcomes and increase efficiency.
- Demonstration projects among a range of hard-to-reach populations, primarily in care settings.

Dental Reimbursement Program

- Reimbursement for partial costs of oral health services for PLWH.
- Eligible institutions:
 - dental schools
 - schools of dental hygiene
 - post-doctoral dental education programs

Community-Based Dental Partnership Program

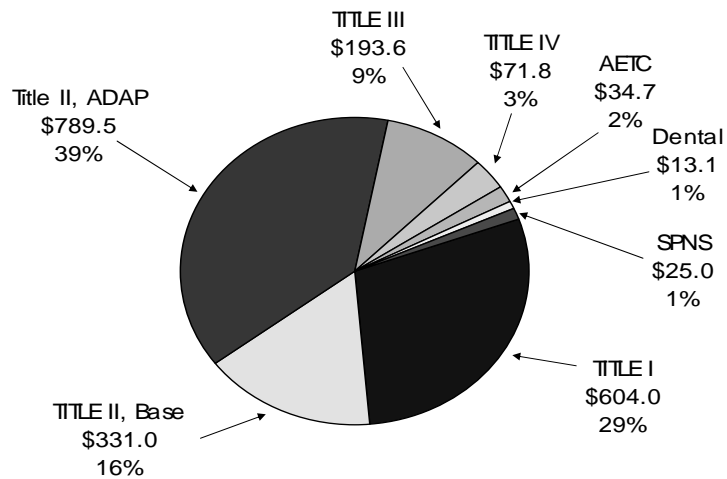
- Grants for cooperative projects with community-based providers of oral health services.
- Goal: to expand access to oral health care while training additional dental and dental hygiene providers.
- Eligible institutions:
 - dental schools
 - schools of dental hygiene
 - post-doctoral dental education programs

AIDS Education and Training Centers (AETCs)

- Purpose – train health care providers to counsel, diagnose, treat, and medically manage individuals with HIV infection and to help prevent high risk behaviors that lead to HIV transmission.
- 11 regional AETCs with over 130 sites
- National Minority AETC, National Resource AETC, National Clinical Consultation Center, National Evaluation AETC

FY 2006 CARE Act Appropriations

Total Amount = \$2.06 Billion*

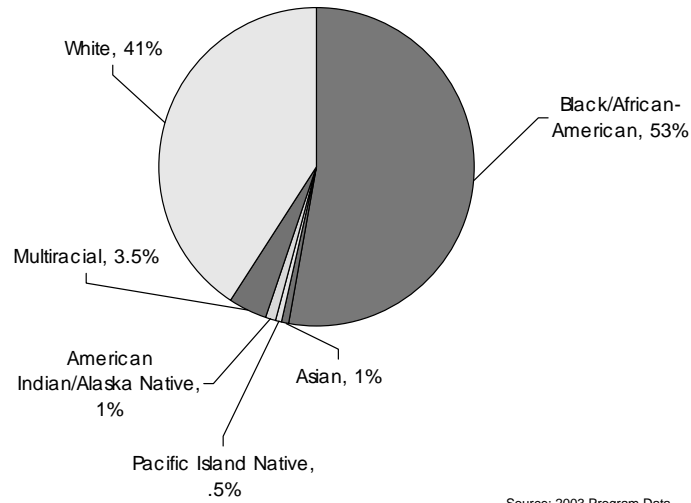


*Includes \$25 million for SPNS funding from Evaluation Set-Aside
Source: HAB/HRSA Budget Office

Clients Served

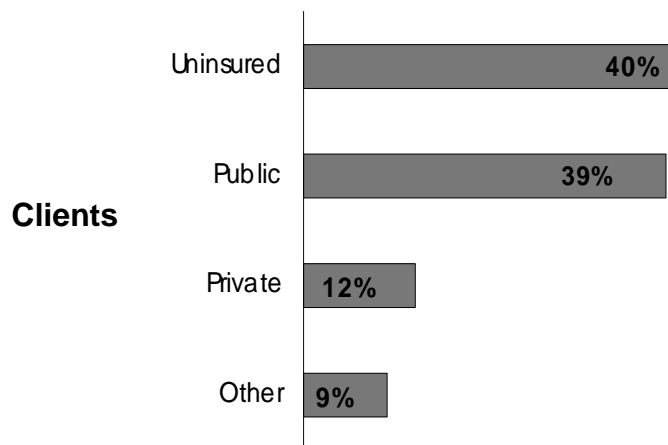
- Approximately 571,000 people served every year.
- Clients live in urban, suburban, rural and frontier areas.
- Most of clients receive clinical care, medications and some support services.

Clients: Race



Source: 2003 Program Data
Race was unknown or unreported for 174,644 of the 1,120,646 duplicated clients served in 2003.

Insurance Status



Source: Title III EIS Clients by 2001 Program Data.

Clients: Gender

- Sixty-six percent are male
- Thirty-three percent are female
- One percent are transgendered

Source: 2003 Program Data
Gender was unknown/unreported for 52,777 clients.

HRSA's Role in CDC's Advancing HIV Prevention (AHP) Initiative

- BPHC working with CDC to evaluate HIV testing within CHCs.
- RWCA AETCs actively involved in training around rapid testing and prevention with positives.
- HAB established Perinatal hotline to assist clinicians with perinatal transmission questions.
- CDC, HRSA, and CMS developing integrated case management guidelines.

CARE Act Accomplishments

- Reach over 571,000 uninsured and underinsured persons affected by HIV/AIDS annually.
- Provide lifesaving medications to an estimated 143,711 persons living with HIV/AIDS in 2003.
- Reach those most in need, with an estimated 65 percent racial minorities, 31 percent women, and 79 percent uninsured/underinsured or receiving public health benefits.
- Build networks and systems of care with and between public and private providers for a comprehensive response to the epidemic.
- Extend our knowledge base and expertise to improve the quality of HIV/AIDS care and treatment across the health care system.

CARE Act Challenges

- Increased demand for RWCA services in an environment of few new resources, rising costs and growing HIV/AIDS prevalence.
- Expanding access to life-saving medications at the lowest possible price.
- Fair and equitable distribution of CARE Act resources.
- Prioritizing primary care services to meet the essential needs of a growing number of people depending on CARE Act.
- Assuring sound fiscal management and stewardship of scarce CARE Act resources.

Family Planning and HIV

- Preventive health services including STD and HIV screenings
- Assist individuals in preventing STIs including HIV and concomitant conditions

Title X and the CARE Act

- Title I Planning Council Representation – providers of HIV prevention services
- Title I EIS with follow-up referral at “health care points of entry”, which include family planning clinics.
- Title I funded providers and formal relationships with “health care points of entry”. See <http://www.caear.org/foundation/index.htm>.
- Title II has mirror requirements.

Title X and the CARE Act

- Title III – eligible grantees.
- AETC – protocols and training relative to prenatal and other gynecological care for women; also have the 4TC initiative.

Principles for Reauthorization

- In his 2005 and 2006 State of the Union Address, and in his 2005 World AIDS Day message, President Bush called for the reauthorization of the RWCA based on the principles of focusing Federal resources on life-extending care; ensuring flexibility by targeting resources to address areas of greatest need; and achieving results.
- The Administration's further refinement of those principles for reauthorization of the RWCA to:
 - Serve the Neediest First
 - Focus on Life-Saving and Life-Extending Services
 - Increase Prevention Efforts
 - Increase Accountability
 - Increase Flexibility

Principles for Reauthorization

- Serve the Neediest First
 - Establish objective indicators to determine severity of need for funding core medical services.

Principles for Reauthorization

- Focus on Life-Saving and Life-Extending Services.
 - Establish a set of core medical services.
 - Require that 75 percent of funds for Titles I, II, III and IV be spent on core services.
 - Establish and maintain a list of core medications for the AIDS Drug Assistance Program (ADAP).

Principles for Reauthorization

- Increase Prevention Efforts
 - Require States to implement routine voluntary HIV testing in public facilities.
 - Work with private health care providers to implement routine voluntary HIV testing.

Principles for Reauthorization

- Increase Accountability
 - Require States to submit HIV data by 2007.
 - Strengthen payor-of-last-resort provisions.
 - Require State and local coordination of care.
 - Eliminate double counting of AIDS cases between Eligible Metropolitan Areas (EMAs) and States.
 - Eliminate “hold harmless” provisions.
 - Hold grantees accountable for reporting on system and client-level data and progress.

**Determining the Feasibility of Implementing Client Level
Data Reporting for the Ryan White CARE Act:
A Client-Level Data Assessment**

1. Conduct a consultation with grantees to obtain input on content of client-level data feasibility assessment (completed)
2. Select a sample of grantees and sub-grantee service providers
3. Prepare topic guide to facilitate discussions with sample grantees and providers
 - Software/hardware capabilities
 - Current data collection processes

**Determining the Feasibility of Implementing Client Level
Data Reporting for the Ryan White CARE Act:
A Client-Level Data Assessment**

3. Prepare topic guide to facilitate discussions with sample grantees and providers - continued
 - Existing client level data systems
 - Estimate of resources needed to report client-level data (e.g., staff, equipment)
4. Using the topic guide, obtain input from sample on the feasibility of reporting client-level data
5. Determine the current capacity of grantees and service to report client-level data

Principles for Reauthorization

➤ Increase Flexibility

- Allow Secretary of HHS to redistribute unallocated balances based on severity of need.
- Allow planning councils to:
 - Be voluntary.
 - Serve as advisory bodies to mayors.

For More Information
Visit Our Website



<http://hab.hrsa.gov>

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