

THE AIDS EPIDEMIC AND THE RYAN WHITE CARE ACT



PAST SUCCESSES +
FUTURE CHALLENGES

2004 - 2005





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FUTURE CHALLENGES

2004 - 2005

U.S. Department of Health and Human Services
Health Resources and Services Administration
HIV/AIDS Bureau
www.hab.hrsa.gov



LIVING WITH HIV DONNA JEAN NAVARRO, OKLAHOMA CITY, OK

PHOTOGRAPHS FOR THIS REPORT WERE GENEROUSLY PROVIDED BY *THE FACES OF AIDS*, TWO PROJECTS THAT CHRONICLE THE LIVES OF PEOPLE LIVING WITH HIV DISEASE [IN](#) || MIDWESTERN STATES AND IN NEW YORK CITY.

PART I. SUCCESSES AND CHALLENGES



FEW NEW CARE ACT
FINANCIAL RESOURCES



GROWING HIV/AIDS
PREVALENCE



RISING COSTS OF
HEALTH CARE AND
BREAKTHROUGH DRUGS



GROWING CHALLENGES
IN THE FACE OF SUCCESS



SANFORD GAYLORD, CHICAGO, IL



DEBBIE MATA, CHICAGO, IL

HIV/AIDS:

SUCCESSES



CHALLENGES

CDC study finds U.S. perinatal transmissions fall 80% in past decade due to testing of pregnant women and use of ARV drugs (7/9/02)

FDA approves buprenorphine, the first medication for opiate addiction that can be prescribed in primary care setting (10/02)

FDA approves convenient, easy-to-use OraQuick rapid HIV test (11/7/02)

HHS extends availability of OraQuick rapid test to more than 100,000 sites nationwide (1/31/03)

For first time since 1993, CDC reports increase in AIDS diagnoses in the United States (2/12/03)

THE RYAN WHITE CARE ACT

THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT AUTHORIZES HIV/AIDS SERVICES FOR PEOPLE WITH NOWHERE ELSE TO TURN. FIRST SIGNED INTO LAW IN 1990, AND REAUTHORIZED IN 1996 AND AGAIN IN 2000, THE LEGISLATION CREATED A SET OF DIVERSE PROGRAMS, DESCRIBED IN PART IV OF THIS REPORT.

THE FOCUS OF THE CARE ACT IS TO PROVIDE PRIMARY CARE, TREATMENT, AND ESSENTIAL SUPPORT SERVICES TO PEOPLE LIVING WITH HIV/AIDS. THE SERVICES ARE DELIVERED BY ORGANIZATIONS ACROSS THE COUNTRY THAT RECEIVE CARE ACT FUNDS—PRIMARILY THROUGH GRANTS. EACH YEAR, THEY REACH ABOUT 533,000 UNDERSERVED PEOPLE, MORE THAN HALF OF ALL THOSE ESTIMATED TO BE LIVING WITH HIV/AIDS IN THE UNITED STATES.



JIMAYA, IOWA CITY, IA

BOOG, RURAL KANSAS

President announces Emergency Plan for AIDS Relief, a 5-Year Global HIV/AIDS Strategy (2/23/03)

Six biggest ADAP programs meet with drug companies to seek lower prices on AIDS drugs (2/28/03)

FDA approves Fuzeon—first of a new class of treatments for advanced HIV disease (3/13/03)

New CDC Advancing HIV Prevention initiative to reduce new HIV infections and the number of people not in care (4/17/03)

Once-daily protease inhibitor Reyataz gets FDA approval for HIV infection (6/20/03)

HIV cases on rise in the United States. CDC reports first increase in diagnoses since 1993—blacks, Hispanics, and MSM most affected; number of newly diagnosed cases among MSM rises for third straight year (7/28/03)

Much about HIV/AIDS has improved in the United States. Perinatal transmission of HIV has fallen precipitously. AIDS mortality continues its decline. The quality of life and productivity of many people living with HIV/AIDS has never been higher.

The greatest success of the Ryan White CARE Act is that it has extended these benefits to hundreds of thousands of people who otherwise would have gone unserved.

The CARE Act community's greatest challenge in 2004 and beyond is to continue to reach people who have nowhere else to turn in an age of increasing HIV/AIDS prevalence, ever-increasing health care costs, and a growing burden of HIV among the uninsured and underserved.



JOY AND DANTE SANDLER, WATERLOO, IA



MODESTO "TICO" VALLE, CHICAGO, IL

Combination ARV therapy increases risk of heart attack, study finds (11/22/03)

Abbott raises price of longtime HIV drug Norvir 400%, spurring debate over domestic pricing policies (12/19/03)

International Association of Physicians in AIDS Care publication indicates that 300,000 people in the United States are HIV/HCV coinfectd (1/04)

Overall health care spending up 9.3% in 2002—the largest increase in 11 years—to \$1.55 trillion; prescription drugs account for much of increase (1/04)

15 State ADAPs have waiting lists, access restrictions, NASTAD reports (1/27/04)

Although single dose of Nevirapine at labor and delivery helps prevent vertical transmission of HIV, the mother may develop drug resistance, study finds (2/10/04)

S U C C E S S E S

MORE THAN 2,700 CARE ACT-FUNDED PROVIDERS REACH OVER HALF-MILLION PEOPLE EVERY YEAR.

CARE ACT CLIENTS REFLECT THE DEMOGRAPHICS OF THE AIDS EPIDEMIC.

PROVIDERS ARE REACHING PEOPLE WHO ARE POOR AND WHO HAVE INADEQUATE HEALTH INSURANCE.

CARE ACT RESOURCES ARE BEING USED FOR PRIMARY CARE AND TREATMENT.

FUNDS ARE AWARDED THROUGH A COMPETITIVE PROCESS THAT ENSURES MONEY IS BEING INVESTED WHERE IT CAN DO THE MOST GOOD.

CARE ACT PROVIDERS ARE BUILDING NETWORKS WITH OTHER PUBLIC AND PRIVATE PROVIDERS TO BUILD A COMPREHENSIVE RESPONSE TO THE EPIDEMIC.

C H A L L E N G E S

THE CAPACITY OF PROVIDERS WORKING IN UNDERSERVED COMMUNITIES MUST BE INCREASED.

PROVIDERS MUST ADAPT TO AN ENVIRONMENT OF FEW NEW RESOURCES, RISING COSTS, AND GROWING HIV/AIDS PREVALENCE.

THE CARE ACT COMMUNITY MUST ENSURE ACCESS TO MEDICATION AT THE LOWEST POSSIBLE PRICE.

CARE ACT PROVIDERS MUST CONTINUE TO PRIORITIZE FUNDING OF PRIMARY CARE SERVICES.

CARE PROVIDERS MUST CONTINUE TO INCREASE THEIR FOCUS ON MEASURABLE OUTCOMES, EVALUATION, AND PRODUCTIVITY.

THE CARE ACT COMMUNITY MUST WORK TO ENSURE THAT THE CARE ACT IS ALWAYS THE PAYER OF LAST RESORT.



RAVEN AND MICHELLE LOPEZ, NEW YORK, NY



MARTÍN GONZALES ROJAS, CHICAGO, IL

AIDS hitting young black men in college; increase in HIV infection feared across the South (2/11/04)

Many new HIV infections acquired heterosexually, CDC says (2/20/04)

Protein in monkeys may block HIV infection; finding may help development of HIV prevention strategies in humans (2/25/04)

HIV vaccine not likely in next decade, UNAIDS executive director says; human clinical trials for HIV vaccine begin at UMass (3/24/04)

FDA approves OraQuick rapid test for detection of HIV-1 and HIV-2 antibodies (3/25/04)

The number of HIV-positive people is rising faster in the South than in any other region of the United States, study finds (3/29/04)

Thousands of diverse organizations and individuals collaborate to implement the Nation's CARE Act programs. Their ability to adapt to an environment of growing pressure will do much to determine whether the country is able to serve underinsured and underserved people living with HIV disease who need care in the future.

Enhancements in treatment, like once-daily dosing, are going to break down barriers to extremely demanding—and sometimes debilitating—antiretroviral regimens. Innovations like rapid testing, increased CARE Act emphasis on outreach to the 400,000 to 500,000 HIV-positive people not in care, and the Centers for Disease Control and Prevention (CDC) Advancing HIV Prevention: New Strategies for a Changing Epidemic initiative are going to successfully reach people

living with HIV disease. Unless the economic profile of communities disproportionately affected by HIV disease changes dramatically—and there is no indication that it will—many people reached are not going to have private health insurance or personal resources to pay for care. Many will be ineligible for Medicaid. Who is going to take care of them?

This is not a new question—and in many ways it is the very question that led to the CARE Act in the first place. But needs today are in many ways very different from in 1990, when the CARE Act was first signed into law. We now have antiretroviral therapy. Hospital care is required for fewer and fewer people. But as inpatient costs continue to fall, outpatient costs continue to rise—and rise dramatically. And with more people

living with HIV disease in the United States than ever before, and with few new public resources available to care for them, many CARE Act-funded providers and programs face a set of real-world circumstances that pose serious challenges to people seeking care—and for people seeking to provide it.

Yet the glass is half full. The CARE Act community—and the entire HIV prevention and care system in the United States—has never had more to offer. And we have the capacity to adapt to new realities. We are able to apply rigorous principles to managing resources. We can ensure that we operate as efficiently and productively as possible. And we can redouble our commitment to investing resources where they can do the most good.

CONNECTING WITH POPULATIONS IN UNDERSERVED COMMUNITIES

AIDS incidence and mortality have fallen among underinsured people because CARE Act–funded providers are very good at reaching populations historically underserved by the larger health care system, such as racial and ethnic minorities, who constituted about 65 percent of CARE Act clients in 2002.

CARE Act–funded providers are also very good at responding to the changing demographics of AIDS. For example, about one-third of all clients are now women. Almost one-third are 45 or older. And providers are redoubling efforts to reach young people, a

population that is among the most underserved in America and that continues to experience extremely high HIV incidence in some communities.

Like most CARE Act successes, client reflectiveness of the epidemic hasn't happened because of the actions of a single group or single program. It has happened because of locally conducted, science-based needs assessments. It has happened because of innovative outreach programs. And, critically, it has happened because of the work of organizations such as communities

of faith, public health departments, social services organizations, and substance abuse treatment centers.

The CARE Act community knows organizations like these as “key points of entry” into the medical system. They provide critical services to populations that are often both hard to reach and at risk for HIV disease. By building linkages with those organizations, CARE Act providers reach affected populations, sometimes long before the changing demographics of the epidemic are reflected in public data.

REACHING THOSE MOST IN NEED

The “E” in CARE Act stands for “emergency.” It's the word on which the entire CARE Act initiative pivots.

CARE Act clients come from big cities and small towns, suburban communities and the rural heartland. And wherever they live, they face a common problem: They simply cannot afford essential HIV/AIDS care and support services.

When the epidemic emerged, communities were not prepared for a disease like AIDS. No one had ever imagined a disease like it—and there were simply no resources to

respond to the emergency created by debilitating illness and its economic results: loss of employment, loss of health insurance, and loss of the capacity to meet even basic subsistence needs like food and housing.

The scenario is quite different today, but the word “emergency” still applies. With treatment, many people are able to work and support themselves and their families. But infection rates have climbed among people who were at disproportionate risk for poverty before becoming infected. It is a fact reflected in the demographics of CARE Act clients. In 2002

- at least one of every two lived below the Federal Poverty Level
- fewer than 1 in 10 had any private health insurance; and
- only 27.9 percent were enrolled in Medicaid.

CARE Act program success in ensuring that breakthroughs in treatment reach the underserved is due in large part to the capacity to reach people whom many providers in America's health care system do not serve.

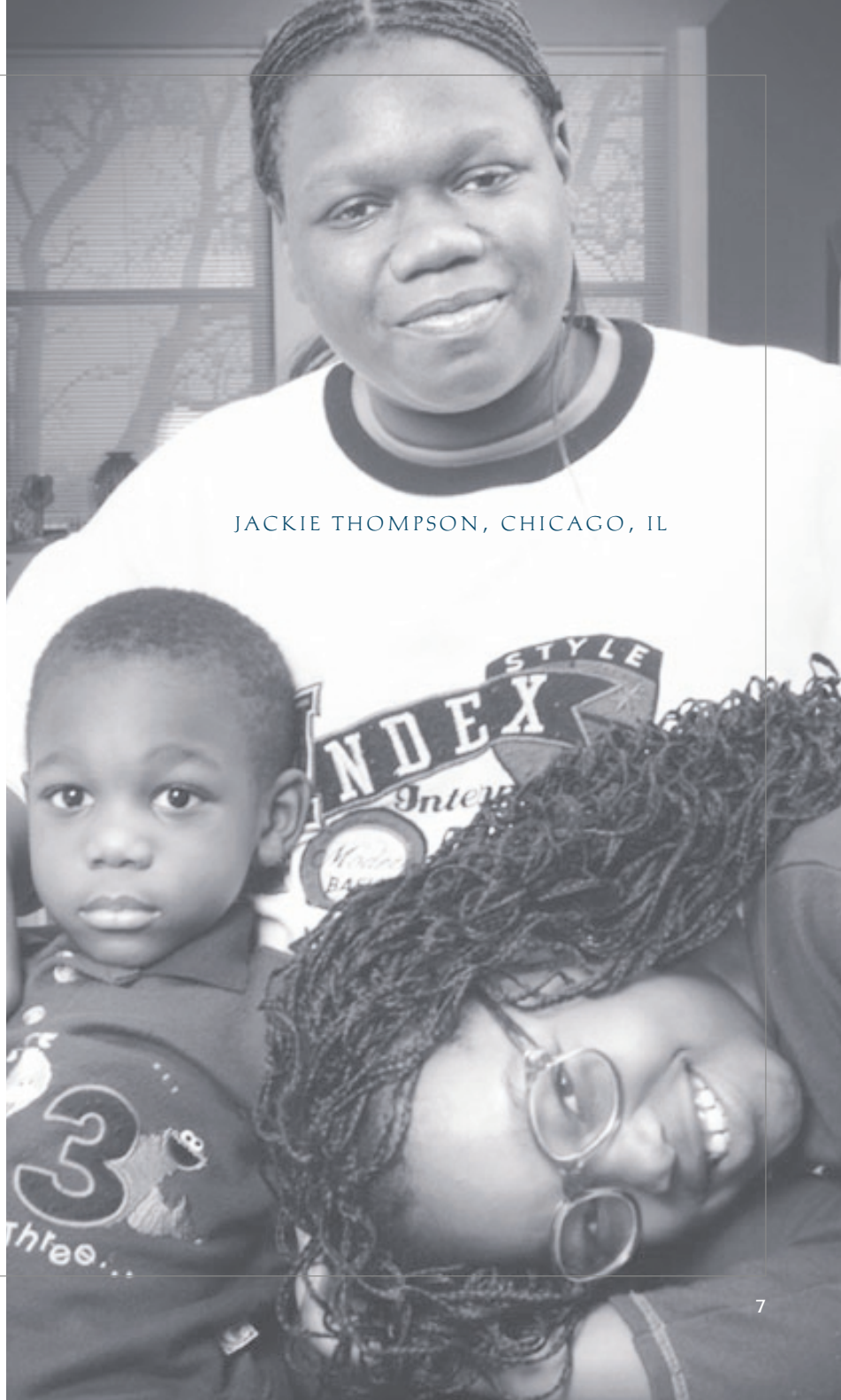
CARE ACT CLIENTS

CARE ACT CLIENTS ARE “UNDERSERVED” AND “UN/UNDERINSURED.” (SEE CHARTS, PAGE 17.) BUT THOSE WORDS BELIE THE RESILIENCY AND COURAGE OF PEOPLE WHO OFTEN OVERCOME INCREDIBLE ODDS TO COUNTER THE PHYSICAL AND SOCIAL EFFECTS OF HIV/AIDS.

CARE ACT CLIENTS ARE INVOLVED IN THEIR OWN CARE. MANY PLAY ACTIVE ROLES IN SERVICE PLANNING AT THE STATE, COMMUNITY, AND PROVIDER LEVELS. MANY ARE LEADERS IN RESEARCH, ADVOCACY, AND SERVICE DELIVERY. AND MANY, LIKE THOSE WHOSE PICTURES FILL THE PAGES OF THIS REPORT, HAVE MUCH TO TEACH US ABOUT HIV/AIDS.

LIKE MARY SWINTON FROM WICHITA, KANSAS, WHO SAYS, “THE SAME THING CAN HAPPEN TO ANY OTHER WOMAN IN MY CHURCH.”

OR LIKE DAVE BERGQUIST, WHO LIVES IN STURGEON LAKE, MINNESOTA. “AROUND HERE,” HE SAYS, “THEY THINK IT CAN’T EXIST BECAUSE THERE ARE NO GAY PEOPLE. THAT MAKES THEM ILL-INFORMED ON TWO COUNTS. I KNOW THREE PEOPLE WITHIN 10 MILES OF ME WHO HAVE HIV. ONE IS STRAIGHT, ONE IS A LITTLE GIRL, AND ONE IS A GAY MAN.”



JACKIE THOMPSON, CHICAGO, IL

EXPANDING SERVICE CAPACITY IN UNDERSERVED COMMUNITIES

CARE Act providers increasingly reflect the underserved communities they exist to serve. In more than 1 in 3 CARE Act–funded providers, a majority of professional staff members are racial and ethnic minorities.

Through capacity building and planning grants, the CARE Act expands service delivery capacity in historically underserved, often minority communities. In 2002, for example, 60 planning grants and 59 capacity-building grants helped providers prepare to provide services where, in many cases, no other providers existed.

We can't address AIDS without health care. And we can't provide health care without providers in communities that need it. Continuing to invest service resources in under-resourced communities is a must if we are to reach those not in care.

DOING MORE WITH LESS—AND ALWAYS MAKING THE CARE ACT THE PAYER OF LAST RESORT

Doing more with less is a familiar concept to CARE Act–funded organizations. Most are either public agencies or nonprofits well accustomed to fluctuations in charitable giving and public and private funding. They understand that the Nation is facing new challenges. And they realize that they must work harder than ever to make sure that the CARE Act is always the payer of last resort.

Individuals outside the CARE Act community sometimes believe that CARE Act programs are entitlements like Social Security and Medicare. Unlike those programs, however, which guarantee certain benefits to individuals who meet eligibility requirements, CARE Act funding is discretionary.

This is a critical distinction, and it means that resources are not unlimited. To ensure that CARE Act resources are there when needed, it is essential that they be used only to serve people who have nowhere else to turn.



VIGILANCE IN A TIME OF DISTRACTION

RESPONDING TO AIDS IS ABOUT MORE THAN RESPONDING TO AN INFECTIOUS DISEASE. IT IS ABOUT DEALING WITH THE PERCEPTION THAT ANTI-RETROVIRAL THERAPY HAS STOPPED AIDS. AND IT IS ABOUT DEALING WITH POOR ACCESS TO HEALTH INFORMATION AND HEALTH CARE—BOTH OF WHICH HAVE FUELED THE EPIDEMIC SINCE ITS INCEPTION.

THE CARE ACT COMMUNITY MUST REMAIN VIGILANT IN ITS EFFORTS TO STEM THE EFFECTS OF HIV/AIDS AT A TIME WHEN THE EPIDEMIC SEEMS TO TAKE UP A SMALLER PLACE IN THE AMERICAN CONSCIOUSNESS. FINDINGS FROM A 1987 GALLUP POLL INDICATED THAT 68 PERCENT OF AMERICANS BELIEVED HIV/AIDS WAS THE NATION'S MOST URGENT HEALTH PROBLEM, A NUMBER THAT HAD FALLEN TO JUST 17 PERCENT IN 2002, ACCORDING TO A FOLLOW-UP STUDY. THE NUMBER OF NEWS STORIES ON DOMESTIC AIDS HAS ALSO DECLINED OVER THE PERIOD, AND ORGANIZATIONS RELYING ON VOLUNTEERS AND PRIVATE DONATIONS REPORT DROPS IN GIVING.'

ANTONIO HERNANDEZ, NEW YORK, NY
DECEASED

PRIORITIZING DELIVERY OF PRIMARY CARE

More than two-thirds of all CARE Act funds were used for primary care and treatment in 2002. Almost 3 times more clients used primary care than used the most often used support service. (See charts, pages 14, 20, and 21.) Access to some support services is associated with increased utilization of primary care, and those services must continue to be funded where essential. But primary

care and treatment dollars harness the power of today's science from the laboratory into the lives of people the CARE Act was created to serve. Without these funds, reductions in perinatal transmission and AIDS mortality could never have been achieved. Nor could we address the health issues faced by an aging HIV-positive population.

Continuing prioritization of primary care is about more than allocating as many CARE Act resources as possible to providing care and treatment. With growing treatment costs, the aging of the HIV-positive population, and growing HIV prevalence, CARE Act providers can never meet total need for primary care services—and they were never intended to.

BUILDING A GROWING COALITION

CARE Act providers use case managers, counselors, and advocates to link HIV-positive individuals to non-CARE Act programs for essential services. For example, eligible individuals are referred to Medicaid, which frees CARE Act resources to assist those who are not Medicaid eligible. (27.9 percent of clients were enrolled in Medicaid at the end

of 2002.) Providers also link clients to charitable and publicly supported organizations, such as departments of health and federally funded community and migrant health centers.

Yet, too often, CARE Act-funded providers are called on to deliver care that could be—

and should be—provided by others in the community. Only by building a broader coalition of organizations that address HIV/AIDS in local communities can the Nation reach everyone not in care and ensure the availability of CARE Act-funded services in cases where there are no other options.

IDENTIFYING EXISTING INFECTIONS AND PREVENTING NEW ONES THROUGH CARE

True primary care includes a disease prevention component. Lack of access to such care represents a lost opportunity to prevent all kinds of diseases and adverse conditions. And it is one reason that millions of people living with a range of diseases—and hundreds of thousands of HIV-positive individuals—have never been diagnosed. By directing as many CARE Act and non-CARE

Act resources as possible to primary care, the United States can reduce the number of undiagnosed HIV infections, reduce the number of HIV-positive people not in care, and reduce new HIV infections.

People unaware and unsuspecting of their serostatus are less likely to incorporate prevention behaviors into their lifestyles than are

those who have been diagnosed and are in care. Innovative programs and new tools like rapid testing offer real potential for reaching even larger numbers of people previously unaware of their serostatus. Linking newly diagnosed people with care and then helping them adopt preventive behaviors represent major opportunities for stemming the tide of AIDS in the United States.

A black and white portrait of a man with a beard and mustache, wearing a patterned sweater and a necklace with a large white pendant. He is looking directly at the camera. The background is a blurred outdoor setting with a large archway.

KENNY BELL, ST! LOUIS, MO

RESPONDING TO AN INTERNATIONAL CRISIS

THE NATION'S COMMITMENT TO ADDRESSING AIDS IN RESOURCE-CONSTRAINED SETTINGS IS REFLECTED IN THE PRESIDENT'S EMERGENCY PLAN FOR AIDS RELIEF. THROUGH THIS AMBITIOUS PLAN, THE UNITED STATES IS PROVIDING MUCH-NEEDED SUPPORT IN THE 15 AFRICAN, CARIBBEAN, AND SOUTHEAST ASIAN NATIONS MOST AFFECTED BY HIV/AIDS.

THE HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) IS RESPONSIBLE FOR IMPLEMENTING THE CARE ACT, THE LARGEST U.S. PROGRAM SPECIFICALLY FOR PEOPLE LIVING WITH HIV/AIDS. IT ALSO IS PLAYING A CRUCIAL ROLE IN IMPLEMENTING THE PRESIDENT'S EMERGENCY PLAN. THE HRSA APPROACH HAS FOUR COMPONENTS: CARE AND TREATMENT; EDUCATION, TRAINING, AND HUMAN-CAPACITY BUILDING; TECHNICAL ASSISTANCE; AND FOSTERING OF PARTNERSHIPS. THROUGH ACTIVITIES IN EACH AREA, THE AGENCY BRINGS EXPERTISE AND ASSISTANCE TO SETTINGS THAT FACE ENORMOUS CHALLENGES.

EXPANDING ACCESS TO TREATMENTS AT THE BEST PRICE

The CARE Act community scored a critical victory in 2003 by ensuring access to the drug Norvir at a price almost four times lower than on the open market. Agreements like this one, and cost-cutting mechanisms at

State AIDS Drug Assistance Programs (ADAPs) (see page 36), and discount programs provide access to medications for many who could not afford even one month of antiretroviral therapy. Providing access to

appropriate treatment is the whole point of patient-centered primary care. CARE Act grantees must continue to work to get the best possible price for medications.

BEING ACCOUNTABLE

In recent years the CARE Act community has made great strides in focusing on quantifiable, measurable outcomes data. All programs have strong evaluation components and are working to increase their capacity to measure success.

CARE Act providers exist to serve clients, but they could not achieve their mission without Federal support. By focusing on core primary

care and essential support services, and by providing clear, concise outcomes data, providers in the CARE Act community become better stewards of the resources entrusted to them every year. And by becoming better stewards, CARE Act providers increase their productivity and their ability to reach those still not receiving appropriate care.

Rising health care costs, limited resources, and many other problems facing the CARE Act community are not new. But they must be approached with a renewed sense of mission. The health and quality of life of hundreds of thousands of people living with HIV disease depend on how well today's challenges are met.

PART II. PROGRAM DATA, FY 2002



BUILDING
ON SUCCESSES



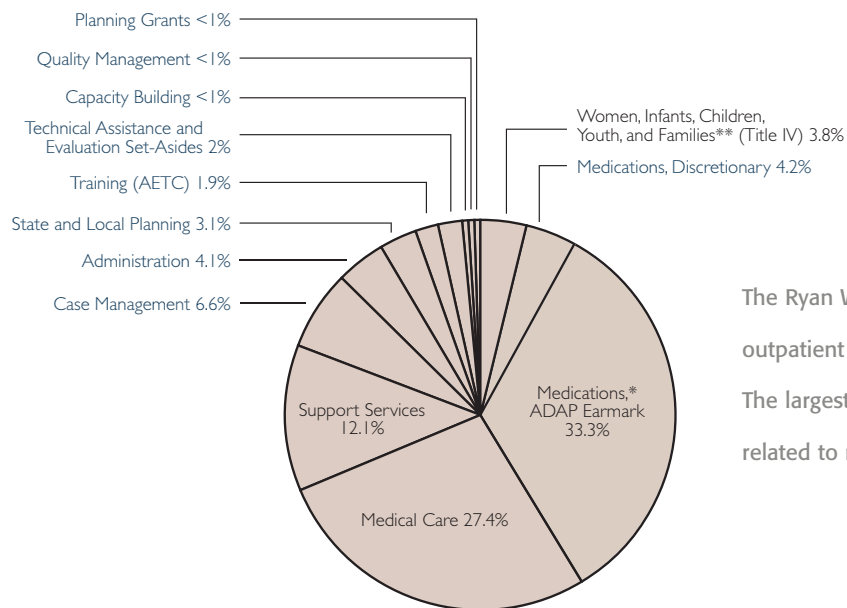
RESPONDING TO
NEW DYNAMICS



MEETING GROWING
DEMAND FOR
CARE ACT SERVICES

GREGORY AND KEVIN HUANG-CRUZ, NEW YORK, NY

CARE ACT SPENDING, FY 2002 APPROPRIATION: \$1.9 BILLION



The Ryan White CARE Act authorizes funding for outpatient medical care and essential support services. The largest portion of CARE Act spending is for services related to medical care.

Spending data in this chart are based in part on provider-reported estimates.

*Approximately 3.5 percent of spending under "Medications, ADAP Earmark" was for health insurance and adherence support.

**Title IV reflects only a portion of CARE Act spending for women, infants, children, youth, and families.

CARE ACT REPORTING

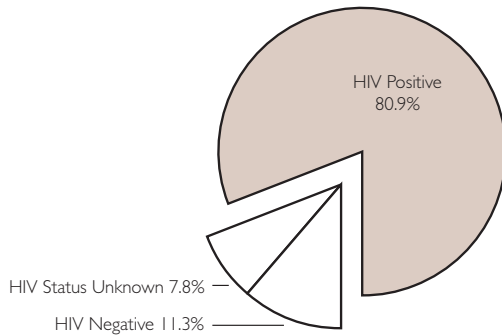
THE DATA ON THE FOLLOWING PAGES ARE DRAWN FROM THE CARE ACT DATA REPORT, WHICH PROVIDES NEW INFORMATION ON CARE ACT PROGRAMS.

WHEN THE CARE ACT BECAME LAW IN 1990, ITS DIVERSE PROGRAMS WERE IMPLEMENTED BY SEVERAL BUREAUS AND OFFICES WITHIN HRSA, EACH WITH ITS OWN MANDATES, POLICIES, AND APPROACHES. TODAY, ALL CARE ACT PROGRAMS ARE MANAGED THROUGH THE HIV/AIDS BUREAU. THAT CHANGE HAS GIVEN THE AGENCY THE OPPORTUNITY TO CONSTRUCT A MORE UNIFIED REPORTING SYSTEM.



CLIFF AND GLORIA MOSLEY, NEW YORK, NY

HIV STATUS OF CARE ACT-FUNDED PROVIDER CLIENTS, DUPLICATED,* 2002 (N = 1,044,172)**

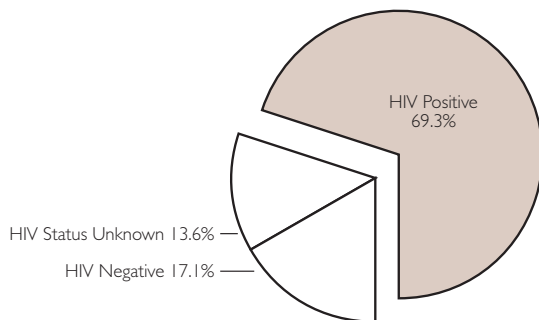


The CARE Act is fundamentally a care program for people living with HIV disease. Therefore, the vast majority of clients are HIV-positive. Some clients, however, are HIV-negative—for example, some who receive HIV counseling and testing through early intervention services. In addition, affected family members, such as HIV-negative children of HIV-positive mothers, may receive services through the Title IV program for women, infants, children, youth, and families.

*Data are from the *CARE Act Data Report*. The utility of this source is limited by duplicated client counts. Data from the report collected and reported by individual providers are generally unduplicated. However, an individual client may receive services from more than one provider, and there is no way of knowing that the counts of individuals served by one provider are not also included in the counts of another provider. Thus, aggregating provider data to the national level results in duplicate client counts.

**Percentages may not add to 100 due to rounding.

HIV STATUS OF NEW* CARE ACT-FUNDED PROVIDER CLIENTS,** 2002 (N = 370,059)



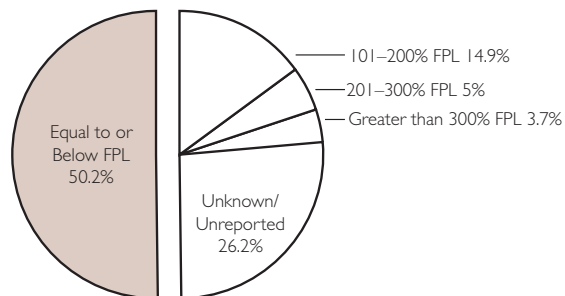
CARE Act providers reach out to individuals not in care and serve many new clients each year. Some clients receive many CARE Act services over time; others might receive only one service. Still others may be referred to non-CARE Act providers, ensuring that the CARE Act is always the payer of last resort.

New clients are those who first received services from a particular provider agency during the reporting period (2002), although they might have received services from another CARE Act-funded provider at a different time.

**Duplicated client counts. See note above.

POVERTY LEVEL OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)

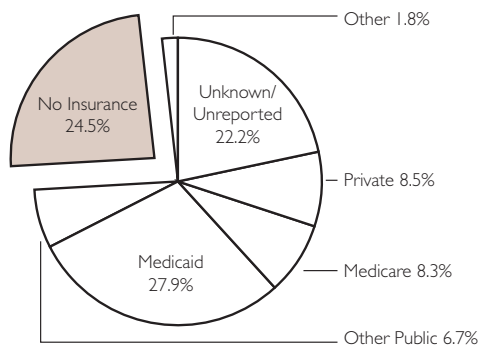
In 2002, a year in which the Federal Poverty Level (FPL) was \$18,100 for a family of four and the cost of antiretroviral therapy was as much as \$14,000, 50 percent of HIV-positive CARE Act clients were living at or below the FPL.² Poverty among CARE Act clients underscores the vital nature of essential support services—for example, food banks and transportation—and the importance of linking clients with other public and private programs for which they are eligible.



*Duplicated client counts. See note, page 16.

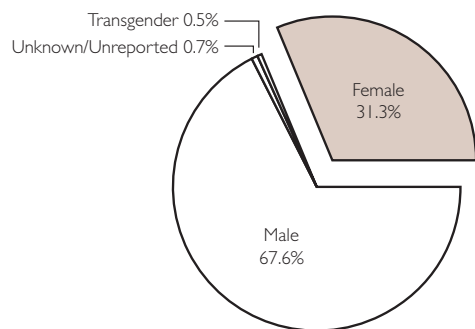
HEALTH INSURANCE STATUS OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)

In 2002, only 8.5 percent of CARE Act clients had any private health insurance, and only 27.9 percent were enrolled in Medicaid. The situation increases pressure on CARE Act programs in an age of rising outpatient treatment costs.



*Duplicated client counts. See note, page 16.

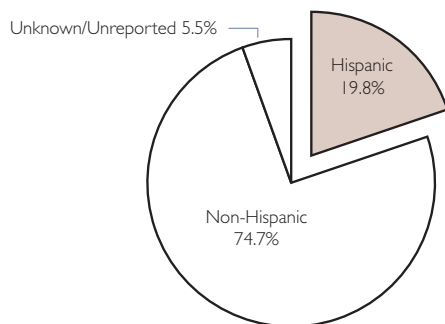
GENDER OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)



The proportion of female HIV-positive clients served by CARE Act-funded providers reached 31.3 percent in 2002. That year, women accounted for an estimated 21.5 percent of all people living with AIDS in the United States, 26 percent of new AIDS cases, and 28.4 percent of new HIV infections reported in the 30 areas with confidential name-based HIV infection reporting.³

*Duplicated client counts. See note, page 16.

ETHNICITY OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)

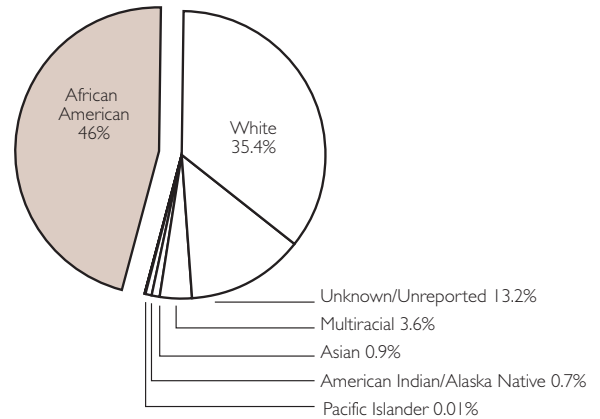


Hispanics account for roughly 1 in 5 CARE Act clients. At the end of 2002, 19.8 percent of the people living with AIDS in the United States were Hispanic.⁴

*Duplicated client counts. See note, page 16.

RACE OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)

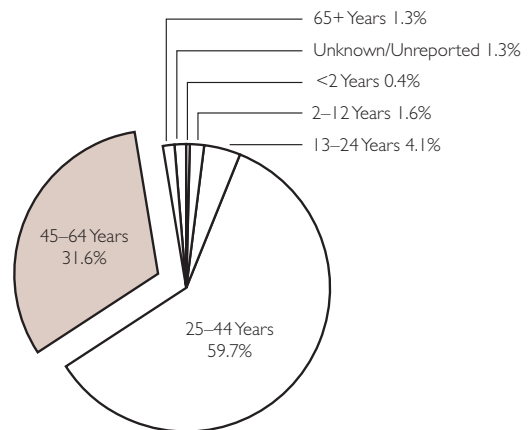
In FY 2002, approximately 65 percent of CARE Act clients were racial minorities. At the end of 2002, they were served in roughly equal proportion to their representation among people living with AIDS.⁴



*Duplicated client counts. See note, page 16.

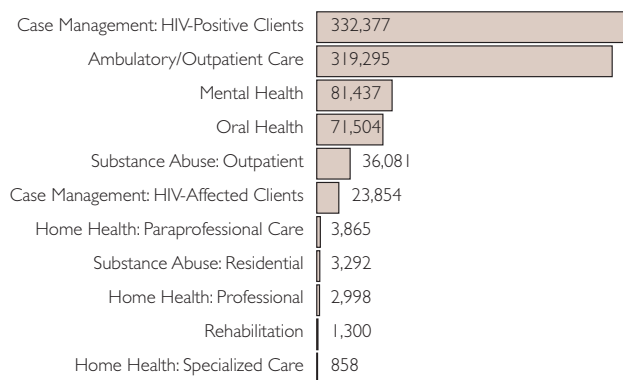
AGE OF HIV-POSITIVE CLIENTS* SERVED BY CARE ACT-FUNDED PROVIDERS, 2002 (N = 844,687)

Antiretroviral therapy has led to longer, healthier lives, and now almost one-third of CARE Act clients are age 45 or older. These data echo trends in surveillance, which show that 41.3 percent of people living with AIDS in 2002 were age 45 or older.⁴ Just two percent of CARE Act clients are children age 12 or younger, in large part because of advances in the prevention of perinatal transmission of HIV.



*Duplicated client counts. See note, page 16.

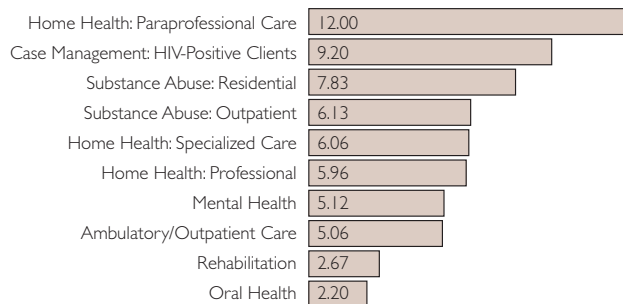
TYPE OF SERVICE USED BY CARE ACT-FUNDED PROVIDER CLIENTS,* 2002



In 2002, 319,295 clients received outpatient medical care through CARE Act-funded providers, almost four times the number receiving any other service except case management. The number of clients relying on those providers for outpatient medical care illustrates the inability of other public programs to meet demand.

*Duplicated client counts. See note, page 16.

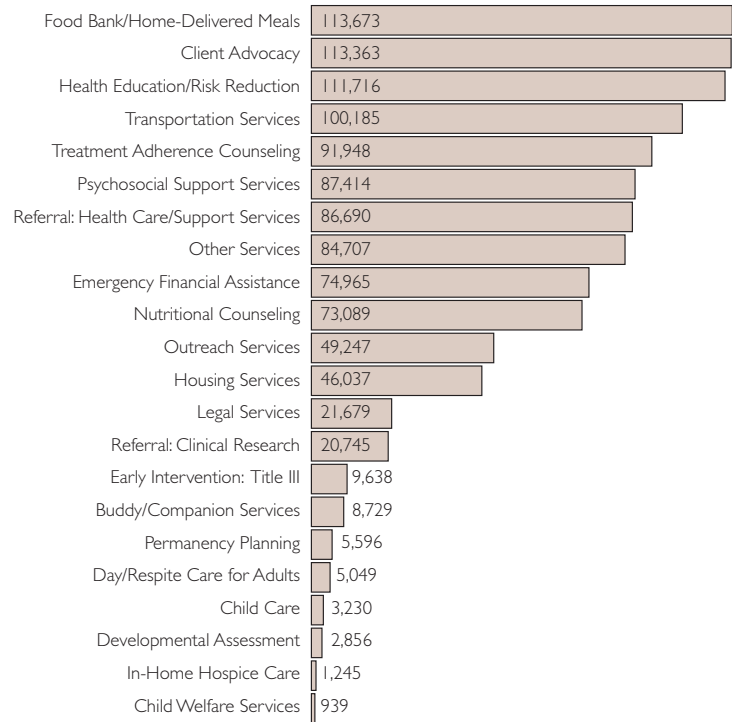
HEALTH CARE SERVICES USED BY CARE ACT-FUNDED PROVIDER CLIENTS,* BY MEDIAN NUMBER OF VISITS PER YEAR, 2002



*Duplicated client counts. See note, page 16.

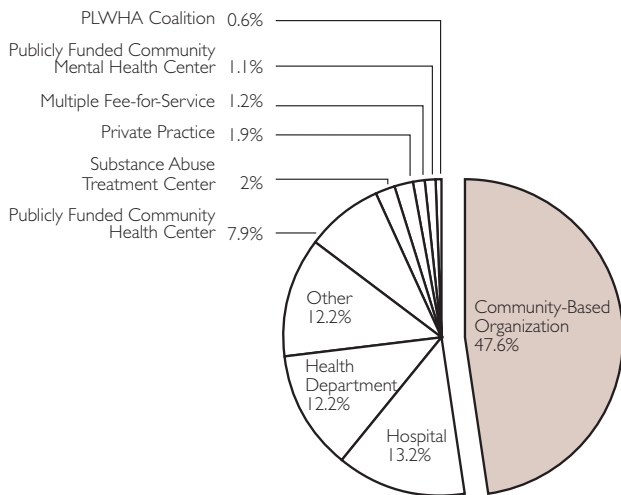
SUPPORT SERVICES USED BY NUMBER OF CARE ACT-FUNDED PROVIDER CLIENTS,* 2002

Many essential support services funded through the CARE Act are directly related to primary health care. For example, services such as treatment adherence counseling, health education risk reduction, nutritional counseling, and food bank/home-delivered meals are inextricably linked to the health status of people living with HIV and AIDS because such supports help keep people in care.



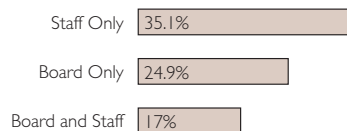
*Duplicated client counts. See note, page 16.

ORGANIZATION TYPE OF CARE ACT-FUNDED PROVIDERS, 2002 (N = 2696)



Community-based organizations constitute the largest segment (47.6 percent) of the CARE Act provider community, accounting for more than three times the number of providers in the next largest category, hospitals.

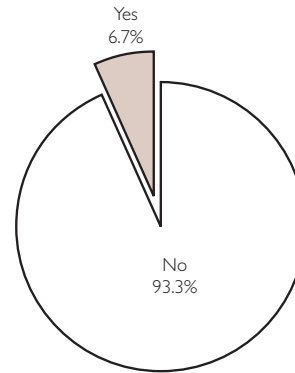
MINORITY PROVIDERS: CARE ACT-FUNDED PROVIDERS WITH >50 PERCENT MINORITY REPRESENTATION ON THE BOARD OF DIRECTORS AND PROFESSIONAL STAFF, 2002, BY PERCENTAGE OF PROVIDERS (N = 2,696)



Minorities are playing a vital role in reaching individuals living with HIV/AIDS in their communities. Approximately one-fourth of all CARE Act providers in FY 2002 had boards of directors in which more than 50 percent of board members consisting of more than 50 percent racial and ethnic minorities. For about 35 percent of providers, more than half of all professional staff members were minorities.

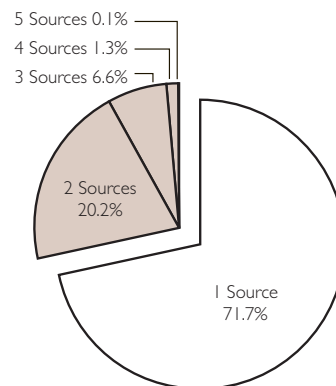
PUBLIC HEALTH SERVICE SECTION 330 FUNDING AMONG CARE ACT-FUNDED PROVIDERS, FY 2002 (N = 2,696)

Less than 7 percent of CARE Act providers also receive Public Health Service Section 330 funds, which support the Nation's federally funded community and migrant health centers.

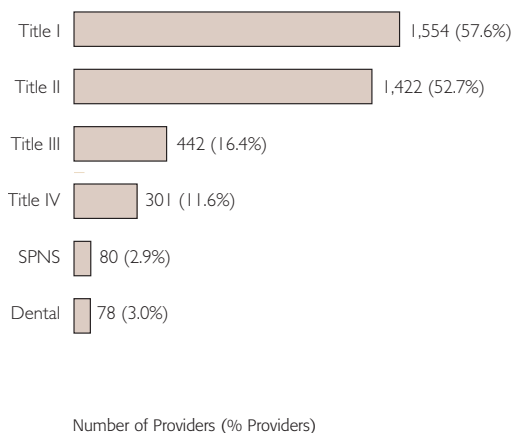


NUMBER OF CARE ACT FUNDING SOURCES FOR CARE ACT-FUNDED PROVIDERS, FY 2002 (N = 2,696)

In 2002, 28.2 percent (763) CARE Act providers received funding through more than one CARE Act source. More than half of those funded by multiple programs were funded through Titles I and II.



CARE ACT FUNDING SOURCES BY NUMBER OF PROVIDERS, 2002 (N = 2,696)



The Title I program, which funds 51 Eligible Metropolitan Areas across the United States, provides support to more organizations than does any other CARE Act program.

The Title II program, which includes the AIDS Drug Assistance Program (ADAP), supports grants to States and Territories.

The Title III program funded 273 Early Intervention Services grants, 60 planning grants, and 59 capacity-building grants in 2002.

The Title IV program funds services for women, infants, children, youth, and families. Of the 301 Title IV grants in 2002, 36 were funded through the Title IV Youth Initiative.

The Special Projects of National Significance (SPNS) program funded 80 agencies in 2002 through a variety of initiatives, which included adherence and outreach to HIV-positive individuals who were not in care.

The reauthorization in 2002 provided for two CARE Act dental programs. In 2002, 66 organizations received funding through the Dental Reimbursement Program, and 12 received Community-Based Dental Partnership grants.

PART III. THE CHANGING EPIDEMIC



INCREASING
DRUG COSTS



INCREASING
DEMAND



PRESSURE ON
ADAPS

RAYMOND RODRIGUEZ, CHICAGO, IL

THE EPIDEMIC CONTINUES TO GROW

Today, the Ryan White CARE Act is being implemented in the context of a growing epidemic. The number of people living with HIV/AIDS in the United States has likely surpassed 900,000 and is perhaps more than 1,000,000.⁵

In 2000, an estimated 400,000 to 500,000 people were not receiving care that was in keeping with treatment guidelines: Between 180,000 and 280,000 did not know that they were HIV positive, and an additional 220,000 knew their serostatus but for a host

of reasons, including treatment side effects, poverty, mental illness, and the effects of HIV/AIDS stigma, were not receiving care regularly if at all.⁵ Four years have passed since those estimates were made, and during that time CARE Act providers—and those supported by other funding streams—have intensified outreach initiatives to reach those individuals. Many have been reached, but hundreds of thousands still remain out of care. The result is that, as CARE Act providers strive to respond to health care inflation and cost constraints so that they

can serve their current clients, they also must position themselves to serve individuals not yet in care.

ESTIMATED INCREASE IN HIV/AIDS PREVALENCE, 2002

New HIV Infections	40,000 ⁶
Deaths From AIDS	16,371 ⁷
Net Increase in Prevalence	23,629

STIGMA

THE EFFECTS OF HIV/AIDS STIGMA EXCEED WHAT MOST OF US HAVE THE CAPACITY TO UNDERSTAND. STIGMA IS ASSOCIATED WITH DELAYS IN HIV TESTING, DELAYS IN ACCESSING HIV CARE, AND DELAYS IN DISCLOSING SEROSTATUS TO FRIENDS AND LOVED ONES. IN 1999—20 YEARS AFTER THE ONSET OF AIDS IN THE UNITED STATES—ONE-FOURTH OF PEOPLE INCLUDED IN A TELEPHONE SURVEY SAID THEY FELT UNCOMFORTABLE HAVING CONTACT WITH PEOPLE WITH AIDS. NEARLY ONE-THIRD SAID THEY WOULD AVOID SHOPPING AT A NEIGHBORHOOD GROCERY KNOWN TO BE OWNED BY A PERSON WITH AIDS—A FACT THAT RAISES A SERIOUS QUESTION: HOW MANY EMPLOYERS FEEL COMFORTABLE OFFERING A JOB TO SOMEONE LIVING WITH HIV DISEASE?⁸

HIV IS NOT THE ONLY CHALLENGE FACED BY MANY PEOPLE LIVING WITH HIV DISEASE

A large number of HIV-infected people are dealing with much more than HIV disease. As CARE Act data reveal (see charts, page 17) approximately one-half of current clients live at or below the Federal Poverty Level and fewer than 1 in 10 have any private health insurance. CARE Act clients commonly live in more dire circumstances than do other people living with HIV disease, and HIV-infected people in general are more likely than the noninfected population to be economically disadvantaged.⁹ It is clear that a significant portion of individuals who do not know their sero-status and are not in care will have to rely on public resources—including those of CARE Act-funded providers—for services once they are enrolled in care.

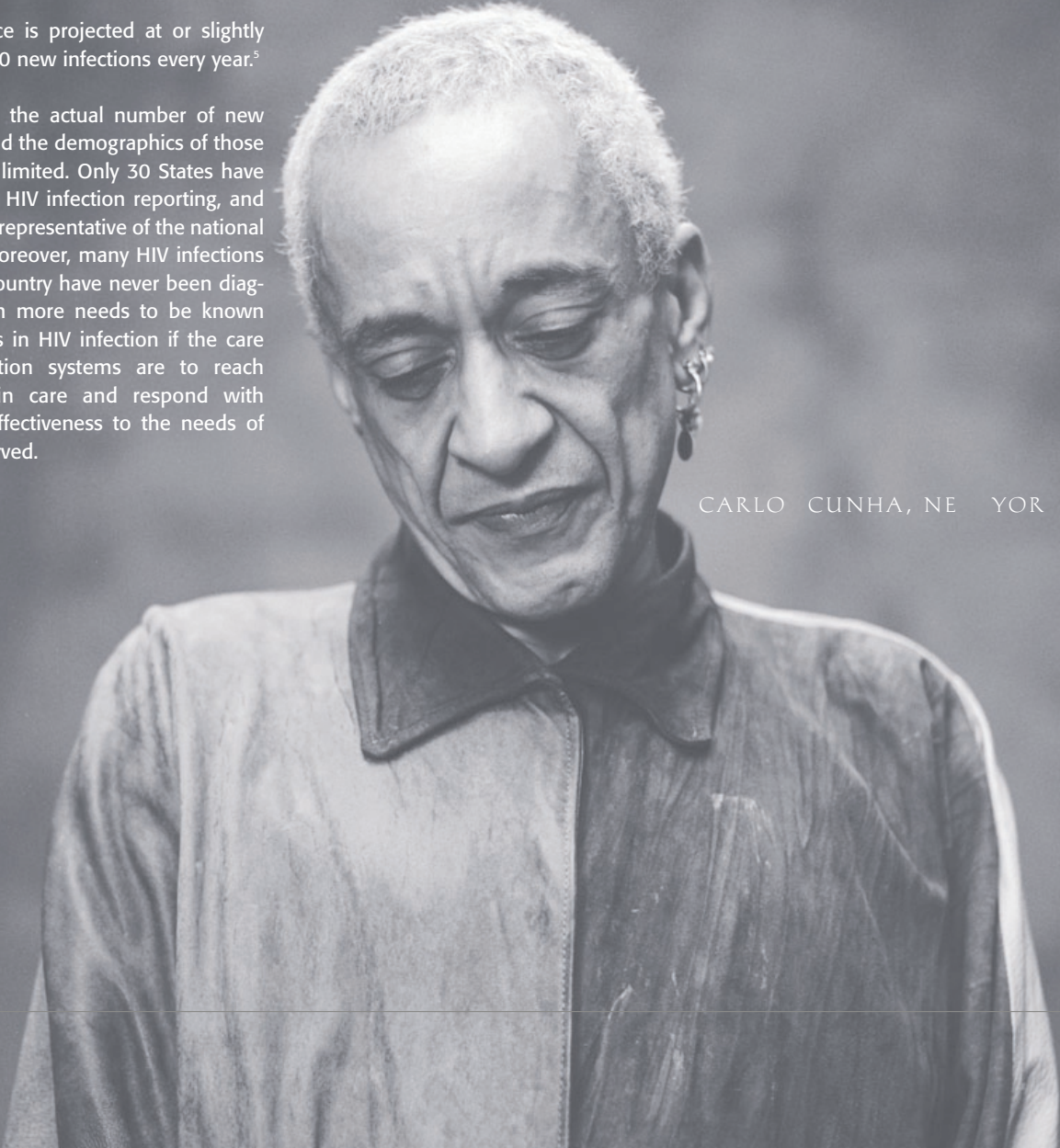
In addition to challenges related to poverty and lack of adequate health insurance, people living with HIV disease commonly face other problems. Many are related to health.

- Drug use is directly related to the AIDS epidemic. Injection drug use accounted for about 24 percent of new AIDS cases and 25.7 percent of people living with AIDS in 2002.^{4,10} Use of injected and noninjected substances, such as alcohol; heroin; and “club” drugs like cocaine, MDMA (“ecstasy”), ketamine (“special K”), and crystal methamphetamine (“tina,” “crystal,” “krank,” “tweak,” “ice”), are related to HIV transmission, primary and secondary HIV prevention, adherence to treatment, and disease progression. Data on usage rates are scarce, but the rates are believed to be high among some subpopulations.
- AIDS-related dementia develops in as many as one-quarter of people living with AIDS.¹¹ In addition, in the United States and Europe, severe mental illness occurs in 20 to 50 percent of people living with HIV disease.¹² Illnesses include major depression; anxiety, panic disorder, or posttraumatic stress disorder; impulsivity or personality disorder; and drug-related disorders and psychoses. The overlap between substance abuse and mental illness is significant.
- Homelessness, poor housing conditions, and risk for homelessness occur at extraordinary rates among some HIV-positive populations. The U.S. Department of Housing and Urban Development cites estimates that one-third to one-half of all people living with AIDS “are either homeless or in imminent danger of losing their homes.”¹³ Rapidly rising housing costs in many major cities are increasing the housing crisis among some HIV-positive subpopulations.
- Many other problems, such as tuberculosis, hepatitis C, oral health problems, and poor nutrition threaten people living with HIV disease.^{14,15,16,17,18} Wherever they occur, they pose serious challenges for patients and for providers with inadequate resources. Because of comorbidities, HIV infection cannot be treated in isolation. Instead, a comprehensive approach is required.

NEW HIV INFECTIONS: WHAT WE KNOW

HIV incidence is projected at or slightly above 40,000 new infections every year.⁵

But data on the actual number of new infections and the demographics of those infected are limited. Only 30 States have name-based HIV infection reporting, and they are not representative of the national epidemic. Moreover, many HIV infections across the country have never been diagnosed. Much more needs to be known about trends in HIV infection if the care and prevention systems are to reach those not in care and respond with increasing effectiveness to the needs of the underserved.



CARLO CUNHA, NEW YORK, NY

IS AIDS INCIDENCE RISING?

For the first time in more than a decade, the number of new reported AIDS cases increased in 2002. The total increase was small—just 2.2 percent—and in real terms, the number of cases reported in 2002 was less than half that reported in 1993.¹⁰

But the increase raises many questions: Does it reflect a new trend? Did it occur at least in part because of anomalies in reporting? Do the data reflect diminishing benefit from antiretroviral therapy? It is far too early to answer those questions, but we know that the increase occurred across multiple demographic markers—among men and women, among all races and ethnicities except

Hispanics, and among all age groups except children under 13 years of age and adults 25 to 34. The rise was also geographically widespread, affecting every area of the country except the Northeast. The South is bearing a disproportionate burden, accounting for 44 percent of all reported cases in 2002.¹⁰

Particularly disturbing in 2002 was the continued increase in cases related to heterosexual contact. Since 1999, the proportion of reported AIDS cases attributable to heterosexual contact has risen 19.4 percent—faster than any other category.¹⁰

Also alarming is the number of AIDS cases related to the men who have sex with men (MSM) exposure category, which rose 4.0 percent in 2002 over 2001.¹⁰ MSM accounted for 40.2 percent of all reported cases in 2002, a proportion roughly equal to that in 1998. This rise in AIDS incidence among MSM combines with reports of high HIV prevalence among subpopulations of MSM to raise concerns of resurgence among the population hardest hit by the epidemic in America.

The growing burden of AIDS among women was readily apparent in AIDS surveillance

data from more than a decade ago, and that burden continues to increase today. AIDS incidence among females has increased in 3 of the past 5 years, rising 6.5 percent since 1998.¹⁰ Something that has not changed is the extraordinary proportion of female cases among racial and ethnic minority women—65.2 percent among African Americans and 16.6 percent among Hispanics in 2002.¹⁹

There was some good news in 2002, in that injection drug use (IDU) continued to play a diminishing role in AIDS incidence. Accounting for 24 percent of new cases in 2002, reported AIDS cases for which HIV exposure was IDU declined 17 percent from 1998 to 2002.¹⁰

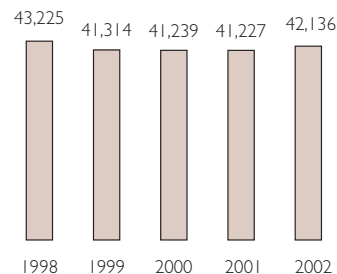
TRENDS IN AIDS¹⁰

The South accounted for 44 percent of new cases in 2002.

The heterosexual transmission rate increased by 19 percent from 1999 to 2002.

New cases related to the MSM exposure category rose in 2001 and 2002.

Estimated AIDS Incidence
United States, 1998–2002¹⁰



AIDS MORTALITY CONTINUES TO FALL

In 2002, 16,371 people died from AIDS in the United States, the lowest number since 1993.⁷

Between 1998 and 2002, the decline in AIDS mortality was 13.9 percent.⁷ Deaths decreased much more among some subpopulations.

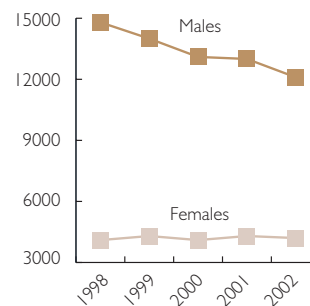
Reflecting pronounced reductions in perinatal transmission over the past decade, the most significant decline in AIDS mortality during this period was among children under age 13 (68.3 percent). People ages 25 to 34 also experienced a substantial decrease (47.9 percent), largely as a result of antiretroviral therapy.⁷

There was a decidedly downward trend in AIDS mortality among men, which decreased by approximately 17.9 percent from 1998 to

2002—most significantly in cases associated with MSM (23.9 percent). Trends among women are much less discernable: Increasing in 1999, falling in 2000, and then rising in 2001, AIDS mortality in women fell in 2002, but by only 2.4 percent—less than one-third the rate of decline among men (7.1 percent). About 1 in 4 (25.8 percent) of all deaths from AIDS in 2002 were among women.⁷

AIDS mortality continues to rise among some subpopulations. From 1998 to 2002, increases were experienced among people over age 45 (13.2 percent) and among people for whom the HIV exposure category was heterosexual contact (5.3 percent).⁷ Those changes reflect the aging of the HIV-positive population in America since the introduction of antiretroviral therapy and the steady increase in AIDS incidence related to heterosexual contact.

AIDS Deaths Among
U.S. Adults and Adolescents,
1998–2002⁷



PEOPLE LIVING WITH AIDS TODAY

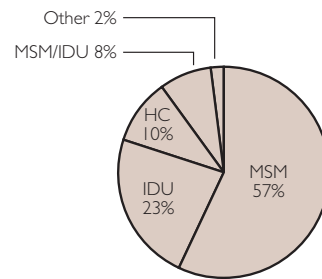
By the end of 2002, estimates of the number of people living with AIDS in the United States had risen to 384,906. This number represents more than one-third of all those estimated to be living with HIV disease in the United States, and it exhibits a 33-percent increase in AIDS prevalence since 1998.⁴

A comparison of data from 1998 to 2002 reveals that AIDS demographics continue to change. In 2002, people living with AIDS were

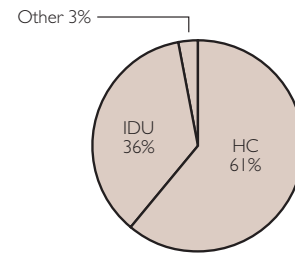
- more likely to be female (19.9 percent of all cases in 1998 versus 21.5 percent in 2002);
- less likely to be children under age 13 (1.1 percent in 1998 compared with 0.6 percent in 2002); and
- much more likely to be age 45 or older (29.9 percent in 1998 compared with 41.3 percent in 2002).⁴

But the most dramatic statistic is not about age or gender or even change. It is the one about the continuing toll of HIV disease in the United States among racial and ethnic minorities.

Estimated U.S. Males Living With AIDS⁴
2002, by HIV Exposure Category
(N = 298,248)



Estimated U.S. Females Living With AIDS⁴
2002, by HIV Exposure Category
(N = 82,764)



HC - Heterosexual contact
IDU - Intravenous drug use
MSM - Men who have sex with men

AIDS AMONG RACIAL AND ETHNIC MINORITIES

At the end of 2002, more than 4 in 10 people living with AIDS in the United States were African American and approximately 2 in 10 were Hispanic. Almost two-thirds (63.4 percent) were racial or ethnic minorities, up from 60.8 percent in 1998.⁴

Not only do minorities account for an increasing proportion of people living with AIDS, they represent an ever-growing number of people dying from it. More than 7 in 10 deaths from AIDS in the United States (72.2 percent) during 2002 occurred in racial or ethnic minorities—52.3 percent of deaths were among African Americans and 18.7 percent were among Hispanics.⁷

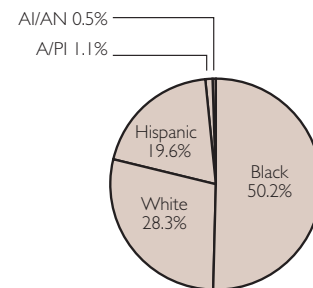
Minorities account for a growing number of reported AIDS cases, with increases occurring in African Americans, Asian/Pacific

Islanders (A/PI), and American Indian/Alaska Natives (AI/AN) from 1998 to 2002.¹⁰ In 2002, the number of cases per 100,000 adult and adolescent African Americans (AIDS rate) was 76.4—approximately 10 times that for whites and three times that for Hispanics.

There is no good news to report about the disproportionate burden of AIDS suffered by racial and ethnic minority women. African Americans accounted for 65.2 percent of female cases reported in 2002; Hispanics accounted for another 16.6 percent.¹⁹

Among males, in 2002, 65.4 percent of reported AIDS cases were among racial and ethnic minorities, 44.1 percent among African Americans and 19.6 percent among Hispanics.²⁰

AIDS Incidence Among Adolescents and Adults, 2002, by Race/Ethnicity¹⁰



AI/AN - American Indian/Alaska Native
A/PI - Asian/Pacific Islander

PART IV. ADMINISTRATION AND PROGRAMS



OUTCOME
MEASURES

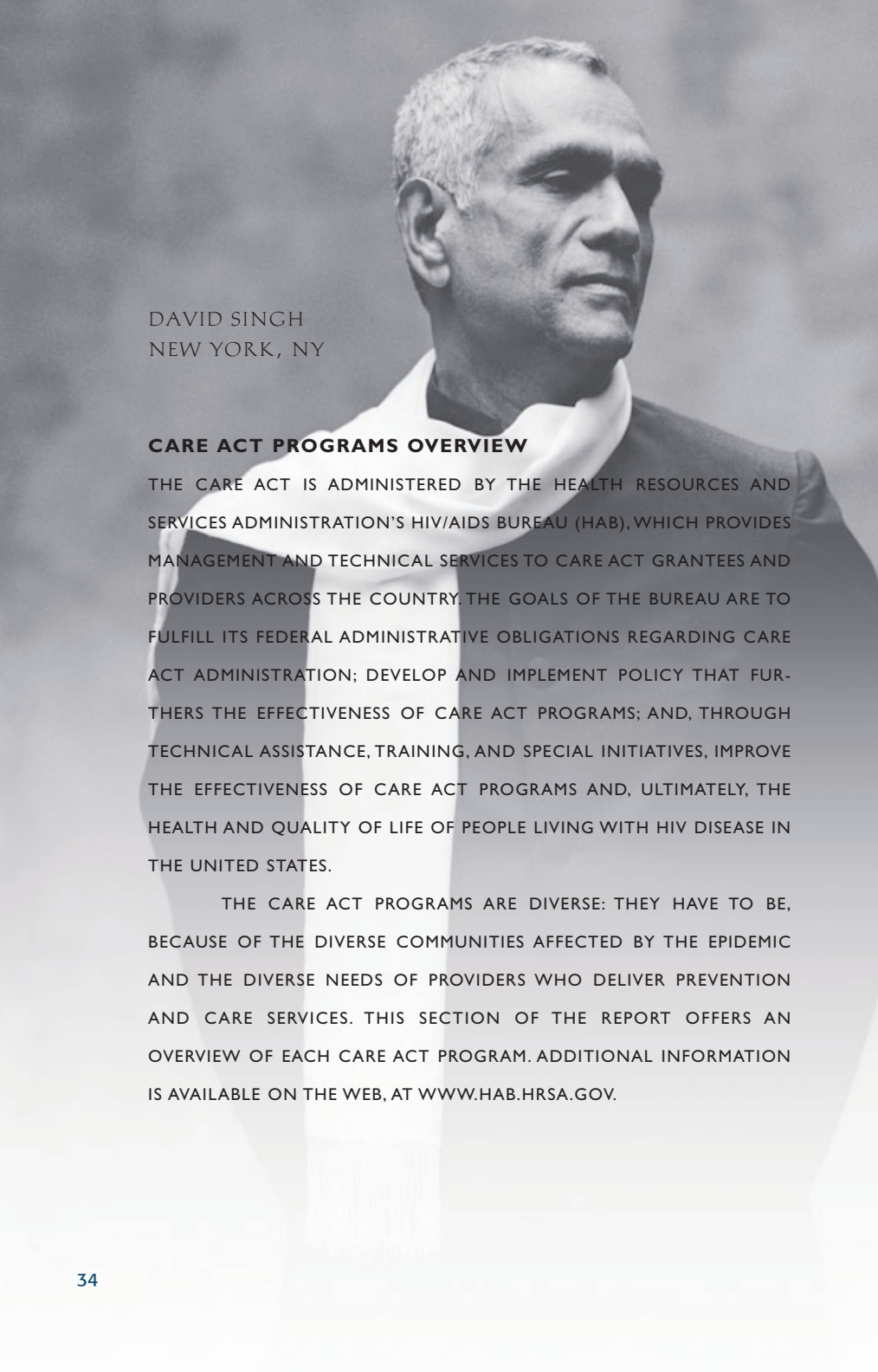


PROGRAM
EVALUATION



INCREASINGLY
PRODUCTIVE
CARE ACT
PROGRAMS

ILLINE CHUNG-EDDIE, NEW YORK, NY

A black and white portrait of David Singh, a middle-aged man with short, graying hair, wearing a dark suit jacket over a white shirt. He is looking slightly to the right of the frame with a neutral expression. The background is a soft, out-of-focus light gray.

DAVID SINGH
NEW YORK, NY

CARE ACT PROGRAMS OVERVIEW

THE CARE ACT IS ADMINISTERED BY THE HEALTH RESOURCES AND SERVICES ADMINISTRATION'S HIV/AIDS BUREAU (HAB), WHICH PROVIDES MANAGEMENT AND TECHNICAL SERVICES TO CARE ACT GRANTEEES AND PROVIDERS ACROSS THE COUNTRY. THE GOALS OF THE BUREAU ARE TO FULFILL ITS FEDERAL ADMINISTRATIVE OBLIGATIONS REGARDING CARE ACT ADMINISTRATION; DEVELOP AND IMPLEMENT POLICY THAT FURTHERS THE EFFECTIVENESS OF CARE ACT PROGRAMS; AND, THROUGH TECHNICAL ASSISTANCE, TRAINING, AND SPECIAL INITIATIVES, IMPROVE THE EFFECTIVENESS OF CARE ACT PROGRAMS AND, ULTIMATELY, THE HEALTH AND QUALITY OF LIFE OF PEOPLE LIVING WITH HIV DISEASE IN THE UNITED STATES.

THE CARE ACT PROGRAMS ARE DIVERSE: THEY HAVE TO BE, BECAUSE OF THE DIVERSE COMMUNITIES AFFECTED BY THE EPIDEMIC AND THE DIVERSE NEEDS OF PROVIDERS WHO DELIVER PREVENTION AND CARE SERVICES. THIS SECTION OF THE REPORT OFFERS AN OVERVIEW OF EACH CARE ACT PROGRAM. ADDITIONAL INFORMATION IS AVAILABLE ON THE WEB, AT WWW.HAB.HRSA.GOV.

TITLE I: GRANTS TO ELIGIBLE

THE BASICS

- ELIGIBLE METROPOLITAN AREAS (EMAs) ARE DEFINED AS THOSE WITH MORE THAN 2,000 REPORTED AIDS CASES IN THE PAST 5 YEARS AND A POPULATION OF AT LEAST 500,000.
- THE NUMBER OF EMAs TRIPLED FROM 16 IN 1991 TO 51 IN 2004.
- THERE ARE EMAs IN 22 STATES, PUERTO RICO, AND THE DISTRICT OF COLUMBIA.
- EACH EMA ESTABLISHES A PLANNING COUNCIL TO ASSESS LOCAL NEEDS, SET PRIORITIES, AND DEVELOP A COMPREHENSIVE PLAN FOR PROVIDING SERVICES.

METROPOLITAN AREAS

Most AIDS cases continue to be reported in large metropolitan regions, which must build comprehensive systems of HIV/AIDS care and services to reach the scores of underserved individuals in their jurisdictions.

Title I of the CARE Act provides resources to metropolitan areas most severely affected by HIV/AIDS. Regions eligible for assistance under Title I are called Eligible Metropolitan Areas, or EMAs, defined as those with

- a population of at least 500,000 and
- at least 2,000 reported AIDS cases in the previous 5 years.

The number of EMAs has grown from 16 in 1991 to 51 in 2004. EMAs are found in 22 States, Puerto Rico, and the District of Columbia.

FUNDING

Title I grants are awarded in two parts. The “formula” portion is based on the estimated number of living AIDS cases in the EMA over the most recent 10-year period. The second, or “supplemental,” portion is based on a variety of factors, including the severity of need in the EMA.

SERVICES

Title I funds are used to fill gaps in the continuum of medical and essential social services

for underserved people living with HIV disease in EMAs. The range of services includes

- primary care services, including disease prevention and referrals to specialty care;
- medications;
- substance abuse and mental health treatment;
- case management; and
- support services—from nutritional counseling to emergency housing assistance—that enhance the benefit of health services and help people stay in care over time.

Local service providers receive CARE Act Title I funding following a rigorous application process. Funded local providers typically include health clinics, community-based organizations, and social services agencies.

USING TITLE I RESOURCES: HIV SERVICES PLANNING COUNCILS

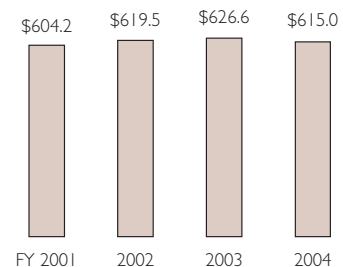
The Title I program is, at its heart, a local endeavor. Within broad Federal guidelines, communities are empowered to address shortages in services for the underserved in their areas. Each EMA is charged with establishing a Planning Council, which is responsible for setting spending priorities according to local unmet needs.

Planning Council members are experts from a variety of fields, such as mental health, public health, and HIV specialty care, and at least 33 percent of the members must be people living with HIV disease who receive CARE Act services. Each council is required to develop a comprehensive plan for providing services, including ways to identify HIV-positive persons not in care.

ADMINISTRATION

Title I funds are awarded to large metropolitan regions consisting of multiple counties and, in some cases, several States. Funds are awarded to the local government serving the greatest number of people living with AIDS in the EMA. For example, in the Philadelphia EMA, which covers nine counties and parts of two States, funds are administered by the City of Philadelphia Department of Health.

CARE Act Title I Appropriations
(in millions)



TITLE II: GRANTS TO STATES AND U.S. TERRITORIES

THE BASICS

ADAP

- GRANTS ARE MADE TO STATES AND TERRITORIES FOR PURCHASING MEDICATIONS, ADHERENCE SUPPORT SERVICES, AND HEALTH INSURANCE WITH A PRESCRIPTION DRUG BENEFIT.
- ADAP IS THE LARGEST CARE ACT PROGRAM.
- EACH STATE OR TERRITORY ESTABLISHES ITS OWN ENROLLMENT CRITERIA AND DRUG FORMULARIES.

CARE GRANTS TO STATES AND TERRITORIES

- GRANTS SUPPORT A RANGE OF CARE AND ESSENTIAL SUPPORT SERVICES.
- GRANTS ARE AWARDED USING A FORMULA BASED ON REPORTED AIDS CASES.

CARE GRANTS TO EMERGING COMMUNITIES

- COMMUNITIES WITH 500 TO 1,999 REPORTED AIDS CASES IN THE PREVIOUS 5 YEARS ARE ELIGIBLE.
- ELIGIBLE COMMUNITIES ARE SEGMENTED INTO TWO TIERS:
 - TIER 1: CITIES WITH 1,000–1,999 REPORTED AIDS CASES (4 CITIES IN FY 2004)
 - TIER 2: CITIES WITH 500–999 REPORTED AIDS CASES (25 CITIES IN FY 2004).

Title II of the CARE Act authorizes emergency resources for States, Territories, and emerging communities (those reporting between 500 and 1,999 AIDS cases over the most recent 5-year period). Title II includes three primary initiatives:

- AIDS Drug Assistance Program (ADAP)
- Care grants for States and Territories
- Care grants for Emerging Communities

AIDS DRUG ASSISTANCE PROGRAM

Given the high cost of medications for treating HIV/AIDS and the growing number of underinsured people living with the disease, it is no surprise that ADAP is the single largest CARE Act activity. ADAP funds may be used to purchase medications, subsidize health insurance coverage with a prescription drug benefit, or provide treatment adherence support services. Nationally, more than 80 percent of ADAP clients have incomes at 200 percent or less of the Federal Poverty Level.

Every State and Territory is charged with establishing its own ADAP, each with its own eligibility criteria and drug formulary. Some ADAP formularies have more than 200 medications, and some provide only a

few. ADAP reaches approximately 90,000 people in any given month and 136,000 in any given year, but the need for ADAP services has outstripped available resources—and demand continues to grow. As a result, some ADAPs must make enrollment criteria more stringent and drug formularies more restrictive. Some have established waiting lists for new enrollees.

In FY 2004, \$748.9 million was designated for ADAP in the Federal budget. Total ADAP funds typically exceed Federal budget allocations, however, because Title I EMAs as well as States and Territories receiving care grants under Title II (see below), may contribute a portion of their awards to ADAP.

ADAP awards to States and Territories are calculated using a formula based on AIDS prevalence. Three percent of the ADAP appropriation is reserved for supplemental grants to States and Territories with a severe need for drug assistance.

CARE GRANTS TO STATES AND TERRITORIES

Care grants provide resources to fund a range of primary care and support services. Grants are awarded to the 50 States, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands. In addition, grants of

\$50,000 are awarded to American Samoa, the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, and the Republic of Palau.

Grantees have considerable latitude in deciding which services to fund. Services eligible for funding under Title II include

- primary health care and home-based health care;
- insurance coverage;
- medications;
- support services, such as nutritional counseling and emergency transportation assistance;
- outreach to people with HIV who know their HIV status; and
- early intervention services, such as HIV counseling, testing, and referral.

Grants are awarded using a formula based on reported AIDS cases. Most States provide some services directly through AIDS service organizations and HIV consortia, which are associations of providers that plan, develop, and deliver services.

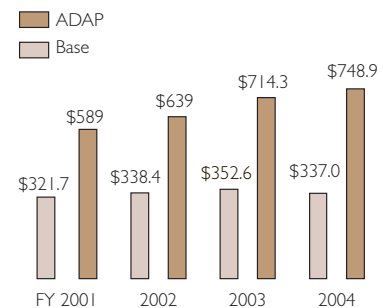
EMERGING COMMUNITIES

The CARE Act amendments of 2000 established a program for providing supplemental grants to States with Emerging Communities,

that is, cities with between 500 and 1,999 reported AIDS cases in the most recent 5-year period. The legislation segments these communities into two tiers. Tier 1 consists of cities with 1,000 to 1,999 reported AIDS cases (4 cities in FY 2004); Tier 2 consists of cities with 500 to 999 cases (25 cities in FY 2004).

Funding for the Emerging Communities program is \$10 million for FY 2004, which, as required in the legislation, is divided equally between the two tiers.

CARE Act Title II Appropriations
(in millions)





TITLE III: EARLY INTERVENTION SERVICES, CAPACITY DEVELOPMENT, AND PLANNING GRANTS

THE BASICS

- 98 PERCENT OF FUNDS ARE FOR EARLY INTERVENTION SERVICES (EIS) GRANTS, AWARDED DIRECTLY TO PROVIDERS.
- OTHER GRANTS ARE FOR PLANNING AND CAPACITY BUILDING.
- IN FY 2003, 363 ORGANIZATIONS RECEIVED EIS GRANTS, 39 RECEIVED CAPACITY-BUILDING GRANTS, AND 6 RECEIVED PLANNING GRANTS.

EARLY INTERVENTION SERVICES

Title III early intervention services (EIS) grants fund outpatient medical services for HIV-positive individuals in underserved communities. EIS grants totaled \$183 million in FY 2003 and accounted for 98 percent of all Title III grant funds; 363 organizations received awards.

Almost all Title III EIS grantees are in communities where they are the only EIS provider accessible to uninsured and underinsured individuals. The typical Title III EIS provider uses approximately 75 percent of its award for comprehensive primary care services, which include HIV counseling and testing, onsite primary care, specialty care (both onsite and by referral), and adherence support. Providers also fund case management and other essential services.

Title III grants are awarded directly to primary care providers, rather than to cities (as in Title I) or to States and Territories (as in Title II). Grantees include, among others,

- federally funded community and migrant health centers,
- other health centers,
- city and county health departments, and
- outpatient university and hospital medical centers.

Many Title III providers are in communities of color and in rural areas, where HIV medical resources typically are scarce.

CAPACITY DEVELOPMENT

Title III also funds grants for strengthening organizational infrastructure and bolstering the capacity to develop, manage, and evaluate HIV service delivery systems. Capacity development grants are used for

- identifying, establishing, and improving clinical, administrative, managerial, and management information systems;
- developing financial management units;
- purchasing clinical supplies and equipment;
- developing organizational strategic plans for HIV care; and
- educating board members and staff.

Capacity-building grants can cover up to a 3-year period and total \$150,000. For FY 2003, 39 capacity-building grants were awarded, totaling \$2.3 million.

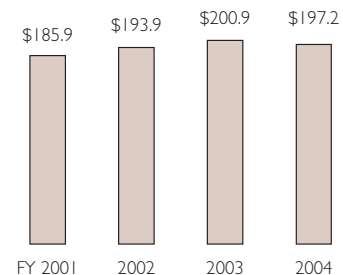
PLANNING

Title III planning grants are 1-year awards to help organizations plan for providing EIS in the future. Activities include building relationships with key stakeholders and potential

collaborators and forming programmatic linkages and referral networks within the community—especially with medical specialists and providers of social services. Planning grants also can be used to help organizations conduct comprehensive needs assessments and apply for operational grants.

Six \$50,000 awards were made in FY 2003, for a total of \$300,000.

CARE Act Title III Appropriations
(in millions)



THE BASICS

- FUNDING TARGETS WOMEN, INFANTS, CHILDREN, YOUTH, AND THEIR FAMILIES.
- IN FY 2003, 89 GRANTS WERE AWARDED: 73 TO ORGANIZATIONS SERVING ALL TITLE IV TARGET POPULATIONS; AND 16 TO THOSE SPECIFICALLY SERVING YOUNG PEOPLE.
- GRANTEES PROVIDE FAMILY-CENTERED CARE, STRESSING THE IMPORTANCE OF CO-LOCATED, COORDINATED SERVICES FOR THE ENTIRE FAMILY.



HIV strikes disproportionately among people who live in poverty and lack access to health and social services. This is especially true for the populations targeted by the CARE Act's Title IV program: HIV-positive women, infants, children, youth, and their affected family members.

For FY 2003, 89 grants were awarded through the Title IV program. (FY 2004 awards will be made in August 2004.) Of these awards

- 73 grants totaling \$58.5 million were awarded to organizations serving all Title IV target populations and
- 16 grants totaling \$5.9 million were part of the Title IV Youth Initiative and were awarded to organizations addressing the unique barriers to care faced by HIV-positive youth.

The target populations served by the CARE Act Title IV program must overcome many interrelated challenges in addition to HIV/AIDS. Most common are poverty and the issues that go with it, such as poor housing, lack of transportation and child care; non-HIV-related illnesses; and the absence of a social support system. Those challenges can be intensified by any one of several circumstances—for example, when there is

more than one HIV-positive person in a single family or when, as is often the case, an HIV-positive person is the primary caregiver for a child or relative.

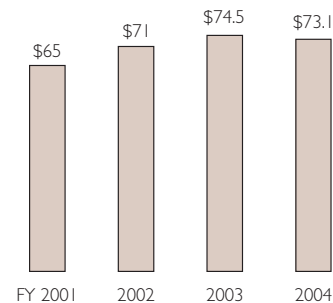
Experience shows that a comprehensive and coordinated service approach is essential for delivering HIV treatment to women, infants, children, youth, and their affected family members. Title IV grantees build a comprehensive care system for their clients, coordinating what would otherwise be a disjointed array of providers and services. In doing so, Title IV clients are given access to

- primary care and HIV specialty care for HIV-positive clients;
- supportive care for caregivers of HIV-positive women, infants, children, and youth;
- neonatal and pediatric specialty care;
- substance abuse and mental health services;
- case management;
- essential support services, such as transportation, child care, and housing assistance;
- coordination of all services for the entire family; and
- education and access to clinical trials and clinical research.

PREVENTING MOTHER-TO-CHILD TRANSMISSION OF HIV

Although new HIV infections among newborns have dropped significantly since the introduction of AZT-based regimens, mother-to-child transmission of HIV continues to occur—most often in poor, medically underserved families. The Title IV program has supported special initiatives to help identify HIV-positive pregnant women and ensure that they have access to care that can improve their health and prevent perinatal transmission.

CARE Act Title IV Appropriations (in millions)

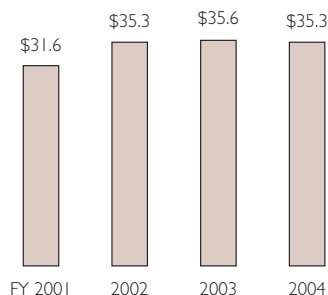


AIDS EDUCATION AND TRAINING CENTERS

THE BASICS

- 11 REGIONAL CENTERS AND 130 ASSOCIATED SITES PROVIDE CLINICAL TRAINING IN CITIES AND TOWNS ACROSS THE NATION.
- FOUR NATIONAL CENTERS SERVE PROVIDERS NATIONWIDE.
- AETCS ARE INSTRUMENTAL IN CONTINUING THE EDUCATION OF CLINICIANS IN ONE OF MEDICINE'S MOST RAPIDLY ADVANCING FIELDS.

CARE Act AIDS Education and Training Centers Appropriations (in millions)



The evolution of the HIV epidemic and changes in medical care for HIV-infected people in the United States continue to present challenges and opportunities for the AIDS Education and Training Center (AETC) program. Several trends are particularly relevant:

- The increasing impact of HIV/AIDS on the underserved, minority, and marginalized segments of American society
- The dramatic impact of medical care, particularly the use of highly active antiretroviral therapy (HAART) on health outcomes of people living with HIV infection, with the best outcomes associated with the highest quality care
- Evidence that many HIV-infected individuals in this country are not receiving regular medical care
- Increased emphasis on reducing transmission by HIV-infected persons.

Additionally, the AETC program has received a considerable proportion of its funding in recent years through the Minority AIDS Initiative, the mandate of which is to increase capacity for HIV/AIDS care and services in communities of color.

The AETC program is the clinical training component of the CARE Act. It provides ongoing education to clinicians in rural, suburban, and urban areas across the country.

Eleven regional centers and 130 associated local performance sites provide ongoing clinical training and technical assistance to health care providers serving people living with HIV disease.

Like other CARE Act programs, regional AETCs base their activities on local needs, continually assessing and revising their efforts to serve people living with HIV/AIDS and the clinicians who treat them. The program targets providers who treat minority, underserved, and vulnerable populations in the communities most affected by the HIV epidemic and providers who are primarily associated with Ryan White CARE Act—supported organizations.

The clinical management of HIV/AIDS, particularly the use of HAART, is the central focus of training. Innovative training methods—skill-building workshops and clinical practice placements—augment traditional didactic education. AETCs also provide clinical consultation and decision support to clinicians regarding care and the use of HAART and technical assistance in improving service delivery at the organizational level.

The term “innovative” connotes the adoption of approaches in venues that are not likely to be supported by private-sector (i.e., pharmaceutical and other) interests without AETC

support. The goal is to increase the number of providers who are educated and motivated to counsel, diagnose, and treat people living with HIV disease. From July 1, 2002, to June 30, 2003, the AETCs provided training to 62,032 clinicians.

In addition to regional endeavors, the AETC program operates on a national level:

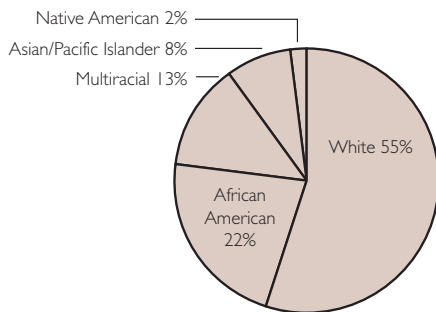
- The National Minority AETC (www.nmaetc.org) was established with funding from the Minority AIDS Initiative to increase HIV/AIDS clinical expertise in underserved communities of color.
- The National HIV/AIDS Clinical Consultation Center (www.ucsf.edu/hivcntr) provides timely responses to clinical

treatment questions through the “WarmLine” (800-933-3413). The Center’s “PEPLine” addresses questions related to possible health care worker exposure to HIV and other blood-borne pathogens (888-448-4911). A perinatal hotline is in development.

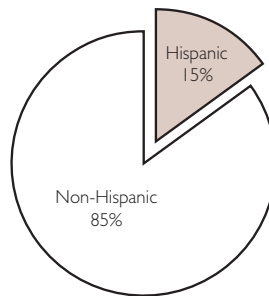
- The AETC National Resource Center (www.aids-ed.org) is a Web-based resource for rapid dissemination of time-sensitive developments, such as new treatment advances, changes in treatment guidelines, and posting and dissemination of training curricula.
- The National Evaluation Center monitors the effectiveness of AETC education, training, and consultation activities.

The AETC program is the largest comprehensive education program in the United States dedicated to improving HIV care for the underserved populations affected by HIV/AIDS. Together, the centers provide training, clinical consultation, technical assistance, training resources, and evaluation services. Trainees include physicians, physician assistants, nurses, nurse practitioners, oral health practitioners, pharmacists, and clinical school faculty. Trainees come from public and private treatment institutions, community-based organizations, and other CARE Act–supported institutions.

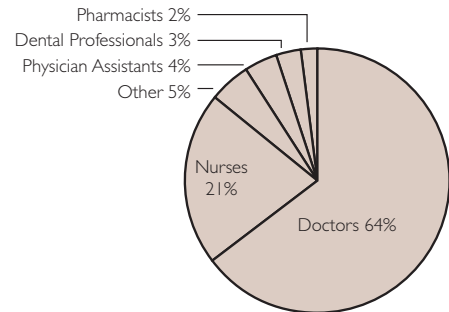
Race of Training Participants, All Levels
(N = 62,032)



Ethnicity of Training Participants, All Levels
(N = 62,032)



Professional Discipline of Participants in Individual Clinical Consultations
(N = 4,668)



THE BASICS

- ORAL HEALTH PROBLEMS OCCUR IN 30 TO 80 PERCENT OF PEOPLE LIVING WITH HIV/AIDS.
- THE DENTAL REIMBURSEMENT PROGRAM PROVIDED \$9.8 MILLION IN REIMBURSEMENTS TO 64 INSTITUTIONS IN FY 2003.

THE COMMUNITY-BASED DENTAL PARTNERSHIP PROGRAM PROVIDES 5-YEAR GRANTS TO DENTAL EDUCATION PROGRAMS. \$2.9 MILLION IN GRANTS WAS AWARDED TO 12 INSTITUTIONS IN FY 2002 AND 2003. DUE TO BUDGET RESTRICTIONS, NO NEW GRANTS WERE AWARDED IN FY 2003 OR 2004.

A black and white portrait of a woman with curly hair, wearing a denim jacket over a light-colored top. She is looking slightly to the right of the camera with a neutral expression.

BRENDA WISE
NEW YORK, NY

People living with HIV disease often experience oral health problems. Conditions like thrush, warts, and gum disease are often among the first manifestations of HIV disease, and they occur in 30 percent to 80 percent of people living with HIV/AIDS worldwide.

Oral health care is essential for the HIV-positive person because of its relationship to good nutrition. Ongoing dental care and treatment are critical to minimizing long-term dental complications.

The CARE Act's Dental Reimbursement Program improves access to oral health care for people living with HIV disease. The program provides reimbursements to dental schools, hospitals, and other institutions with dental education programs for otherwise uncompensated services provided to people living with HIV/AIDS.

By offsetting the costs of HIV care in dental education institutions, the Dental Reimbursement Program achieves two fundamental objectives:

- expanded access to oral health care for people living with HIV/AIDS and
- improved training for new dentists and dental hygienists on caring for people living with HIV disease.

Services covered by the Dental Reimbursement Program include diagnostic and preventive care; oral health education and health promotion; restorative, periodontal, prosthodontic, and endodontic services; oral surgery; and oral medicine services.

In FY 2003, the Dental Reimbursement Program provided \$9.8 million in reimbursements to 64 institutions in 23 States and the District of Columbia and Puerto Rico.

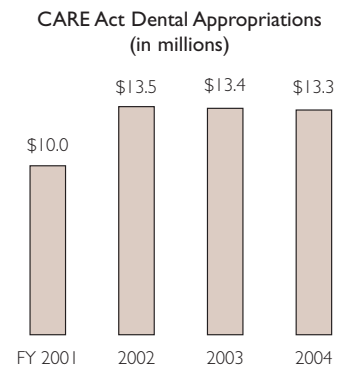
COMMUNITY-BASED DENTAL PARTNERSHIP GRANTS

Community-Based Dental Partnership grants provide funds to eligible dental education programs to increase access to oral health services and enhance provider training in community settings. The grants are designed to provide care, under the supervision of dentists and in community-based settings, while supporting, educating, and training students and residents enrolled in accredited dental education programs.

Funded activities include

- provision of oral health services for people with HIV/AIDS;
- clinical rotations for students and residents in community-based settings; and
- data collection, management, and reporting.

In FY 2003, a total of \$2.9 million in funding to 12 institutions was provided through the program.



SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

THE BASICS

- SPNS GRANTS PROVIDE FUNDING FOR IMPROVED MODELS OF CARE DELIVERY THAT ARE REPLICABLE IN THE PROVIDER COMMUNITY.
- 72 GRANTS IN 17 INITIATIVES ARE UNDER WAY.
- INITIATIVES FOCUS ON DISCRETE CARE CHALLENGES, INCLUDING ADHERENCE, BUPRENORPHINE IN THE HIV CARE SETTING, AND PREVENTION WITH POSITIVES.
- TOTAL ANNUAL FUNDING IS \$25 MILLION.

It is estimated that as many as one-third of all those living with HIV/AIDS in the United States do not know it. Many others are aware of their serostatus but are not in care. The Nation must develop increasingly effective programs for reaching infected individuals if it is to stem the tide of the epidemic and mitigate the effects of HIV disease. It is for this reason that the CARE Act's Special Projects of National Significance (SPNS) program was established.

SPNS INITIATIVES

The SPNS program supports the development, evaluation, and replication of innovative models of HIV care and services delivery. For the majority of its endeavors, the SPNS program establishes initiatives that focus on key issues in HIV care. Current and past initiatives seek more effective and efficient service delivery models related to HIV/AIDS and

- integrating buprenorphine and substance abuse treatment in HIV primary care settings,
- MSM of color,
- adherence,
- services along the U.S./Mexico border,
- outreach and intervention,

- information technology,
- care in Caribbean populations,
- prevention strategies for HIV-positive persons,
- correctional settings,
- services for American Indians and Alaska Natives with HIV, and
- substance abuse and HIV treatment.

SPNS GRANTS

SPNS grants are awarded within the context of each initiative. Each year, SPNS funds about \$25 million in grants. There are currently 72 grants in 11 initiatives.¹¹ Some, such as the HIV Prevention, Intervention, and Continuity of Care Within Correctional Settings and the Community initiative, are funded in collaboration with the Centers for Disease Control and Prevention. Grants—averaging about \$350,000 each—are awarded competitively and last 3 to 5 years. Grantees include

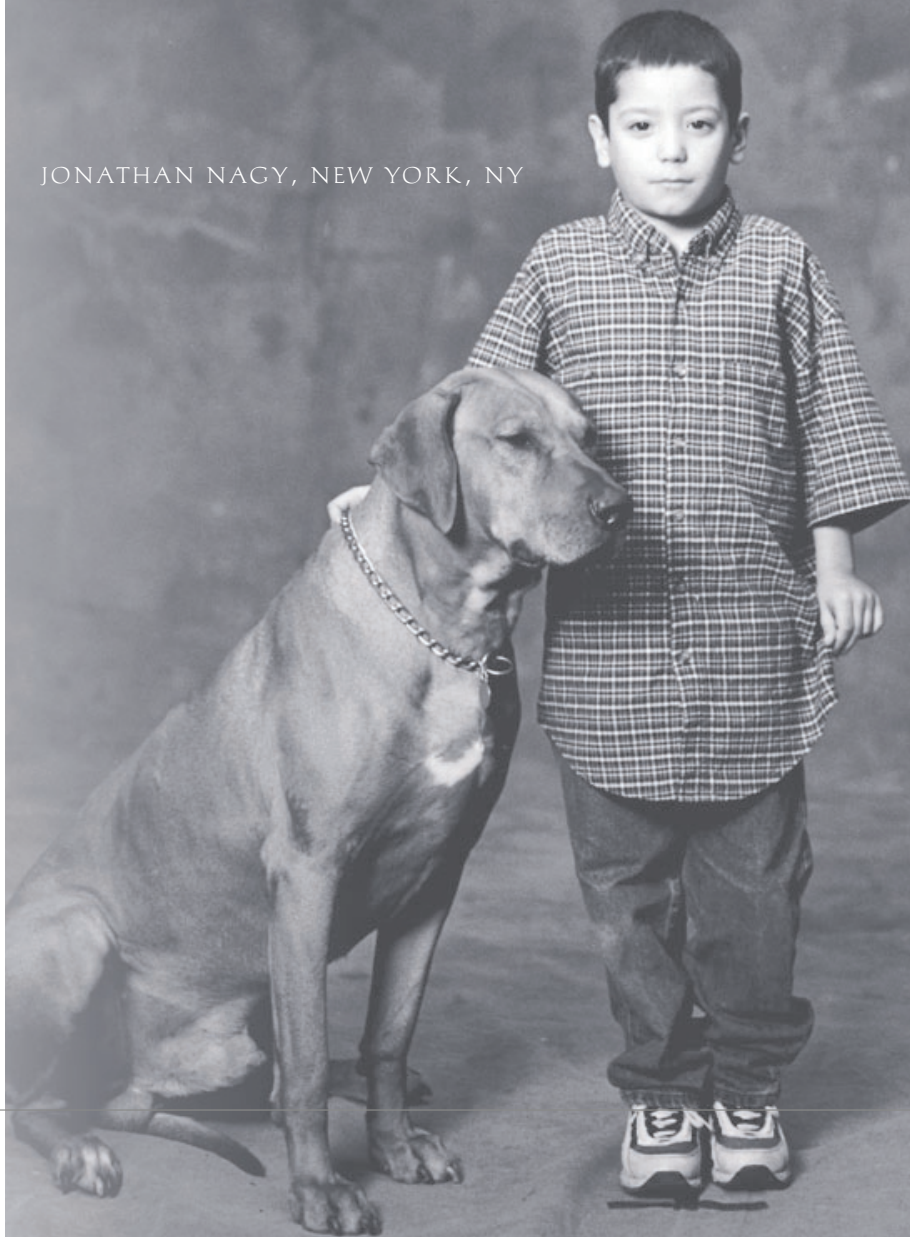
- university clinics (29%),
- community clinics (26%),
- evaluation centers (17%),
- local/State health departments (15%),
- community-based organizations (7%),
- miscellaneous and nonprofit agencies (6%).

DISSEMINATION OF SPNS FINDINGS

Most recipients of SPNS grants provide services to underserved individuals during the course of the project. But the goal of SPNS is to identify more effective models of service delivery that can then be disseminated throughout the care community. This goal is accomplished through several mechanisms. Each SPNS grantee develops and implements a dissemination plan, which typically involves submitting articles to leading periodicals, such as the *Journal of Acquired Immune Deficiency Syndrome* or the *American Journal of Public Health*. In addition to disseminating findings through peer-reviewed journals, monographs, and the HAB Web site (www.hab.hrsa.gov), grantees make presentations at local, national, and international conferences that highlight findings from their projects.

Simultaneously, HRSA implements its own dissemination strategy, which includes the development of white papers and publications summarizing key findings from SPNS initiatives. In addition, SPNS outcomes are regularly featured in the HRSA/HAB publication *HRSA CAREAction*, and HRSA staff make presentations at conferences. In August 2003, findings from the SPNS Adolescent Initiative were the focus of a special issue of the *Journal of Adolescent Health*.

JONATHAN NAGY, NEW YORK, NY



HIV/AIDS BUREAU: IMPROVING PROGRAM PERFORMANCE

THE HIV/AIDS BUREAU IMPROVES THE HEALTH AND QUALITY OF LIFE OF PEOPLE LIVING WITH HIV/AIDS BY INCREASING THE EFFECTIVENESS AND EFFICIENCY OF CARE ACT PROGRAMS.

Through technical assistance and training initiatives mandated in the legislation, the HIV/AIDS Bureau helps grantees and providers respond more effectively to local care needs. For example, the AETC program described on page 42 of this report provides clinical care training to thousands of clinicians across the country each year. Through activities such as nationwide conference

calls and resources such as the CARE Act Technical Information and Education library (www.hab.hrsa.gov/Catie/), individuals gain access to practical tools for addressing care and service delivery challenges.

In a time of rising health care costs, increasing HIV prevalence, and a growing Federal budget deficit, CARE Act-funded entities, now more than ever, must clearly demonstrate effectiveness, efficiency, and positive return on taxpayer dollars. Cross-program activities, such as the new *CARE Act Data Report*, targeted studies of CARE Act programs, and partnership programs with other Federal agencies that address such systemic challenges as projecting the cost of

health care, are helping the Bureau create a more productive and efficient HIV/AIDS care environment.

Critical to improving program performance is HRSA's comprehensive approach to quality, described at www.hrsa.gov/quality. CARE Act grantees are mandated to implement quality management programs, and the Bureau provides several publications and tools to help organizations fulfill this requirement. For example, the Bureau's *Quality Management Technical Assistance Manual* gives providers real-world quality improvement techniques that lead to measurable improvements in the quality of CARE Act services (www.hab.hrsa.gov/tools/QM).



"ULISES," CHICAGO, IL

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Photographs for this report were generously provided by *The Faces of AIDS*, two projects that chronicle the lives of people living with HIV disease in 11 Midwestern States and in New York City. Both projects were developed under the direction of Frank Oldham, Jr. The Midwest project uses personal testimonials and a traveling photo documentary to educate the public about HIV/AIDS and those living with the disease. The New York City project uses similar elements of photography and personal stories to increase HIV/AIDS awareness and education. For more information about the projects, visit www.ci.chi.il.us/Health/FacesSchedule.html and www.nyhiv.com.

The project in the Midwest was produced by the Chicago and Illinois Departments of Public Health, Screamer Design, and Jim Pickett, with photographers Dan Ash, Doug Birkenheuer, Kale Feelhaber, Jason Smith, Sharon Sopher, Andre Vospette, and Israel Wright. The New York Project is being produced by the Office of AIDS Policy Coordination, New York City Department of Health and Mental Hygiene. Photographers are John Sann and Alex Brown.

Front cover and title page photographs: left, Brenda Wise, New York, NY; top right, David Singh, New York, NY; and bottom right, Raymond Herradura, Chicago, IL. Inside front cover: left, Maria Ruiz, New York, NY; top right, Jonathan Nagy, New York, NY; bottom right, Brenda Lee Curry, New York, NY.

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