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RWCA [Ryan White CARE Act] [3]

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FAX TRANSMISSION
DEMOCRATIC OFFICE OF
THE UNITED STATES SENATE
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

TO: Michael

FROM: Scott

FAX #: 456 - 2439

DATE: 2/18 TOTAL PAGES (INCLUDING COVER) 5

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COMMENTS:

They are marked with an *

2/16/00

RYAN WHITE CARE ACT

Specs (DRAFT)

Cross Title

1) **Allow CARE Act providers to use CARE Act funds for early intervention services.** Expand the flexibility of service parameters for grantees and service providers to include HIV early intervention activities to support early diagnoses and linkages into care among populations at high risk from HIV which are accessing other services.

Allow funds to be used for early intervention services. Expand use of funds to include early intervention services, as defined in section 2651(b)(2), in Titles I and II. HRSA would limit the use of Ryan White funds for early intervention services to **only** those provider sites serving as key points of entry to Ryan White services as established as condition of award (see Recommendation #2) or current Ryan White funded medical sites. In addition, these sites would be required to demonstrate other federal, state, or local funds are unavailable to support these early intervention services; essentially complying with payer of last resort requirements. (see NASTAD recommendation under Title II)

2) **Provide resources for quality management.**

Creates a separate 5% cap for Quality management activities.

Incorporate quality management into all CARE Act services.

NORA

Require grantees (and grantees to require providers, as applicable), across all Titles, including ADAP, through the contracting process, to develop and implement a program of quality management, as specified by the Administrator of HRSA, that includes assessments of performance as well as strategies and programs that improve performance. Areas of assessment include: (a) quality of specific services; (b) determining the effectiveness of efforts to bring into the care system individuals who know their HIV status but are not in care, and (c) for those in care, improving access, integration and coordination of services, and, therefore, their health status.

3) **Change administrative caps for Title III 10 percent.** Redefine administrative cap for Title III at 10%; providing limited exceptions for community-based organizations and academic health centers. (see CAEAR recommendation under Title III)

* 4) **Ensure that health disparities are addressed in the planning process.**

NORA, CAEAR

Direct the Secretary to ensure that mechanisms are in place at the federal department and agency level and at the grantee and provider level to assess and address disparities in health outcomes, with particular attention to those disparities related to gender and race/ethnicity. The Secretary should ensure that the mechanisms are appropriate for grantees and providers to assess disparities among their local target populations and establish

plans for addressing them through access to the full range of CARE Act-eligible services, including primary care, supportive services, and early intervention services. (NORA)

- ✧ 5) **Standardize data evaluation and outcome measures.** The Secretary, in consultation with cities, states and affected communities, shall examine the feasibility of developing and implementing a process for the development of standardized data evaluation and outcome oriented assessments for CARE Act funded programs with input from representatives of grantees, consumers, planning councils, consortia, subcontractors and administrative agents. This shall include directing the Secretary to evaluate the utility, cost, and feasibility of developing a widely available, client-level, reporting system as a possible source of useful data. (NORA, CAEAR)
- ✧ 6) **Expand and clarify the Title I and II requirements that funds be spent in accordance with local demographics.** The set-aside requirement for proportionate allocations for infants, children, and women living with AIDS should be expanded to include youth living with AIDS. In addition, the legislation must clarify how the set-aside for children, youth and women is to be calculated, monitored and enforced. (APC)
- 7) **Require linkages with key points of entry to the medical system.**

Title I

- ✧ 1) **Technical assistance for training of planning council members.**
Direct HRSA to use funds from the technical assistance set - aside to provide technical assistance to Title I planning councils in their efforts to strengthen the available training for all people who serve on them. Planning councils work most effectively when their members are knowledgeable of and familiar with both internal and external governing and planning processes. (NORA)
- 2) **Allow Title I and II funds to be used for early intervention services.**
See "Cross Title" Above
- 3) **"Severity of Need" should be defined and count for more in Title I supplemental.**
AIDS Action
Recommended Language (CAEAR) :

SEC. 2603. TYPE AND DISTRIBUTION OF GRANTS

(b) SUPPLEMENTAL GRANTS. B

(1) IN GENERAL.--

Add in paragraph (1) IN GENERAL.--

By FY 2003, the Secretary shall use an evaluation of the success of grantees in identifying health outcome disparities and implementing strategies to address outcome disparities in determining Title I supplemental awards.

SEC. 2603. TYPE AND DISTRIBUTION OF GRANTS

(b) SUPPLEMENTAL GRANTS. B

(2) DEFINITION.--

(B) PREVALENCE. B

Add after current (B) PREVALENCE language

By FY 2002, the Secretary shall develop and implement criteria for measuring severity of need that are standard, equivalent and consistently applied across all Title I areas.

(C) PRIORITY. B

strike subparagraph and replace with:

"The Secretary shall give the severity of need factors a weight of one third in determining Title I supplemental grants beginning in FY 2001 and thereafter."

Alternative Rec:

In order to assess severe need a standardized definitions, which include co-morbid factors, should be developed and implemented. This severe need criteria should play a larger role, at least 33% of possible points, in the final Title I supplemental award decisions. (AIDS Action)

Title II

✖ **1) Create a new Title II supplemental for non-EMA states.**

Create a new supplemental funding portion of the Title II base appropriation, to be supported with new funding, not a redirection of existing resources, to enhance the availability of comprehensive health care services for underserved individuals living in eligible states that do not have principal Title I EMA grantees. (NORA)

✖ **2) Enhance States' ability to coordinate HIV/AIDS health systems.**

a) Institute consistent federal grant periods for Title I and II grantees to facilitate closer coordination of programs, objectives and reporting requirements.

b) Streamline the planning processes by moving to a system of multi-year awards, biannual planning processes and grant continuation cycles. This will reduce administrative burdens and overhead expenses, and help to maximize resources available for client services. (NASTAD)

✖ **3) Increase the minimum Title II base award and eliminate case thresholds.**
(NORA, NASTAD)

Increase in the minimum Title II base award to \$500,000 and eliminate the case thresholds for those minimum grants in order to support states that have severe infrastructure difficulties and may lack the necessary resources to pay for antiretroviral therapies for eligible clients. (NORA)

✖ **4) Allow the use of ADAP funds for medical monitoring, medications adherence support, and laboratory testing.**

These services are key components of HIV treatment and should be considered allowable ADAP expenses at the

discretion of individual states in their planning and priority-setting processes. (NASTAD)

- ✧ 5) **Require HRSA to notify Title II grantees when Title III, Title IV, or SPNS programs are elapsing so that states can consider using Title II funds to continue effective programs.**

Title III

- 1) **Increase the Title III administrative cap to 10 percent.**
(CAEAR)

Other rec:

The administrative cap for the directly funded Title III programs should be increased to 10 percent from their current level of 7.5 percent to correspond to the similar 10 percent cap on individual contractors in Title I.
(CAEAR)

- 2) **Target special populations with recognized limited medical care capacity and infrastructure. The Secretary would give preference in the awarding of planning grants to organizations that are based in minority communities and that have a history of serving minority populations.**

- ✧ 3) **Give grant-funding preference to non-EMA areas.**

Additional language is needed under the Title III of the legislation to allow HRSA to give Title III planning grant-funding preference to non-EMA areas. This will allow for "preferential" rather than "equitable" allocation of CARE Act resources to areas that are under served, especially rural areas.

Title IV

- 1) **Remove the requirement that Title IV grantees enroll a "significant number" of patients in research project.(APC)**

Other Rec:

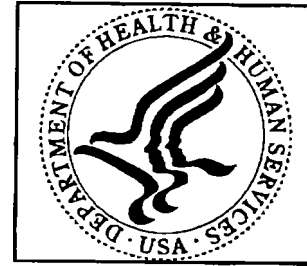
Title IV projects should no longer be required to enroll a "significant number" of clients into research protocols. This requirement creates an improper incentive for health care providers to encourage their clients to enroll in experimental research protocols. Access to health care under any part of the CARE Act should never be contingent upon enrolling in research. Title IV projects should continue to be required to provide education about and access to HIV-related research opportunities. Replace current language with:

"Title IV grantees should be evaluated on the requirement to demonstrate appropriate linkages to research and be required to document that access to research was offered to women, infants, children, and adolescents and report results." (APC)

Drop significant enrollment requirement. Current law requires Title IV grantees projects to enroll a significant number of women, infants, and children, and youth in clinical research. HRSA would maintain the obligation of the Title IV program to offer and encourage voluntary participation in clinical trials, but the agency proposes to drop the requirement of significant enrollment.

Office of HIV/AIDS Policy

Office of Public Health and Science
U.S. Public Health Service/DHHS
200 Independence Avenue, S.W.
Washington, D.C. 20201
Tel. (202) 690-5560



☐ Room 736-E
Fax. (202) 690-6584

TO: Sarah
(202) 456-2439

FROM: Deborah von Zinkernagel

(This fax contains **3 pages+ cover**)

If there are any problems with this transmission, please call Terrie Alvarez at (202) 690-5560



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

APR 12 2000

The Honorable James Jeffords
Chairman
Senate Health, Education, Labor and Pensions Committee
428 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Jeffords:

I am pleased to express my support for S. 2311, The Ryan White CARE Act Amendments of 2000, under consideration by the Committee today. This legislation sustains the longstanding bipartisan tradition of support for the Ryan White CARE Act, and I applaud your leadership and that of Senator Kennedy in its development. The reauthorization of the Ryan White CARE Act in FY 2000 is a high priority for the Administration, and it is my hope that S. 2311 will be reported out with the unanimous support of the Committee.

I commend you for including several important provisions in S. 2311 that respond to the evolving characteristics of the HIV/AIDS epidemic. Careful attention is given to increasing access to care among vulnerable populations, and to reducing disparities in health outcomes. The inclusion of early intervention services at key points of entry into the health care delivery system will help to enter individuals in care so that they may benefit from these treatments and delay the onset of severe illness.

The legislation will also enhance the ability of States and local communities to support the development of primary care capacity in low income, historically under served, and rural settings where such need exists. S. 2311 also contains new measures that will promote the delivery of high quality HIV/AIDS care, consistent with treatment guidelines. New advances in antiretroviral therapies and services to assist persons in sustaining their correct use can now extend both the quality and length of life for persons with HIV disease.

The Ryan White CARE Act has provided a lifeline of essential health and related support services to individuals infected with this disease and their families. I know you share my strong support for the reauthorization of this program. I fully recognize the interest and commitment of Health, Education, Labor and Pensions Committee members as they have participated in the development of this legislation. I would look forward to working with them on any future refinements to this legislation. S. 2311 will set a strong bipartisan foundation for action by the full Senate and ultimately enactment by the Congress this year.

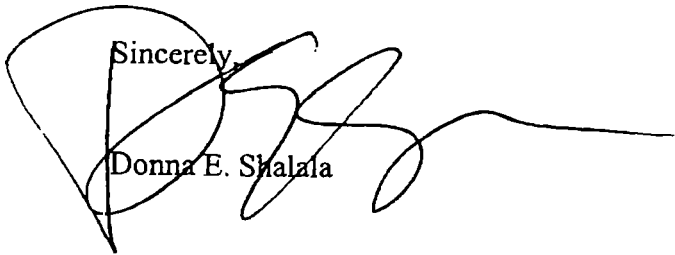
Page 2

I look forward to working closely with you as you consider reauthorization of the Ryan White Care Act, and urge your continued efforts to ensure expedited consideration of S. 2311 by the full Senate with final enactment this year.

Thank you very much for your consideration.

Sincerely,

Donna E. Shalala

A handwritten signature in black ink, appearing to be "Donna E. Shalala", is written over the printed name. The signature is fluid and cursive, with a long horizontal stroke extending to the right.

**National Organizations Responding to AIDS
(NORA)
FAX MEMORANDUM**

To: Full NORA Coalition

From: Juanita Gallion, NORA Coordinator

Date: May 10th, 2000

Re: Reauthorization Letter (this fax is 4 pages)

Last week, the Ryan White CARE Act Reauthorization working group sent a letter, co-signed by almost 30 organizations, to the full Senate, asking for co-sponsors on the S.2311 Ryan White CARE Act Amendments of 2001.

This important letter urges Senators to lend their support to the reauthorization of the CARE act.

Thank you to all of the organizations that signed on to this letter. Your support in this matter is greatly appreciated. We would like to urge organizations to send their own letter encouraging their Senators to co-sponsor this bill.

A copy of the letter, with the names of the organizations that signed-on, is attached for you to view. If you have any questions, please feel free to contact Juanita Gallion at 202-530-8030 x3030, or by e-mail at nora@aidsaction.org

May 5, 2000

United States Senate
Washington, DC 20515

Dear Senator:

On behalf of the undersigned members of the National Organizations Responding to AIDS (NORA), a coalition of over 175 national organizations, we urge you to lend your support for reauthorizing the Ryan White CARE Act by cosponsoring S. 2311, the Ryan White CARE Act Amendments of 2000, introduced by Senators Jim Jeffords and Edward Kennedy on March 29, 2000.

If you are already a cosponsor, we thank you for your support and ask for your help in moving this bill through the legislative process. Since its enactment in 1990, the Ryan White CARE Act has played an unparalleled role in providing health care and related services to people living with HIV and AIDS. In 1999 alone, over 500,000 individuals were served by programs and services supported through the Ryan White CARE Act.

The CARE Act has been the nation's primary health care response to the HIV/AIDS epidemic and this reauthorization will allow the program to continue this success. By providing critically needed medical care, life prolonging treatments, and support services to eligible individuals and families, the CARE Act has played a major role in the dramatic decline in AIDS deaths that our nation has enjoyed since in 1996.

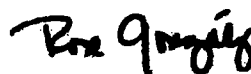
The Ryan White CARE Act provides federal resources directly to the most highly impacted cities and all of the 50 states, the District of Columbia and the territories. It also targets funding to provide primary care and support services in underserved geographic areas and to historically underserved populations, including people of color, women, children and families. Finally, the CARE Act helps to ensure that health care providers have access to HIV/AIDS medical and dental education and training.

NORA sincerely appreciates the commitment you have demonstrated to the CARE Act in the past. Your co-sponsorship of S. 2311 will assist our nation's communities, both urban and rural, in their efforts to continue to address this public health crisis.

Sincerely,



Terje Anderson
Co-Chair



Rose Gonzalez
Co-Chair

Co-Chairs

Terje Anderson
NATIONAL ASSOCIATION OF
PEOPLE WITH AIDS

Rose Gonzalez
AMERICAN NURSES
ASSOCIATION

Executive Committee

David Harvey
AIDS ALLIANCE FOR
CHILDREN, YOUTH AND
FAMILIES

Jeff Jacobs
AIDS ACTION

Seth Kilbourn
HUMAN RIGHTS CAMPAIGN

Miguelina Maldonado
NATIONAL MINORITY AIDS
COUNCIL

Matthew McClain
CAEAR COALITION

Julie Rocchio
NATIONAL ASSOCIATION OF
PUBLIC HOSPITALS

Jane Silver
AMERICAN FOUNDATION FOR
AIDS RESEARCH

AED-Center for Community-Based Health Strategies
Advocates for Youth
AIDS Action
AIDS Alliance for Children, Youth & Families
AIDS Legal Referral Panel
AIDS Nutrition Services Alliance
AIDS Vaccine Advocacy Coalition
Advocates for Youth
American Academy of Pediatrics
American Association for World Health
American Association on Mental Retardation
American Dental Education Association
American Federation of State, County and Municipal Employees
American Foundation for AIDS Research
American Nurses Association
American Psychological Association
American Public Health Association
American Social Health Association
Americans for Democratic Action
Association of Maternal and Child Health Programs
Association of Reproductive Health Professionals
Association of Schools of Public Health
Center for Women Policy Studies
Center for Health and Gender Equity
Childreach/Plan International
Cities Advocating Emergency AIDS Relief Coalition
Committee of Ten Thousand
Elizabeth Glaser Pediatric AIDS Foundation
Gay Men's Health Crisis
Global Health Council
HIV Quality Care Network
Human Rights Campaign
National Alliance of State and Territorial AIDS Directors
National Association for Victims of Transfusion-Acquired AIDS
National Association of Community Health Centers
National Association of County and City Health Officials
National Association of People with AIDS
National Association of Protection & Advocacy Systems
National Association of Public Hospitals & Health Systems
National Association of State Alcohol and Drug Abuse Directors
National Catholic AIDS Network
National Gay and Lesbian Task Force
National Mental Health Association
National Minority AIDS Council
National Youth Advocacy Coalition
Parents, Families & Friends of Lesbians & Gays
Planned Parenthood Federation of America
Project Inform

Service Employees International Union
Sexuality Information and Education Council of the United States
The AIDS Memorial Quilt
The American Dietetic Association—HIV/AIDS Dietetic Practice Group
The National Episcopal AIDS Coalition
The National Latina/o Lesbian, Gay, Bisexual & Transgender Organization
The Partnership for the Homeless
The United States Conference of Mayors
Title II Community AIDS National Network
Union of American Hebrew Congregations

Confirmed ok/ko

Total Pages: 3

LRM ID: RJP279

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
Washington, D.C. 20503-0001

Tuesday, April 11, 2000

LEGISLATIVE REFERRAL MEMORANDUM

TO: Legislative Liaison Officer - See Distribution below

FROM: Ingrid M. Schroeder (for) Assistant Director for Legislative Reference

OMB CONTACT: Robert J. Pellicci

E-Mail: Robert_J_Pellicci@omb.eop.gov

PHONE: (202)395-4871 FAX: (202)395-6148

SUBJECT: HEALTH & HUMAN SERVICES Report on S2311 Ryan White CARE Act Amendments of 2000

DEADLINE: * 4:00 P.M. Tuesday, April 11, 2000 *

In accordance with OMB Circular A-19, OMB requests the views of your agency on the above subject before advising on its relationship to the program of the President. Please advise us if this item will affect direct spending or receipts for purposes of the "Pay-As-You-Go" provisions of Title XIII of the Omnibus Budget Reconciliation Act of 1990.

* COMMENTS: Senate Health, Education, Labor, and Pensions Committee is marking up S. 2311 TOMORROW - April 12th. DEADLINE IS FIRM.

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LRM ID: RJP279 **SUBJECT:** HEALTH & HUMAN SERVICES Report on S2311 Ryan White
CARE Act Amendments of 2000

**RESPONSE TO
LEGISLATIVE REFERRAL
MEMORANDUM**

If your response to this request for views is short (e.g., concur/no comment), we prefer that you respond by e-mail or by faxing us this response sheet. If the response is short and you prefer to call, please call the branch-wide line shown below (NOT the analyst's line) to leave a message with a legislative assistant.

You may also respond by:

(1) calling the analyst/attorney's direct line (you will be connected to voice mail if the analyst does not answer); or

(2) sending us a memo or letter

Please include the LRM number shown above, and the subject shown below.

TO: Robert J. Pellicci Phone: 395-4871 Fax: 395-6148
 Office of Management and Budget
 Branch-Wide Line (to reach legislative assistant): 395-7362

FROM: _____ (Date)
 _____ (Name)
 _____ (Agency)
 _____ (Telephone)

The following is the response of our agency to your request for views on the above-captioned subject:

_____ Concur

_____ No Objection

_____ No Comment

_____ See proposed edits on pages _____

_____ Other: _____

_____ FAX RETURN of _____ pages, attached to this response sheet

The Honorable James Jeffords
Chairman
Senate Health, Education, Labor and Pensions Committee
428 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Jeffords:

I am pleased to express my support for S. 2311, The Ryan White CARE Act Amendments of 2000, under consideration by the Committee today. This legislation sustains the longstanding bipartisan tradition of support for the Ryan White CARE Act, and I applaud your leadership and that of Senator Kennedy in its development. The reauthorization of the Ryan White CARE Act in FY 2000 is a high priority for the Administration, and it is my hope that S. 2311 will be reported out with the unanimous support of the Committee.

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The legislation will also enhance the ability of States and local communities to support the development of primary care capacity in low income, historically underserved, and rural settings where such need exists. S. 2311 also contains new measures that will promote the delivery of high quality HIV/AIDS care, consistent with treatment guidelines. New advances in antiretroviral therapies and services to assist persons in sustaining their correct use can now extend both the quality and length of life for persons with HIV disease.

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I look forward to working closely with you as you consider reauthorization of the Ryan White Care Act, and urge your continued efforts to ensure expedited consideration of S. 2311 by the full Senate with final enactment this year.

Thank you very much for your consideration.

Sincerely,

Donna E. Shalala

HIV/AIDS Bureau
Health Resources and Services Administration
U.S. Department of Health and Human Services

FALL 199



The AIDS Epidemic and the Ryan White CARE Act:
Past Progress, Future Challenges

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Foreword

By the end of 1989, almost 90,000 Americans had died from AIDS. The following year the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed. In the nearly 10 years since then, the CARE Act has been a refuge for hundreds of thousands of HIV-positive Americans who could not afford the care they needed.

Today, the epidemic still rages. There have been more than 400,000 AIDS-related deaths, and the number of Americans living with HIV disease is on the increase. Many are poor and suffer significant medical problems in addition to HIV disease. Many never see a physician. Others receive care only in an emergency room, or live in communities with few health care providers of any kind, much less those who are qualified to treat HIV disease. For these reasons and others discussed in this report, never has there been a greater need for a collaborative public and private response to AIDS.

The Health Resources and Services Administration (HRSA) works with a host of organizations and individuals to implement the CARE Act. We are bound together by our common concern for individuals living with HIV disease who, on their own, cannot meet their health care needs. Our collaboration is key in a nation with escalating treatment costs, hundreds of thousands of undiagnosed HIV infections, unequal access to care, and a need that far surpasses resources.

This report is provided to give you a sense of the epidemic and the CARE Act today. *Where is the epidemic moving? Who is being served by the CARE Act? What services are being provided? How are developments in treatment and coverage affecting people living with HIV disease and the CARE Act programs?* These are just some of the questions we address in this report.

We hope that the information we have provided will help you draw your own conclusions about the epidemic, the response embodied in the CARE Act, and the response that is needed as we enter the third decade of AIDS in America. We look forward to collaborating with you on behalf of the individuals who, supported by the CARE Act, have the chance for improved health and a better life.

Claude Earl Fox, M.D., M.P.H.
Administrator, HRSA

Joseph F. O'Neill, M.D., M.P.H.
Associate Administrator for HIV/AIDS, HRSA

1981

The first cases of "gay-related immune deficiency" are reported. CDC declares the new disease an epidemic.

1982

The new disease is officially named AIDS.

1983

The National Association of People with AIDS is founded.

1984

The HIV virus is discovered.

1985

The first HIV antibody test is licensed.

1986

Condom use is shown to be effective in preventing sexual transmission of HIV.

1987

AZT receives FDA approval.

1988

FDA allows importation of unapproved drugs for persons with life-threatening illnesses.

1989

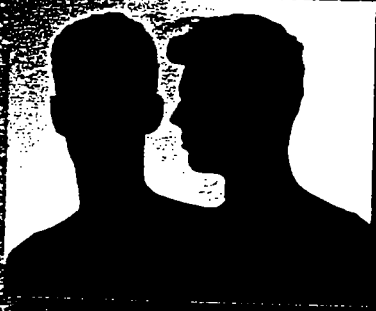
Treatments for CMV and PCP—two opportunistic infections—are introduced.

1990

Ryan White dies and the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is passed.

AIDS

Acquired Immunodeficiency Syndrome



1981

1990

Nearly 10 years after AIDS is declared an epidemic in America, 100,313 Americans are dead from AIDS and 161,073 cases have been reported.

1991

FDA approves ddI.

1992

The definition of AIDS is expanded.

1993

Heterosexual transmission becomes the leading HIV exposure category among females.

1994

AZT is shown to reduce perinatal transmission.

1995

AIDS becomes the leading cause of death for Americans ages 25 through 44.

1996

New antiretroviral therapies change the AIDS treatment landscape.

1997

AIDS mortality declines 45 percent from 1996.

1998

The President declares HIV/AIDS in racial and ethnic minorities to be a severe and ongoing crisis.

1999

Between 650,000 and 900,000 Americans are thought to be living with HIV disease; approximately one-third are unaware of their serostatus. Thousands more are not receiving state-of-the-art care.

*Ryan White Dies of AIDS at 38
His Struggle Helped Break Myths*



**AIDS Deaths in U.S.
Drop by Nearly Half
As Infections Go On**

By STEVEN A. JHOMEN
WASHINGTON — The number of Americans who died from AIDS fell in 1995 last year, almost halving the number of the year before and well below the 45,000 deaths in the peak year of 1993. Government figures released today show the reversal, across its new and effective drug treatments, from the death rate from AIDS in the 1980s since 1987, the first year epidemic data tracked monthly data relative to the disease.

**U.S. to Begin
Minority AIDS
Initiative**
*\$150 Million Campaign
Targets Blacks, Latinos*
By ALAN GOLDBERG
Published Nov. 17, 1998



1995

Nearly 15 years into the epidemic, 313,486 AIDS cases have been reported in America; 315,928 Americans have died.

1999

Almost 20 years after AIDS is declared an epidemic in America, 410,800 Americans are dead from AIDS and 688,360 AIDS cases have been reported.

PART I

The AIDS Epidemic in the United States Today



The AIDS Epidemic in the United States Today

There is still no vaccine and still no cure for AIDS, but antiretroviral therapy is dramatically improving health and quality of life for many individuals living with HIV disease, and AIDS mortality is decreasing. However, the number of HIV-positive individuals in America is growing, and most are not receiving the full benefit from advances in treatment. Consider the following:

- Up to one-third of all HIV-positive individuals remain unaware of their serostatus and are receiving no treatment whatsoever.*
- As many as 200,000 individuals know they are HIV-positive but are receiving substandard care.*
- As late as 1998, less than half of all individuals living with HIV disease had ever been treated with new antiretrovirals (protease inhibitors or non-nucleoside reverse transcriptase inhibitors [NNRTIs]). Many individuals who have access to these medications do not benefit from them because of side effects and drug resistance.³

In the United States today, the number of people living with HIV disease is between 650,000 and 900,000, and the prevalence of the disease is increasing since the number of HIV infections (40,000 per year) is greater than the annual deaths from AIDS (approximately 17,100 in 1998). With so many people infected but unaware, with many others underserved, and with rising HIV/AIDS prevalence, the provision of health care for individuals living with HIV disease will remain a critical issue well into the next millennium.

Epidemiological Terms

- | | |
|-------------------|------------------------------------------------------|
| Prevalence | - Total number of individuals living with a disease. |
| Incidence | - Number of new cases in a given year. |
| Mortality | - Deaths in a given year. |

*The HIV Cost and Services Utilization Study estimated that 335,000 HIV-positive individuals received care during a typical 6-month period in 1996 (95 percent confidence interval [CI] 292,000 to 372,000). Comparing this estimate with CDC estimates that there is an HIV/AIDS prevalence of 650,000 to 900,000—and that up to one-third of all HIV infections are undiagnosed—provides insight into the proportion of the adult HIV-infected population not in care.¹²

The Face of the Epidemic

Data indicating decreases in AIDS incidence and mortality and a leveling of HIV incidence give an incomplete picture of the AIDS epidemic because they mask important demographic shifts occurring in the HIV-infected population. Today, an individual diagnosed with AIDS is more likely than ever to be African American, Latino, and/or female: *

- In 1998, more than 66 percent of new AIDS diagnoses were among minorities. Mortality has declined less significantly among blacks, Hispanics, and females than among white males. *
- The AIDS rate—the number of cases per 100,000 individuals—is more than eight times higher for blacks than for whites. *



- Men of color represented 45 percent of new infections among gay and bisexual men in 1998, compared with 37 percent in 1995.
- More than 23 percent of AIDS diagnoses reported in 1998 were among females. *

Initiative to Combat AIDS in African Americans

In 1999, the Department of Health and Human Services and the Congressional Black Caucus announced a \$156 million initiative to address the AIDS crisis among minorities. Through this endeavor, CARE Act programs received \$12 million in new funds and \$5.8 million in emergency funds.

- Three out of every five females diagnosed with AIDS in 1998 were black, and one of every five was Hispanic. *
- Two out of every three women living with HIV disease are estimated by the Centers for Disease Control and Prevention (CDC) to have at least one child under the age of 19.

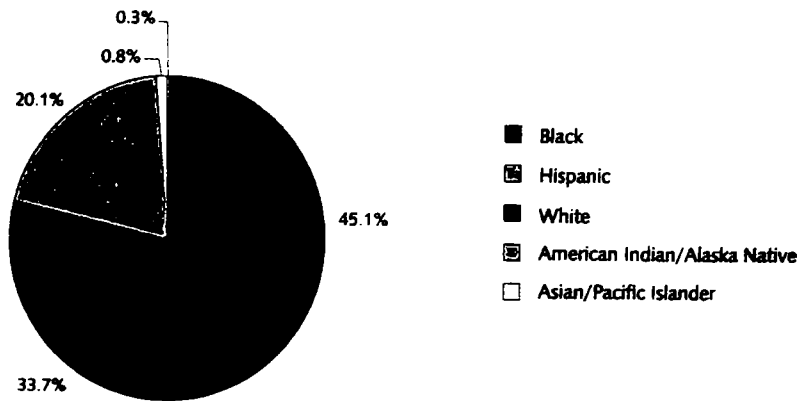
Other segments of the population at high risk for HIV disease include homeless individuals, substance abusers, young gay men, and individuals in the correctional system.

Young People and HIV/AIDS

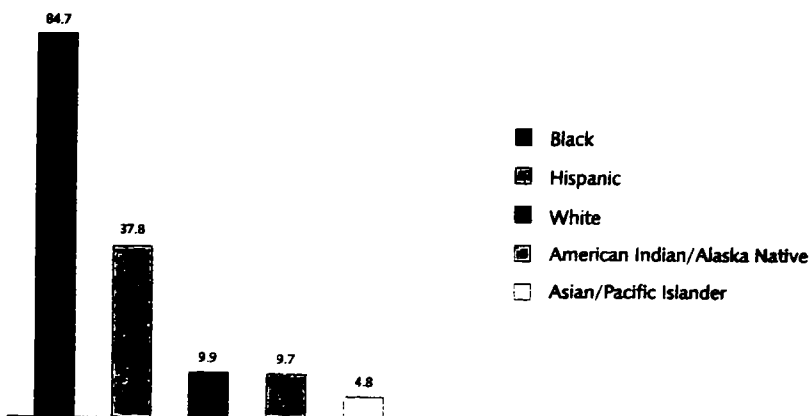
One-fourth of all new HIV infections are estimated to be among individuals 21 years of age or younger. One-half are among individuals under age 25. ⁵ HIV infection is a particular threat among those already coping with major issues—homeless and runaway youth, youth who are victims of abuse, and sexually active minority youth.

* CDC collects surveillance data for the following populations: white non-Hispanic, black non-Hispanic, American Indian/Alaska Native, and Asian/Pacific Islander. To be consistent with CDC, the terms "black" and "Hispanic" are used when referring to CDC data. Elsewhere, these populations are referred to as "African American" and "Latino," respectively.

• **New AIDS Cases, 1998**
(N=47,887)



AIDS Rate, 1998
(Cases per 100,000 adults/adolescents)



Poverty

Low income, lack of private insurance, unemployment, and low education level are predictors of poorer health and less access to health care for people living with HIV disease. These are of growing concern because minorities and women, who compose an increasing proportion of the HIV-positive community, suffer high rates of these problems.



The HIV Cost and Services Utilization Study is the largest and most comprehensive assessment of HIV-positive individuals ever undertaken. Although the study examined patients in care in 1996, its findings, published in the December 1998 *New England Journal of Medicine*,¹ provide important insights into the HIV-positive population today. The study estimated that only 335,000 individuals were receiving at least some care in 1996;

Ryan White CARE Act Client Demonstration Project, HRSA*

Insurance: Only 12 percent of clients at project sites had any private insurance in 1998; 39 percent had no insurance, private or public.

Income: Eighty percent of clients at project sites had incomes less than 300 percent of the Federal poverty level in 1998.

simultaneously, the CDC estimated HIV/AIDS prevalence at 650,000 to 900,000. Of the individuals in care:

- 20 percent had no public or private insurance;
- 29 percent were enrolled in Medicaid;
- 32 percent had private insurance;
- 72 percent had annual household incomes of less than \$25,000, and 46 percent had annual household incomes of less than \$10,000; and
- 63 percent were unemployed.¹

Economics and HIV-Positive Women

HIV-positive women tend to be even poorer than HIV-positive men. In one study, 30 percent had annual household incomes of less than \$5,000. These women are also less educated and less likely to be employed than their male counterparts.¹

*The Ryan White CARE Act Client Demonstration Project represents a sample of providers that receive funding from Titles I, II, III, and IV. These providers served approximately 41,000 HIV-positive clients in 1998. These sites are not representative of all CARE Act providers nationwide. Nonetheless, data from these sites have historically been reflective of national trends.

Multiple Diagnoses

HIV often is just one of the health problems present in an HIV-positive individual.

Mental Illness

Psychiatric disorders are common among HIV patients, and the incidence of mental illness is especially high among HIV-positive substance abusers. Several psychiatric treatment facilities report an HIV/AIDS prevalence rate of 5 percent among their patients, compared to a seroprevalence rate of 0.3 percent in the general population.^{6,7,8}

Substance Abuse

Substance abuse has been reported as a factor in well over half of AIDS cases in some areas of the country. Injection drug use is acknowledged to be a major transmission mechanism for HIV, but the role of non-injected recreational drugs—alcohol and cocaine, for example—in influencing behaviors that increase risk of infection is too often forgotten. Substance abuse and addiction severely

compromise an individual's ability to stay in care. Without substance abuse treatment, the chances of maintaining beneficial HIV treatment are reduced to almost zero.

Other problems abound as well, such as tuberculosis, malnutrition, sexually transmitted diseases, and various strains of hepatitis. Physical and mental health problems concurrent with HIV greatly complicate delivery of care and can have a serious impact on treatment outcomes.

HIV/Hepatitis Coinfection

Conservatively, 14 percent of HIV-positive individuals in the United States are infected with the hepatitis C virus (HCV).⁹ HIV/HCV coinfection rates are several times higher among injection drug users. The best course of treatment for coinfecting patients is only beginning to be understood.

HCV Facts

- HCV is the Nation's leading cause of liver disease and the leading indication for liver transplants.
- There is no cure, and treatment is effective in a minority of patients.
- Approximately 4,000,000 Americans are infected with HCV. Between 8,000 and 10,000 Americans die from HCV each year.¹⁰



Exposure to HIV

New AIDS cases are reported to CDC in terms of an individual's "exposure category" to HIV. These data do not reveal current or future trends. For example, they do not anticipate the feared new wave of infections among young gay men. But they do reveal trends that have occurred in the past.

Men who have sex with men is the leading exposure category in AIDS cases reported in the United States. Despite prevention efforts, the number of new AIDS cases among men who have sex with men was only slightly lower in 1998 (16,642) than in 1989 (19,891).

Injection drug use was the exposure category in 23 percent (11,070) of AIDS cases reported in 1998, as it was in 1989 (8,089). Four percent (1,984) of new cases in 1998, down from 6 percent (2,214) in 1989, were among *men who have sex with men and inject drugs*. Determining which of these two transmission routes was the mechanism for transmitting HIV in these individuals was not possible.⁷

Gay and Bisexual Men

Men who have sex with men remains the leading HIV exposure category for new AIDS diagnoses. Forty-five percent of these men are racial/ethnic minorities.

Heterosexual contact with an HIV-infected individual has become the exposure category in a growing number of reported cases over the last 10 years—6 percent (2,010) in 1989 versus 14 percent (6,736) in 1999.⁴

In 1998, the exposure category was not identified in 23 percent (11,000) of new AIDS cases.⁴



Treatment Advances

No treatment for HIV disease has had the power and promise of highly active antiretroviral therapy (HAART), commonly known as "combination therapy" or a drug "cocktail."

HAART is an antiretroviral regimen that can reasonably be expected to reduce the viral load to less than 50 c/ml in treatment naïve patients.¹¹

An estimated 85 percent of HIV-positive individuals in care in 1996 had, by 1998, received a protease inhibitor or NNRTI (two drugs used in HAART).³ For many of these individuals, HAART has altered the impact of AIDS by achieving sustained suppression of viral load and improvement of immune response. Often, those treated with HAART return to work and have a dramatically improved quality of life.

HAART is not a cure, and its benefits have not reached everyone living with HIV disease. A patient's stage of disease and treatment history can temper its benefit. Side effects can be severe, and exacting dosing requirements have made adherence a problem for many, causing some individuals to forego this therapy altogether. Moreover, hundreds of thousands of HIV-positive individuals are not in care or receive substandard care and receive no benefit from these medications. For individuals who are in care, treatment costs—about \$12,000 per year for HAART alone—can be prohibitive without public assistance.

Pediatric HIV Disease

Between 6,000 and 7,000 HIV-positive women give birth to children in the United States each year. Without intervention, the transmission rate from mother to infant has been in the range of 15 to 30 percent. However, treatment of mother and newborn with AZT-based regimens can cut transmission rates to 8 percent.¹² When these treatment findings first emerged in 1994, the Health Resources and Services Administration (HRSA) disseminated them to providers across the country, and in most CARE Act-funded sites, the vertical transmission rate has dropped dramatically.

Poverty, Race, and Pediatric AIDS

- 62 percent of pediatric AIDS cases reported during 1998 were among African Americans.⁴
- 90 percent of HIV-positive children are enrolled in Medicaid.

At the end of 1998, 3,509 children under the age of 13 were believed to be living with AIDS in the United States.⁴ AIDS incidence in children age 13 and under has decreased, from 947 new cases in 1992 to 382 in 1998.



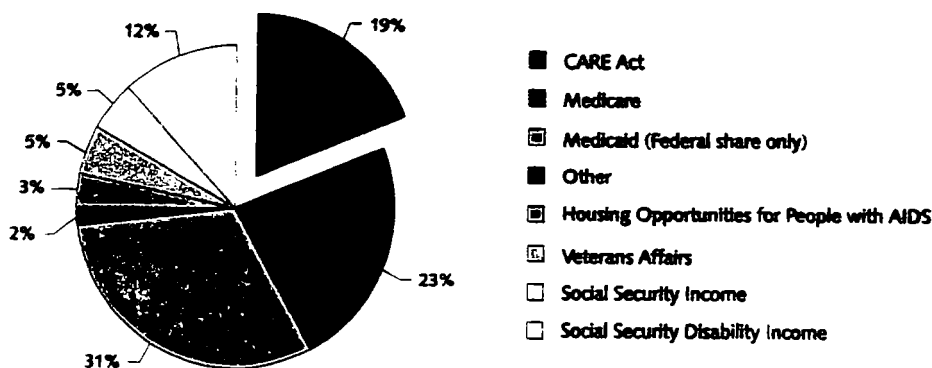
PART II

The Ryan White CARE Act

The Ryan White CARE Act

The Ryan White CARE Act was passed in 1990 in response to the AIDS epidemic in America. The CARE Act was designed to serve HIV-positive individuals who fell through the existing public safety net. It is officially "the payer of last resort" for hundreds of thousands of individuals whose financial status leaves them unable to pay for health care or basic subsistence needs. HIV disease, like many health problems, strikes disproportionately at those in poverty. But one of the devastating results of HIV disease progression is that it also causes poverty: Those infected often lose the ability to work and, with it, health insurance and any hope of carrying the financial burdens of HIV disease on their own.

Federal HIV/AIDS Spending: Care and Assistance by Program, 1998
(Total: \$7,180 million)



Source: Henry J. Kaiser Family Foundation

The CARE Act funds:

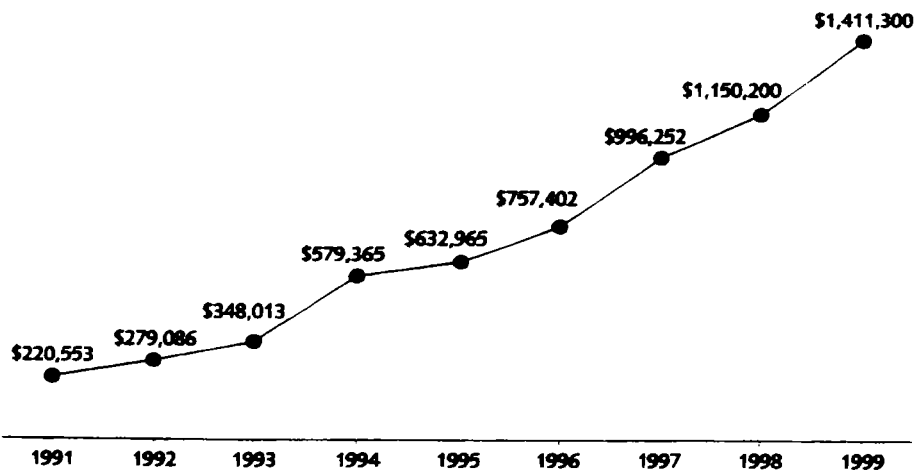
- Care for individuals living with HIV disease;
- Support for HIV-positive mothers, children, and their families;
- Training for clinicians who treat HIV-positive individuals;
- The development of innovative programs that improve treatment outcomes; and
- Technical assistance for organizations providing HIV/AIDS services across the country.

More than 2,500 local organizations provide services funded by the CARE Act.

The CARE Act appropriation has increased with HIV/AIDS prevalence and treatment costs over the last decade.

The congressional "earmark" for medications under the AIDS Drug Assistance Program (ADAP) represents 70 percent of the appropriations increase from 1996 to 1999.

**Ryan White CARE Act Appropriations
FY 1991 - FY 1999
(\$ thousands)**



CARE Act Clients

HIV-positive individuals in care are poorer than the general population. Individuals served through the CARE Act are even poorer.

Income

The annual income of more than 50 percent of CARE Act clients had never exceeded \$25,000 per year, compared with 27 percent of all HIV-positive clients in care in 1996.¹

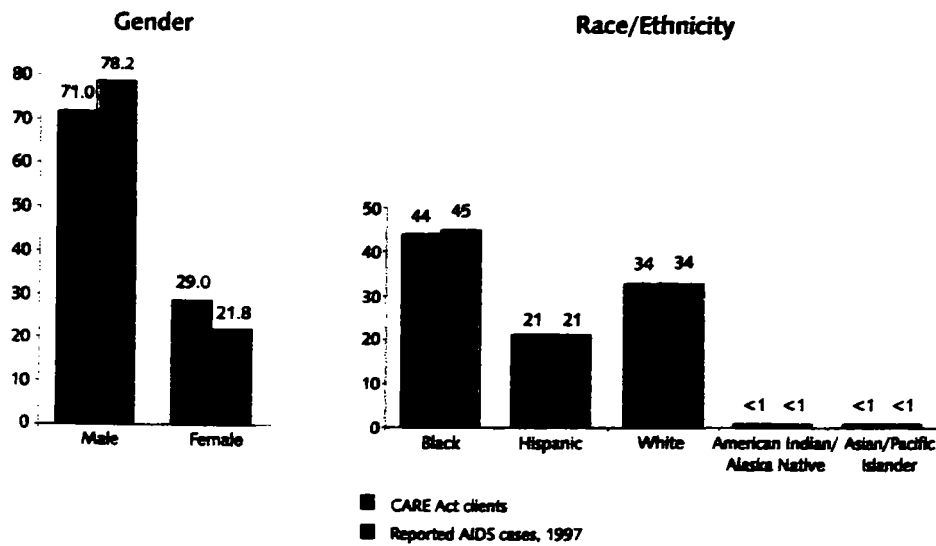
Education and Employment

CARE Act clients are less likely to have any college education. In 1996, 30 percent had not completed high school, compared with 19 percent of all HIV-positive individuals in care. Sixty-six percent were unemployed.¹

Stage of Disease

In one CARE Act program (Title III) in 1997, 25 percent of 22,545 new primary care clients were symptomatic when they entered care. Almost 75 percent had T-cell counts below 499/uL.¹

Ryan White CARE Act Clients, 1997
(By percent)

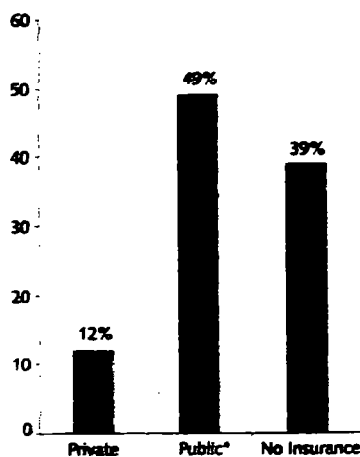


Note:
The mean was used in ranges estimated for CARE Act clients. Ranges are as follows: Male, 70-72%; Female, 28-30%; Black, 43-45%; Hispanic, 19-24%; White, 32-37%; American Indian/Alaska Native and Asian/Pacific Islander, <1-1%.

The Payer of Last Resort

Most CARE Act clients rely on several sources of funding for services. For example, 12 percent have some private insurance and about half are eligible for Medicaid. The CARE Act meets the need for services not covered by other payers. Although concerns regarding anonymity and discrimination preclude tracking services to individual clients, it is estimated that 500,000 Americans receive at least one service funded by the CARE Act each year.³

**Ryan White CARE Act Clients
Type of Insurance, 1998**



Source: Client Demonstration Project, HRSA

* Public insurance includes Medicaid, Medicare, Social Security Disability Income, and Social Security Income.

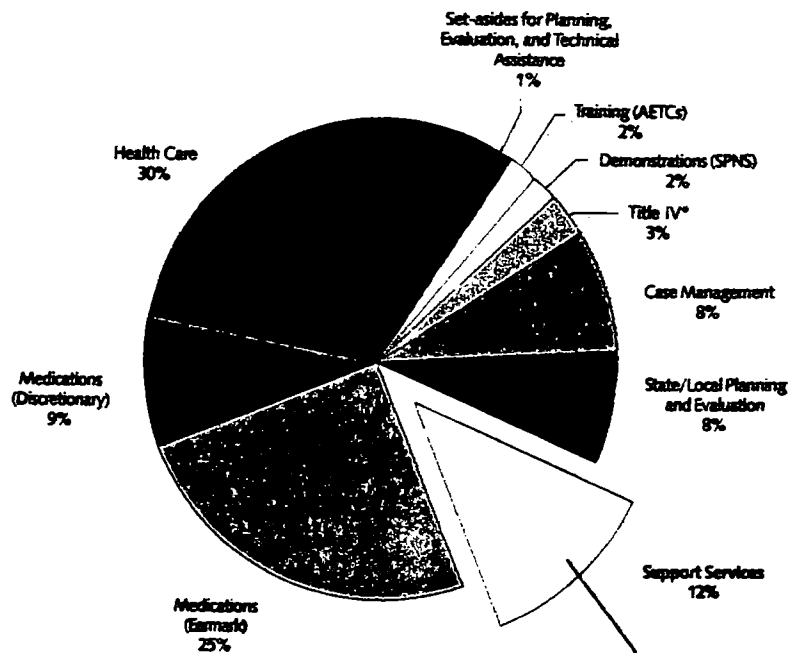
CARE Act Services

The majority of CARE Act funds are used for medical care and treatment. An additional portion is used to fund support services that improve quality of life and increase the potential for individuals to stay in care and benefit from treatment.

CARE Act grantees are given significant local autonomy to allocate resources in their communities. Spending decisions for approximately two-thirds of 1998 CARE Act funds were made not in Washington, DC, but in States and local communities.

State and local health planning bodies allocate funds to provide services based on needs in their areas. Need varies by region and can also change from year to year, so allocations differ considerably by area and over time. However, allocation decisions are based on common principles: (1) the service is essential to sustaining the individual's health and well-being, and (2) no other funding source is available to pay for the service.

Ryan White CARE Act Expenditures, 1998
(\$1.5 billion)

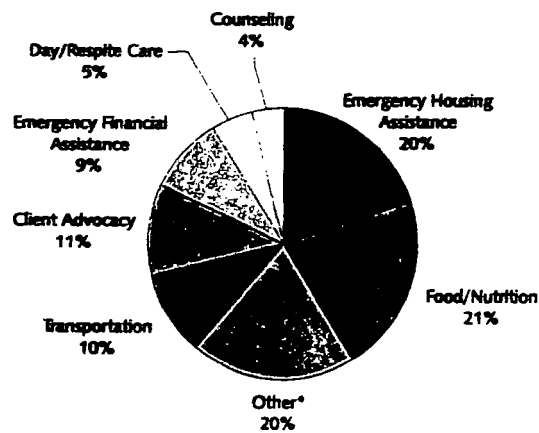


* The Title IV program targets women, children, and families, but does not represent total CARE Act spending for these populations.

Note:

Spending in one program, representing approximately 6 percent of the 1998 CARE Act appropriation, had not been audited at the time this report was prepared. Therefore, 1997 allocation percentages for this program were factored into the total.

Support Services, 1998



* "Other" represents spending in 26 separate service categories, each composing less than 1 percent of total spending for support services.

CARE Act Programs

The CARE Act funds several unique grant programs, each with its own awards criteria. Some grants are based in part on regional demographics. Other grants are entirely competitive and are awarded to applicants based on their ability to meet the needs of HIV-positive individuals in the areas they serve.

Ryan White CARE Act Grants (FY 1999 Funding)

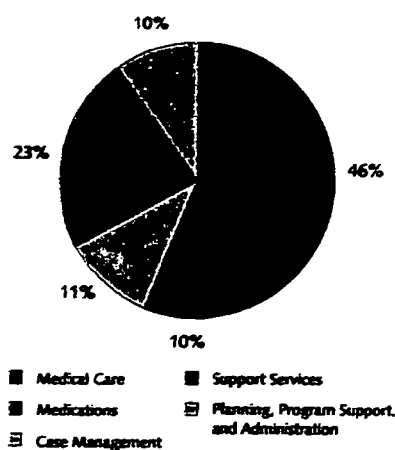
	\$ millions
Title I: Grants to Eligible Metropolitan Areas (EMAs)	505.2
Title II:	
Grants to States and Territories	277.0
AIDS Drug Assistance Program (ADAP)	461.0
Total	738.0
Title III:	
Early Intervention Grants	94.3
Title IV:	
Women, Infants, Children, and Youth	46.0
Part F:	
Special Projects of National Significance (SPNS)	25.0
AIDS Education and Training Centers (AETCs)	20.0
HIV/AIDS Dental Reimbursement Program	7.8

Title I: Grants to Eligible Metropolitan Areas

Metropolitan regions with a population larger than 500,000 and at least 2,000 reported AIDS cases in the previous 5 years are eligible to receive grants under Title I of the CARE Act. In 1991, there were 16 EMAs; by 1997, there were 49. Today there are 51.

EMAs use funding to meet needs for medical and support services that are not met by any other program. Decisions about which CARE Act services to fund are made by each EMA's HIV Health Services Planning Council and are based on service gaps in their region. In addition to direct services, the Planning Council may elect to fund technical support for providers in the service system.

Eligible Metropolitan Areas 1998 Allocations



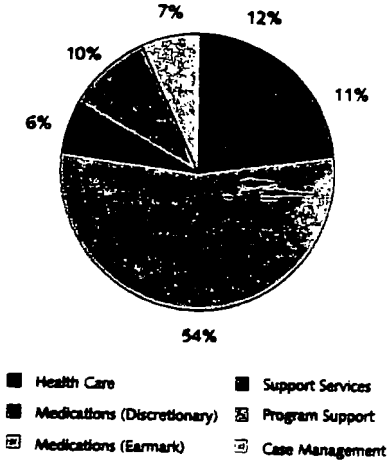
Note:

Expenditures through Title I are approximately 96 percent of their congressional appropriation because of set-asides for SPNS, evaluation and technical assistance.

Title II: Grants to States and Territories

Every State in the Nation, along with the District of Columbia, Guam, Puerto Rico, and the U.S. Virgin Islands, receives HIV care grants through Title II of the CARE Act. HIV Care Consortia allocate funding based on needs for services in these jurisdictions. In recent years, however, an increasing portion of Title II grants has been "earmarked" by Congress to fund medications through ADAPs. The amount grew from \$167 million in 1997 to \$461 million in 1999—33 percent of the total CARE Act appropriation.

States and Territories
1996 Allocations and Medications Earmark

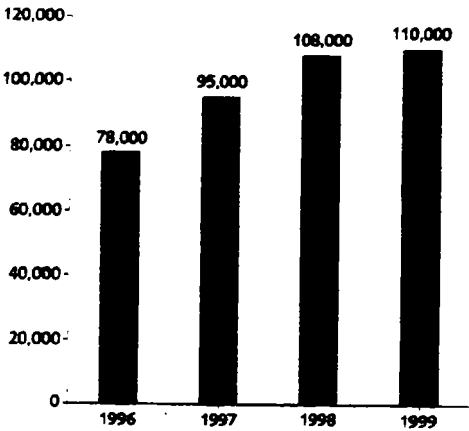


Note:
Expenditures through Title II are approximately 96 percent of their congressional appropriation because of set-asides for SPNS, evaluation, and technical assistance.

AIDS Drug Assistance Programs

Outpatient costs have risen in recent years, largely due to HAART. These changes have resulted in considerable financial pressure on each State's ADAP that, in 1999, will spend approximately 90 percent of their funding on antiretrovirals, a dramatic increase from 43 percent in 1993.

Total ADAP Clients
FY 1996 - FY 1999



Other pressures exist as well. Of particular concern is the availability of drugs through Medicaid. Medicaid eligibility criteria vary from State to State. Drug selection, refills, and/or total spending per person may be limited. The risk of lapse in access to medications as individuals wait for Medicaid eligibility or leave the Medicaid program also is a problem. All of these issues impact the demand for medications through the ADAPs.

States and EMAs may contribute discretionary funds to their State's ADAP, and have increasingly done so in recent years. And, through a variety of initiatives, HRSA has secured deep discounts

for drugs. But these measures have not completely offset the financial demands on ADAPs, and restrictions on access to medications sometimes result.

Access to Medications Through State ADAPs, 1999 Financial Eligibility Criteria, Medical Eligibility Criteria, and Drug Formularies

Financial Eligibility

Percent of Federal Poverty Line (\$8,240)	Number of ADAPs
≤ 100%	2
101-200%	20
201-300%	19
> 300%	12

Medical Eligibility

Medical Criteria	Number of ADAPs
HIV diagnosis	43
HIV diagnosis and CD4 count	10
Specific criteria for protease inhibitors	9

Formulary Coverage

Number of Drugs	Number of ADAPs
11-50	38
51-100	10
101-200	4
> 200	1

Title III: Early Intervention Grants

Title III grants expand the service capacity of organizations providing primary care services to indigent HIV-positive individuals. There were 96,451 HIV-positive primary care clients among Title III grantees in 1997 (data for 1998 are not yet available).

The number of HIV-positive pregnant women served by Title III grantees increased to 1,180 in 1997, up more than 60 percent from 1996. It is unknown which portion of this large increase reflects higher HIV incidence in women of childbearing age and which reflects improved outreach. Title III grantees also reported a substantial rise—41.2 percent—in the number of newly HIV-infected infants and children who were clients from 1996 to 1997.

New Title III Clients in 1997

Title III had 25,764 new clients in 1997, of whom:

- Two-thirds lived at or below the Federal poverty level (\$16,050 for a family of four);
- About one-half received Medicaid; and
- Approximately one-quarter had private insurance of some kind.

Of the 174 organizations that received Title III grants in 1997, 37 percent were federally supported community and migrant health centers; 39 percent were university or hospital medical centers; 20 percent were non-Federal community health centers; and 17 percent were city or county health departments. All Title III grantees receive funding from multiple sources, and most receive funds from other CARE Act programs.

Title III Grantee Expenditures, FY 1997

	Number of Clients	Cost Per Person (\$)	Amount of Title III Funds (\$)
Primary care	96,451	1,780	46,823,070
Case management	70,378	334	5,991,923
Counseling and testing	344,583	61	5,022,929
Referrals	29,663	136	2,173,354
Outreach	718,699	19	2,295,381

Title IV: Women, Infants, Children, and Youth

Several factors distinguish pediatric HIV disease from that in adults. It requires the attention of a specialist experienced in treating HIV-positive children and intensifies the responsibilities of parenting and care giving.

HIV infection in mothers, fathers, and adult family members can stretch a family's resources to the breaking point. The heavy toll on families with an HIV-positive care giver or child is anticipated and responded to in the services funded through Title IV of the CARE Act. Other CARE Act programs provide services for these populations, but the Title IV program funds grants addressing their needs specifically:

- Neonatal and pediatric specialty care;
- Care for women of childbearing age—including pregnant women;
- Care for care givers of HIV-positive children;
- Coordination of care for the entire family; and
- Access to research and clinical trials for women, infants, children, and youth.

In addition to 58 grants, in 1999 Title IV funds were used for special initiatives to address problems in children, adolescents, and women living with HIV disease.

The **African American Children's Initiative** was created to reduce perinatal HIV transmission and to increase access to quality care for African American children threatened by HIV disease. The program increases resources in predominantly African American communities and links current Title IV providers with local health and social service organizations.

Grants for Adolescent Services consists of five grants totaling \$2 million annually that were awarded specifically to improve networks linking adolescents with counseling and testing, primary medical care, support services, and opportunities for clinical research. The goal is to increase the number of HIV-positive youth in care.

The **REACH Project** (Reaching for Excellence in Adolescent Care and Health) is a collaborative project of HRSA, the National Institutes of Health, and several adolescent care sites across the country. The objective is to better understand HIV disease in youth and to design and implement mechanisms for bringing these youth into care and keeping them there.

Other Programs (Part F)

Special Projects of National Significance

The Special Projects of National Significance (SPNS) Program implements and evaluates innovative models of reaching underserved populations and delivering HIV care. Unique Federal expertise in program development and evaluation is combined with organizations with experience in the local community to assure overall program effectiveness. SPNS models are designed to be replicated throughout the country. Results are used to redirect resources into service delivery methods that yield the greatest return. Findings are disseminated to grantees and help to improve outcomes for clients everywhere.



Each year, either 3 percent of the total CARE Act appropriation or \$25 million, whichever is less, is invested in the SPNS Program. Since the program's inception in 1991, projects have focused on improving services to particular segments of society, as well as on systems issues like comprehensive care.

Currently, there are 54 SPNS grants that vary in duration from 1 to 5 years, as well as approximately 30 additional care delivery activities. New projects are addressing palliative care, adherence,

care for individuals leaving correctional institutions, care for substance abusers, and HIV care in managed care networks.

AIDS Education and Training Centers

The national network of AIDS Education and Training Centers (AETCs) provides national leadership in clinical education.

The program leverages HRSA's relationships with leading teaching institutions to deliver the latest in clinical training to clinicians across the country. Thousands of clinicians, many of whom may not have received HIV/AIDS education during their medical training or anticipated providing care for HIV-positive individuals, have been educated through the centers.

As HIV/AIDS care has become more complex, the need for AIDS education and training has become more acute. Currently, there are 14 AETCs that provide education in every State.

A national AETC is being funded for the first time to disseminate the most recent advances in treatment and to coordinate the development of training materials. A national minority AETC also is being funded to build a network that includes historically black colleges and universities, as well as other institutions.



HIV/AIDS Dental Reimbursement Program

Because of impaired immune response, oral health is greatly affected by HIV disease. It is also an important component of HIV diagnosis and treatment, since oral health problems often are the first indication of HIV infection. Prevention and treatment of oral health problems common among HIV-positive individuals are crucial for maintaining good nutrition.

The objectives of the Dental Reimbursement Program are to offset the cost of uncompensated HIV care in teaching institutions, improve access to oral health care, and ensure that dental students and residents are trained to care for persons living with HIV disease.

The Dental Reimbursement Program provides funds to postdoctoral dental programs and accredited dental schools. Between June 1996 and July 1997, participating institutions reported that 90 percent of their 65,934 HIV-positive patients could not pay for the care they received. In 1998, the program funded 101 dental institutions. These funds helped provide care to approximately 66,500 individuals, covering about 48 percent of the cost of this care.



PART III

AIDS Care: Critical Issues



AIDS Care: Critical Issues

HRSA has identified the following as critical issues for the effective provision of care to individuals with HIV disease or AIDS.

These issues will require the attention of all those concerned with HIV/AIDS care in the years to come.

1. Training and Experience, and Their Impact on Quality of Care

More than ever before, HIV disease requires expert care. But many clinicians do not deliver care that meets current standards because they lack essential experience and training in HIV/AIDS medicine. A response to training needs is a necessary component of improving health outcomes for HIV-positive individuals.

2. Care in Underserved Communities

Many HIV-positive individuals live in communities with few health care providers in general and even fewer HIV/AIDS clinicians. The lack of both general and specialized care jeopardizes the health of infected individuals. Greater capacity to provide quality care in minority communities is essential for eliminating the health disparities suffered by African Americans and Hispanics.

3. Comprehensive Care

The incidence of concurrent health problems in individuals living with HIV is common. The presence of multiple diagnoses complicates the delivery of health care and increases costs. Of particular concern is that many individuals who have multiple health problems—especially the poor—currently are not being treated for serious diagnoses like addiction, tuberculosis, and mental health disorders. Without comprehensive health care, the potential for effectively treating HIV is reduced significantly.

4. HIV-Positive Individuals Not in Care

Of the 650,000 to 900,000 individuals living with HIV disease in America, up to one-third do not realize they are HIV positive. Many others have tested positive for HIV but are not receiving care regularly. Still others may begin treatment only when they become symptomatic. Poverty, the stigma attached to HIV infection, and multiple health problems are all part of the problem. Lack of information also is a major factor.

5. Quantifiable Outcomes Data

A better system for measuring service outcomes is essential for allocating CARE Act resources. The HIV/AIDS Bureau is already responding, but there is much left to be done. Improved outcomes data are needed for all CARE Act programs, but are particularly important for State and local CARE Act planning bodies, which must allocate limited resources to meet the overwhelming need for medical and support services.

6. Treatment and Adherence

HAART has improved the lives of thousands living with HIV disease, but its costs are prohibitive, its side effects are severe, and its dosing regimens are very complicated. In one test using placebos, even clinicians often failed to take medications as prescribed. As scientists continue to achieve breakthroughs in their labs, we must simultaneously work with clients to make the promise of today's best treatments a reality in the lives of all HIV-positive individuals.

7. Health Insurance and Financing

In recent years, health care financing has changed significantly, and eligibility for public benefits varies greatly by State. The impact of these changes on quality of care has not always been positive. Managed care, now the country's predominant form of health insurance coverage, also has implications for access to quality care. CARE Act grantees and providers must anticipate and contend with changes in demand resulting from these developments. They must also ensure appropriate care and services for their clients, regardless of the source of payment for the services they provide.



PART IV

About the HIV/AIDS Bureau

About the HIV/AIDS Bureau

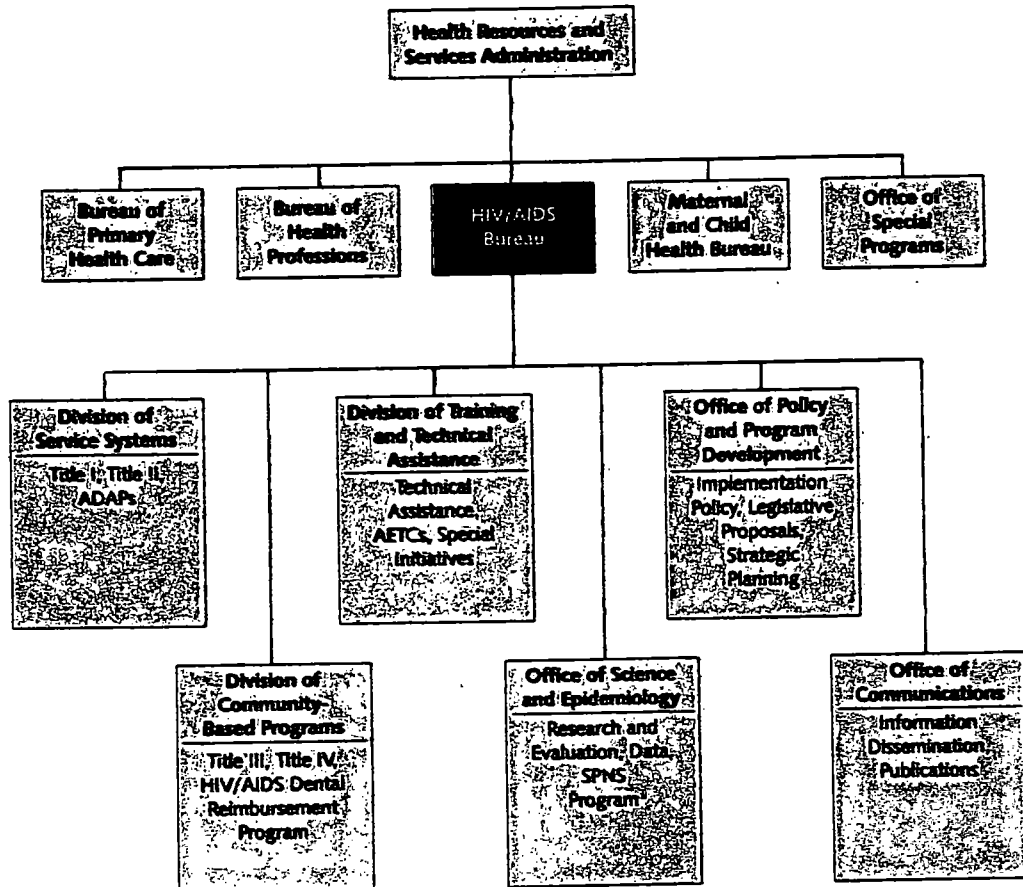
Through the HIV/AIDS Bureau (HAB), HRSA provides national leadership in HIV/AIDS care and in training clinicians serving HIV-positive individuals. The consolidation of administrative responsibility for all CARE Act components into a single Bureau in 1997 has resulted in greater administrative efficiency, enhanced collaboration among grantees and providers, and improved services to individuals living with HIV disease.

With its public, private, and individual partners, HAB is positioned to respond to an evolving epidemic. In addition to working with hundreds of organizations to implement grants more productively, HAB is providing capacity building and technical support where it is needed. This includes support for minority communities, for adolescents, and for grantees who represent the only source of care for the individuals they serve. HAB also is responding to systemwide issues like managed care and telemedicine. It is also working with experts to discover and implement more effective systems for supporting adherence to today's promising but exacting treatment regimens.

The SPNS Program continues to lead the search for new approaches to service delivery that can reach more individuals and improve health outcomes. Today, SPNS findings are being utilized throughout the country. The AETCs represent the Nation's only program solely dedicated to the education of clinicians treating HIV-positive patients. Through 14 institutions across the country and through technology that can reach clinicians wherever they are, the most advanced clinical training is available to all those providing HIV/AIDS care. Through these activities and others, the Bureau is at the forefront of HIV/AIDS care for individuals who have nowhere else to turn.

To find out more about HAB, contact our office at 301-443-6652 or visit our Web site at www.hrsa.gov/hab.

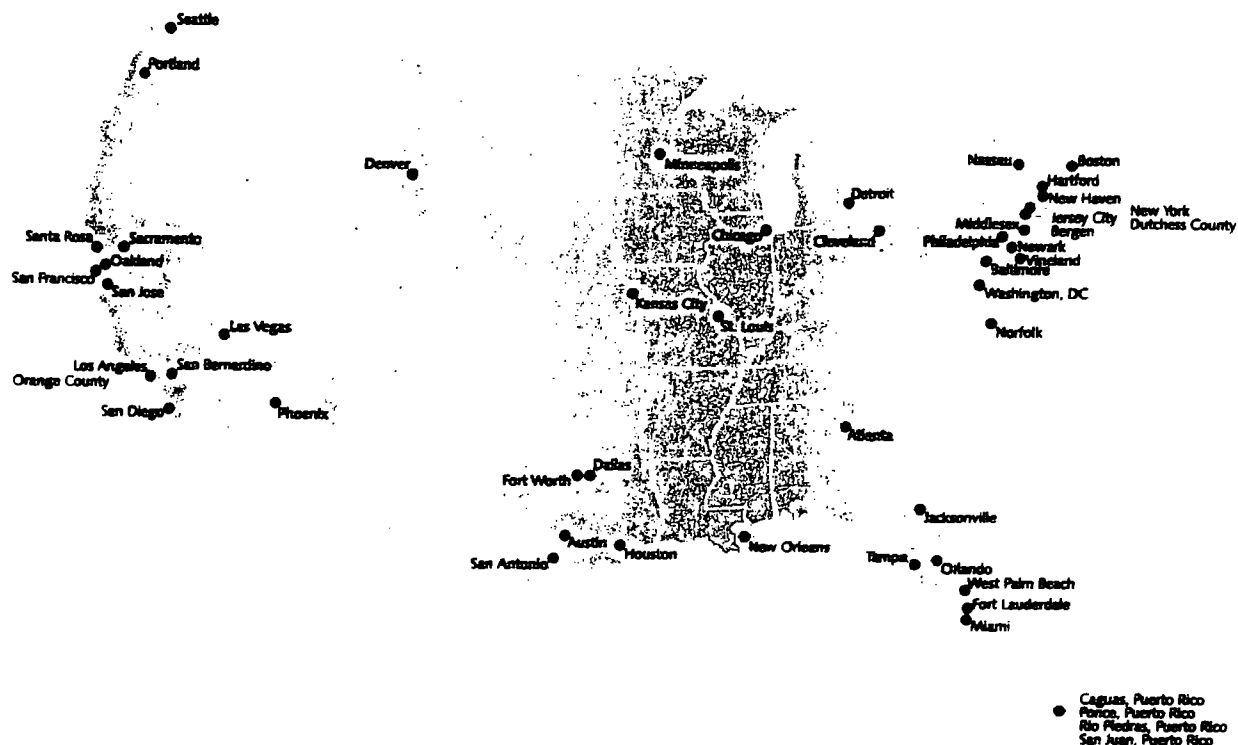
Health Resources and Services Administration Organizational Chart



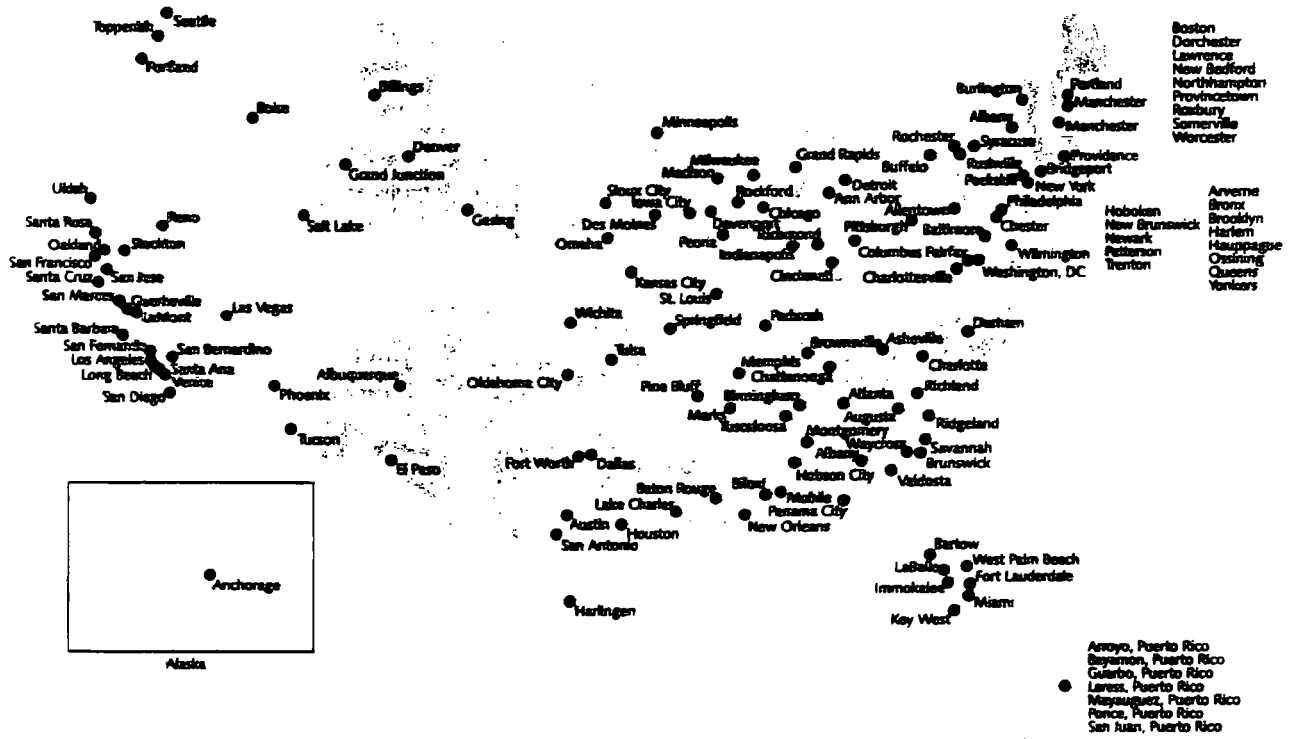
Appendix A: CARE Act Grant Awards by Jurisdiction

As shown in the maps that follow, CARE Act funds reach HIV-positive individuals in need in communities across the country. Since Title II funds are distributed to every State, a map has not been included for the Title II program.

Title I: Grants to Eligible Metropolitan Areas (FY 1999)



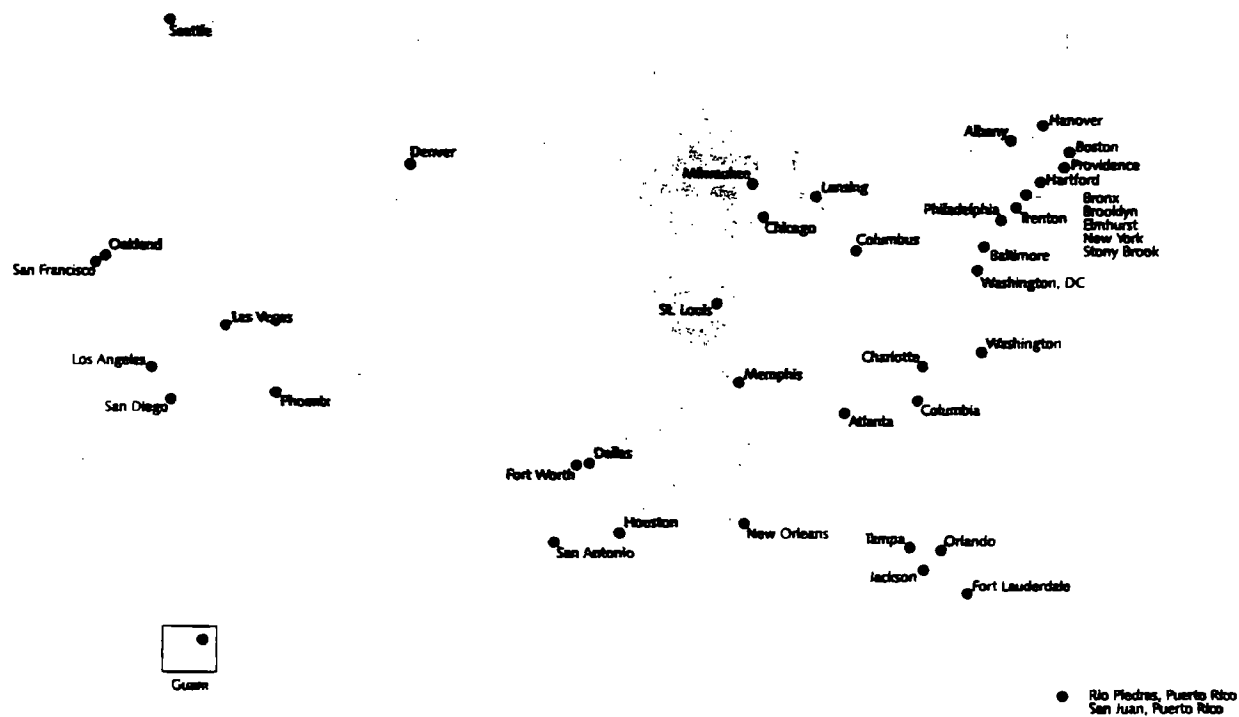
Title III: Early Intervention Grants (FY 1999)



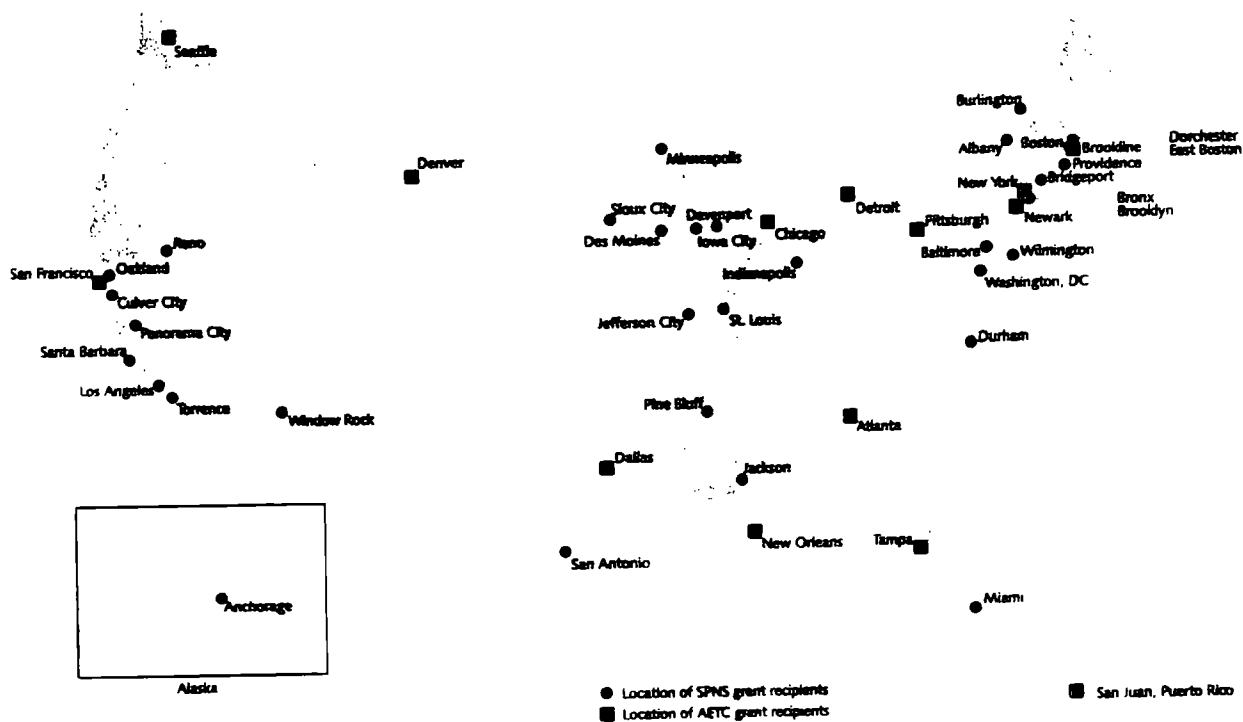
Note :

Because some cities have received multiple grants, the number of points on the map do not reflect the actual number of grants awarded.

Title IV: Women, Infants, Children, and Youth (FY 1999)



Part F: SPNS and AETC Grants (FY 1999)



Note:

Because some cities have received multiple grants, the number of points on the map do not reflect the actual number of grants awarded.

Grant Recipients by State and Territory

State/Territory	Title I	Title II	Title III	Title IV	Part F (SPNS)	Part F (AETC)
Alabama		✓	✓			
Alaska		✓	✓		✓	
Arizona	✓	✓	✓	✓	✓	
Arkansas		✓	✓		✓	
California	✓	✓	✓	✓	✓	✓
Colorado	✓	✓	✓	✓	✓	✓
Connecticut	✓	✓	✓	✓	✓	
Delaware		✓	✓			
District of Columbia	✓	✓	✓	✓	✓	
Florida	✓	✓	✓	✓	✓	
Georgia	✓	✓	✓	✓	✓	✓
Guam		✓		✓		
Hawaii		✓				
Idaho		✓	✓			
Illinois	✓	✓	✓	✓	✓	✓
Iowa		✓	✓			
Indiana		✓	✓		✓	
Kansas		✓	✓		✓	
Kentucky		✓	✓			
Louisiana	✓	✓	✓	✓		✓
Maine		✓	✓		✓	
Maryland	✓	✓	✓	✓	✓	
Massachusetts	✓	✓	✓	✓	✓	✓
Michigan	✓	✓	✓	✓	✓	
Minnesota	✓	✓	✓		✓	
Mississippi		✓	✓		✓	
Missouri	✓	✓	✓	✓	✓	
Montana		✓	✓		✓	
Nebraska		✓	✓		✓	
Nevada	✓	✓	✓	✓	✓	
New Hampshire		✓	✓	✓	✓	
New Jersey	✓	✓	✓	✓	✓	✓
New Mexico		✓	✓		✓	
New York	✓	✓	✓	✓	✓	✓
North Carolina		✓	✓	✓	✓	
North Dakota		✓	✓		✓	
Ohio	✓	✓	✓	✓	✓	
Oklahoma		✓	✓		✓	
Oregon	✓	✓	✓		✓	
Pennsylvania	✓	✓	✓	✓	✓	✓
Puerto Rico	✓	✓	✓	✓	✓	✓
Rhode Island		✓	✓	✓	✓	
South Carolina		✓	✓	✓	✓	
South Dakota		✓	✓		✓	
Tennessee		✓	✓	✓	✓	
Texas	✓	✓	✓	✓	✓	✓
Utah		✓	✓		✓	
Vermont		✓	✓		✓	
Virginia	✓	✓	✓		✓	
Virgin Islands		✓				
Washington	✓	✓	✓	✓	✓	✓
West Virginia		✓		✓		
Wisconsin		✓	✓	✓		
Wyoming		✓				

Key:

✓ = grant recipient

PART V
Appendices

Appendix B: Glossary

ADAP	AIDS Drug Assistance Program
AETC	AIDS Education and Training Center
AIDS	acquired immunodeficiency syndrome
AZT	zidovudine; azidothymidine; Retrovir®
CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act
CDC	Centers for Disease Control and Prevention
CI	confidence interval
CMV	cytomegalovirus
ddI	didanosine; Videx®
EMA	eligible metropolitan area
FDA	Food and Drug Administration
HAART	highly active antiretroviral therapy
HAB	HIV/AIDS Bureau
HCV	hepatitis C virus
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
NNRTI	non-nucleoside reverse transcriptase inhibitor
PCP	<i>Pneumocystis carinii</i> pneumonia
REACH Project	Reaching for Excellence in Adolescent Care and Health Project
SPNS	Special Projects of National Significance

Appendix C: References

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For more information about the Ryan White CARE Act, see HIV/AIDS.gov.
or call 301-443-6652 or visit us on the Web at www.hrsa.gov/hab