excellence

vision

commitment

leadership

knowledge

training

Going the Distance

strategy

innovation

collaboration

initiative

effort

talent

skill

motivation

character

resolve   spirit

          courage

will power

          fortitude

perseverance

          dedication

heart

          inspiration

passion

          teamwork

hope

The Ryan White HIV/AIDS Program

20 Years of Leadership, A Legacy of Care

Contents

FOREWORD

The Ryan White HIV/AIDS Program was borne of a movement that began with the onset of the AIDS epidemic in America. First by the tens, then by the hundreds, then by the thousands, brave and committed people from all walks of life made a decision to get involved. Some were public health officials; others were activists. Some were community leaders, and others—at least until that time—were citizens quietly living their lives.

In this sixth edition of the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) Progress Report, we celebrate the legacy of those first responders. We also celebrate the incredible journey we have taken since 1990, when the first Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was passed into law. Who could have imagined in those early years that we would one day have treatments powerful enough to forestall the progression of HIV/AIDS? Who could have known that we would touch so many lives? This year alone, through scores of grantees and providers* in cities and towns across America, the Ryan White HIV/AIDS Program will serve well over half a million people. We continue to face hurdles in our fight against the epidemic, but we have made enormous progress. Highlights from this year include the following:

- At $2.29 billion, FY 2010 appropriations for the Program were the largest in Program history.
- Our AIDS Education and Training Centers (AETCs) conducted more than 18,000 trainings.
- Under the AIDS Drug Assistance Program (ADAP), we distributed medications to more than 175,000 clients.
- We treated the people most disproportionately affected by HIV: 73 percent of our clients were racial and ethnic minorities, and 88 percent of our clients had no private health insurance.
- We conducted research on innovative, replicable models of HIV care to reduce health disparities in women of color, improve access to oral health care, establish linkages between jail settings and HIV primary care, and expand health information technology and electronic medical systems.
- We have been involved in the Healthy People 2010 broad-based national collaborative to meet the Nation's most pressing health needs.
- We continue to set the standard for HIV/AIDS care using well-respected performance measures.

This response to HIV/AIDS constitutes nothing less than a modern public health miracle. . . and within it lie other miracles, too—like that of an HIV-positive person living into old age, or the promising future that unfolds before the eyes of an HIV-positive adolescent. In this publication, you will read about many of the milestones we have encountered in our 20-year journey and the many qualities that make our team successful. We embarked on a quest that many would not. We stepped up to the plate when others stepped away. And today we constitute a powerful and cohesive force seldom seen in combating a single disease. Our rewards lie in victory after victory over isolation and disease and in the improved lives of our clients. It has been an amazing and empowering journey, and it is not over. We are trained. We are committed. We are full of resolve. And we will not stop.

In this Progress Report, we remember and we honor the determination of those first responders and of Ryan White himself. It was the determination to go the distance for people living with HIV/AIDS, whatever it took and whatever the cost. That determination has never been more alive than it is today.

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* "Grantees" are the recipients of Ryan White HIV/AIDS Program funds responsible for administering the award. "Providers" are organizations that deliver health care and social services to people living with HIV/AIDS.

Our History at a Glance

On August 18, 1990, the CARE Act was passed into law. It was and continues to be the largest federally funded HIV/AIDS-specific program. Since inception there have been four reauthorizations, in 1996, 2000, 2006 and, most recently, in 2009. In 2006 and again in 2009, the Ryan White CARE Act was renamed. In the 2006 reauthorization, it became the Ryan White HIV/AIDS Treatment Modernization Act, and in 2009, the Ryan White HIV/AIDS Treatment Extension Act.

In 1991, the first CARE Act appropriations were made. Monies were given to three programs: Part A (Title I), Part B (Title II), and Part C (Title III). It wasn't until 1994 that the Part D (Title IV) program was added; the AETCs, Special Projects of National Significance (SPNS), and Dental Reimbursement Program were not included in the legislation until 1996. Although the Minority AIDS Initiative (MAI) was providing resources to the Ryan White HIV/AIDS Program as far back as 1999, it did not become an official part of the Program until the 2006 legislation.

Ryan White HIV/AIDS Program Components

Part A

Part A, which targets cities disproportionately affected by HIV disease, evolved out of HRSA's 1986 AIDS Service Demonstration Grants and the Robert Wood Johnson Foundation AIDS Health Services Program. In 1991 there were 16 grantees. Today's 56 grantees include both large Eligible Metropolitan Areas (EMAs) and smaller Transitional Grant Areas (TGAs). TGAs were added to Part A in 2006.

Part B

The Part B program assists U.S. States and Territories and was first funded at $88 million. It has grown to approximately $419 million today. In 1995, ADAP was created under Part B. ADAP evolved out of the 1987 AIDS Drug Reimbursement Program and is now the largest Ryan White HIV/AIDS Program component, with $835 million in funding.

Part C

The Part C program has, since inception, focused on delivering the highest quality primary care services. In 1991, there were 114 grantees; today, there are approximately 375. The largest—and first—Part C program provides early intervention services grants. Planning grants and capacity development grants were added in 1996 and in 2000, respectively.

Part D

In 1994, the Part D program for women, infants, children, youth, and their families was included under the Ryan White CARE Act for the first time. Part D evolved out of the 1988 Pediatric AIDS Demonstration Projects, which were housed in HRSA's Maternal and Child Health Bureau. Since their inclusion in the Ryan White HIV/AIDS Program in 1994, Part D has grown from $22 million to approximately $78 million. Today, there are 98 Part D grantees.

Part F
AIDS Education and Training Centers

AETCs are dedicated to training health care providers to counsel, diagnose, treat, and medically manage people living with HIV disease and to prevent high-risk behaviors that lead

to further HIV transmission. Although they began as a HRSA initiative in 1987, wasn't until the 1996 reauthorization that they became part of the Ryan White CARE Act and housed under HAB. AETCs began with 4 sites but have grown to 11 regional centers and 4 national centers today.

Special Projects of National Significance

Originally housed in Part B, the SPNS program has been a proving ground for innovative and replicable models of care that focus on the most vulnerable populations of people living with HIV/AIDS. Congress moved the program into Part F in 1996. SPNS initiatives are designed to address a specific community or service delivery challenge and are currently funded at $25 million.

Dental Program

The Dental Reimbursement Program was first authorized in 1991 and funded in 1994. It began as a HRSA initiative and was incorporated under the Ryan White CARE Act in 1996. The program provides resources to cover some of the costs of the uncompensated care provided by academic dental institutions to people living with HIV/AIDS. In the 2000 reauthorization, Congress added the Community-Based Dental Partnership Program. First funded in 2002, this program supports collaborations between dental education programs and community-based dentists and dental clinics. Today, the dental programs receive a combined total of $13.6 million.

Minority AIDS Initiative

The MAI began providing resources to HRSA in 1999 through annual appropriations language. It wasn't until the 2006 reauthorization that the MAI was finally codified into the Ryan White HIV/AIDS Treatment Modernization Act. The goal of the MAI is to reduce health disparities among racial and ethnic minorities through outreach and education services and to strengthen the capacity of community-based organizations serving people of color affected by HIV/AIDS.

**HRSA/HAB
Before the
CARE Act:**

1986:

AIDS Service
Demonstration Grants
hab.hrsa.gov/
livinghistory/timeline/
1986.htm

1987:

AZT Reimbursement
Program
hab.hrsa.gov/
livinghistory/timeline/
1987.htm

1988:

Pediatric AIDS Grants
hab.hrsa.gov/
livinghistory/timeline/
1988.htm

1989:

Low-Prevalence
Planning Grants
hab.hrsa.gov/
livinghistory/timeline/
1989.htm

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1. The Pursuit of Excellence
And the Ryan White HIV/AIDS Program

2010

People involved in the Ryan White HIV/AIDS Program today are of every age and every color, striking in their diversity. There are young people beginning their professional lives as well as people a generation beyond who proudly call themselves the pioneers in a pursuit that has changed them, their country and, indeed, the world.

The Ryan White HIV/AIDS Program community is diverse not just in age and race but in gender and faith, temperament and sexual orientation, and in the roles they play in their great uniting cause. And they represent the hundreds of thousands of people in America who have died from what was, just decades ago, a nameless foe. Wherever they come from, whatever their belief system or color or gender, they share a common quest to conquer HIV/AIDS.

And yet absolutely nothing about the involvement of these individuals was a foregone conclusion.

WE DELIVER

FIRST-RATE CARE

IN A **HIGH-NEED** COMMUNITY.

—David Ferris, Internist, Bronx–Lebanon Hospital Center

1986: Early Steps

HIV/AIDS has always demanded fierce determination from anyone who would fight it. Progress against this misunderstood disease—one that stigmatized its victims and became the leading killer of Americans ages 25 to 44 by 1993—has never been an undertaking for the timid.[1] From the outset, addressing HIV/AIDS required the grit to push hard. Few people in the early 1980s had ever seen anything like it.

The early commitment to address HIV/AIDS united people from all walks of life. Among gay men and activists, scientists and public health officials, this first offensive against the new disease was an emotionally charged undertaking. Middle-aged nurses embarked on an unexpected career course. Private citizens began to act against a public problem. And public health professionals took up the challenge of their lives.

The responses to the first cases of HIV/AIDS took place in the scattered offices of a few bewildered clinicians or in big-city emergency rooms—and then the torrent of people seeking help for this mysterious disease began. By 1985, communities faced staggering need and few resources with which to address it. Despite the science-driven late 20th century, in which antibiotics could treat most contagious diseases and vaccines had wiped out so many lethal illnesses, so little could be done about such a powerful killer.

At HRSA, the need for resources in overwhelmed communities was championed by public health officials who were awed by the pace at which HIV was spreading and the need for immediate intervention. They worked to create a Federal commitment to provide services to people affected by the emerging epidemic.

In 1986—the same year in which AZT (zidovudine) was introduced—their determination led to the government's first AIDS-specific care program: the AIDS Service Demonstration Grants. In the Program's first year, 4 grants were awarded, and the number grew each year thereafter, reaching a total of 24 grants in 1990.

HRSA's AIDS Service Demonstration Grants drew heavily on the work of the Robert Wood Johnson Foundation, whose AIDS Health Services Program also began in 1986. The demonstration grants, in turn, informed other groundbreaking efforts within HRSA, which introduced three additional grant programs by 1990.

The first Federal AIDS programs in America didn't just happen. These programs were fought for by dedicated people, both in and out of government, who dared to advocate for a population that was marginalized by the majority of Americans. Their efforts were augmented by widespread community activism among people living with or caring for people with AIDS.

The late 1980s were a time of cruel public condemnation against HIV-positive gay men and injection drug users. Calls were made to blame and even punish those who became infected with the disease. The first AIDS programs at HRSA were created in this kind of environment. When we read about those programs now, the determination of the HIV/AIDS pioneers stands out in brilliant relief. (Find out more about pre-Ryan White HIV/AIDS Program

Friends consoling one another at the funeral of AIDS victim Jon Greenberg, New York City, July 16, 1993.

activities at hab.hrsa.gov/livinghistory/timeline/1986.htm.)

1990: New Power

If we compare the history of the Ryan White HIV/AIDS Program to a long-distance run, we were well past the starting line when the CARE Act was enacted on August 18, 1990. The Program was aptly named after Ryan White, an HIV-positive Indiana teenager who fought AIDS stigma and misunderstanding, a mission the Program continues today. HRSA, which would administer the new Program, had been awarding grants for addressing AIDS for 5 years. When the first CARE Act grants were awarded in 1990, some organizations receiving

funding had been caring for people living with HIV/AIDS for the better part of a decade.

To the entities that received the first CARE Act grants, Federal funds brought an extraordinary level of new capacity. Distributed through various CARE Act programs, the grants facilitated broader, deeper advances against AIDS suffering. And the new CARE Act brought more than money: It brought the power of individual and community experience and medical care, social support, and public health expertise to bear on the problem.

The power of the CARE Act also lay in its incorporation of the community action that had driven the Nation's first re-

sponses to HIV/AIDS. The CARE Act was designed to respond to the needs of individual communities by incorporating community members into the decision making as to how funds would be distributed.

The CARE Act brought new attention to the enormous suffering and heroic determination of people living with HIV/AIDS. Over time, the Program recruited thousands of new professionals into HIV/AIDS care and formed a gifted team that the country needed to be successful in the fight against AIDS. In an era when the disease said, "You can't!" the country responded, "Oh, yeah? Watch this!"

1994: A Big Leap Forward

Thirteen years into the epidemic, much had been learned about how to prevent HIV infection, and drugs such as AZT and DDI (didanosine) were providing measurable benefits to some patients. In perinatal transmission of HIV, however, little progress had been made, but that was about to change.

On February 21, 1994, the AIDS Clinical Trial Group (ACTG) announced—or, one might say, shouted from the rooftops—preliminary results from its 076 Protocol. Findings showed a 67.5 percent reduction in the risk of HIV transmission from mother to child among pregnant women who took AZT.

Everyone in the Ryan White HIV/AIDS Program community worked tirelessly to ensure that this giant leap forward in research was matched by a giant leap
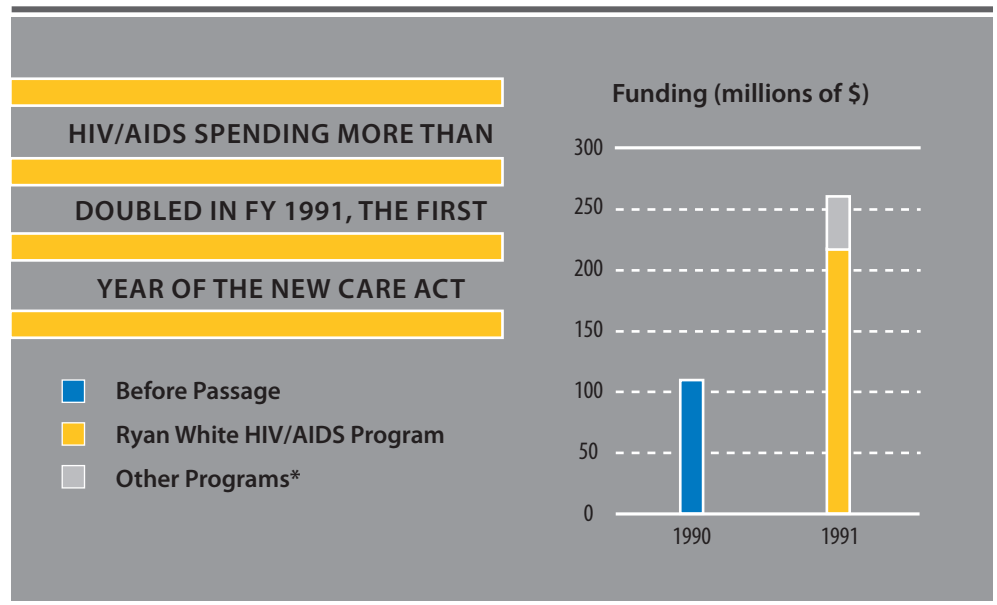
forward in care for HIV-positive pregnant women. We worked with partners throughout the U.S. Public Health Service to create guidelines for administering the AZT regimen. We ensured that the regimens used by clinics in the study (many of which were HRSA grantees) were disseminated to *all* Ryan White HIV/AIDS Program grantees as well as to grantees of other HRSA programs.

In 1994, we launched the Perinatal Initiative and a National HIV Pediatric Resources Center to provide technical assistance to clinics nationwide. Grant applicants of what is now the Part D program were required to show how they were using ACTG–076 Protocol results.

And we kept pushing forward. We incorporated the new standard of care for HIV-positive pregnant women into expectations for Part D program grantees, and then we made training, techni-

cal assistance, and onsite support available to *all* organizations funded through the Federal Community and Migrant Health Centers Program.

Continued success requires continuous evolution, and the Ryan White HIV/AIDS Program's response to the ACTG–076 Protocol results illustrates our capacity to translate research into practice. Applying the results of that first breakthrough in clinical prevention was not always easy. After all, many AIDS service organizations and community-based organizations at that time were set up to serve gay men. But the commitment to do our best for everyone affected by the AIDS epidemic ensured that our patients would receive the full benefit of all that is known about HIV/AIDS prevention and care. As a result of our efforts, in many Ryan White-funded clinics, the perinatal HIV infection rate is now zero.

HIV/AIDS SPENDING MORE THAN

DOUBLED IN FY 1991, THE FIRST

YEAR OF THE NEW CARE ACT

Funding (millions of $)

- Before Passage
- Ryan White HIV/AIDS Program
- Other Programs*

300
250
200
150
100
50
0
      1990   1991

* Other programs include AIDS Education and Training Centers—funded outside the Ryan White HIV/AIDS Program until 1997—and Pediatric AIDS Demonstration Grants—first funded through the Program in FY 1994 as Part D.

1995: The Breakaway

Most of the time, success is achieved in tiny increments through day-to-day work. Achievements come from commitment and discipline rather than immediately perceptible results. And then there are those wonderful moments when something really big happens—a glorious breakthrough that changes the playing field forever.

When the FDA approved the first protease inhibitor in 1995, the way we think about HIV/AIDS was destined to change forever. The approval of other drugs that would constitute highly active antiretroviral therapy (HAART) soon followed. Although there was still so much that we didn't know, it only took until 1996 to see the new treatment's incredible power. That year, the regimen became widely available to patients who could afford it—and, as the Ryan White community made sure, to those who couldn't.

Breakthroughs are never isolated events: They almost always have far-reaching consequences. In 1996, ADAP was funded at $52 million; with the advent of HAART, that number more than tripled to $167 million in 1997.

Appropriations to ADAP continued to increase sharply in the coming years, and the newly formed HAB coalesced into a galvanizing force for state-of-the-art medical care. Through the AETC program, clinicians were given cutting-edge training on administering new treat-

ADAP APPROPRIATIONS

GROWTH

FY 1996–2000
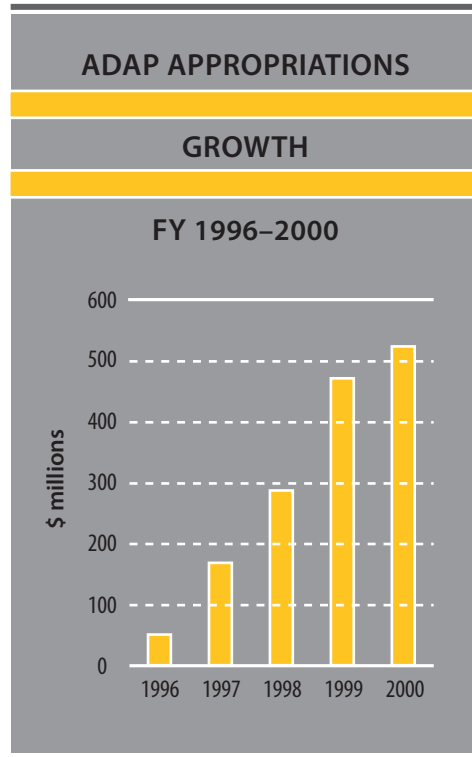
ments. HAB supported development of treatment guidelines that were widely disseminated in print, on the Internet, and via interactive Web conferencing.

The response to HAART at the community level was extraordinary. Grantees and providers from every corner of the United States reconfigured their programming to help clients comprehend the rigors of HAART, make informed treatment decisions, and conquer HAART's exacting adherence requirements. They created and implemented programs for supporting adherence and helping clients deal with the drug treatment's frequently severe side effects. And they worked with their clients to help them reach a level of stability that could make the promise of HAART a reality in their lives.

The result of grantees' work, of increased appropriations to ADAP, and of support from HRSA is clear: steep declines in AIDS morbidity and mortality among all populations, including the historically underserved.

1999: Digging Deep

When the history of AIDS in America is publicly discussed, it is often lost that the disease has *always* impacted disproportionately among minority populations. Tragically, its toll has become increasingly disproportionate over time. (See chart, p. 10.)

After the advent of HAART, U.S. AIDS incidence and mortality declined sharply overall, but declines were much smaller among minorities, particularly African-Americans and Hispanics. These populations also experienced the greatest portion of new HIV infections. In 1999, 47 percent of new reported AIDS cases (21,900) and 51 percent of deaths from AIDS were among Blacks, although they represented just 13 percent of the U.S. population.* Hispanics accounted for 19 percent of new AIDS cases (9,021) and 18 percent of deaths but just 14 percent of the U.S. population.[2,3,4]

The Ryan White HIV/AIDS Program responded forcefully to evidence that minorities were not reaping the same benefits as Whites from new treatment and prevention strategies. The Program redoubled its longstanding focus on meeting the needs of underserved minorities—creating a number of SPNS

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* *Black* is the term used by the U.S. Department of Health and Human Service, Centers for Disease Control and Prevention.

WHEN I GOT MYSELF
TOGETHER, I STARTED
THINKING ABOUT
WHAT I WANTED TO
DO IN LIFE. I'M A
SUPPORTIVE PEER.
I VISIT SICK PATIENTS
IN THE HOSPITAL.
I SIT AND LISTEN
TO THEM AND
COMFORT THEM.

—Clyde Robinson
HIV/AIDS survivor and peer
The Center for Comprehensive Care
St. Luke's–Roosevelt Hospital Center
New York, NY

HIV DEATH RATES and INTRODUCTION in 1995 of

HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART)
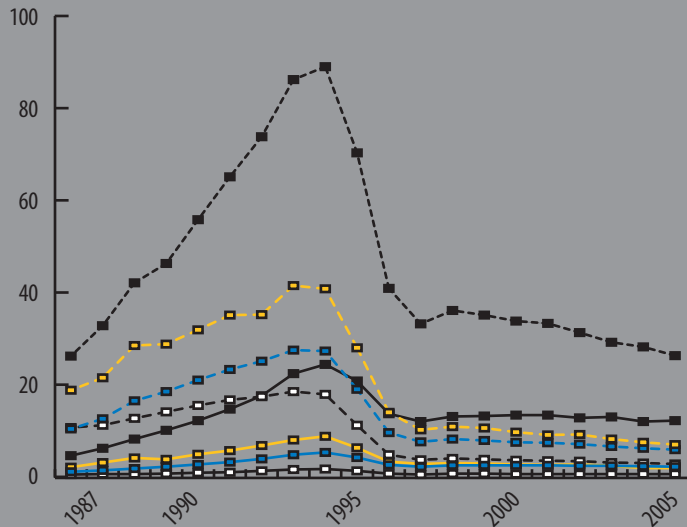
Legend:
- - - ■ - - - Male (blue)
- - - ■ - - - Black male
- - - ■ - - - Hispanic male (yellow)
- - - □ - - - White, not Hispanic male
——— ■ ——— Female (blue)
——— ■ ——— Black female
——— ■ ——— Hispanic female (yellow)
——— □ ——— White, not Hispanic female

initiatives to identify new and better strategies, including:

- Targeted HIV Outreach and Intervention Model Development and Evaluation for Underserved HIV-Positive Populations Not in Care

- Demonstration and Evaluation Models that Advance HIV Service Innovation Along the U.S.–Mexico Border

- Innovative HIV Service Delivery Models for Native American Communities.

Studies among subpopulations such as men of color who have sex with men also were undertaken. HRSA's overall goal was to create a Program that was reflective of the communities affected by the epidemic.

In 1999, the Minority AIDS Initiative (MAI) brought renewed public focus and critical financial resources to the important mandate of addressing HIV/AIDS among minorities. Administered by the U.S. Department of Health and Human Services (HHS), the MAI supported new prevention, care, and research efforts through several Federal agencies, including HRSA, which received $22.3 million in MAI funding in 1999. The MAI became part of the Ryan White HIV/AIDS Treatment Modernization Act in 2006.

This new funding allowed the Ryan White HIV/AIDS Program to further expand its emphasis on serving minority populations. In 1999, 79 Part C planning grants were awarded that focused primarily on organizations indigenous to and serving minority communities, up from just 15 the previous year. The National Minority AETC was established to increase provider capacity to address HIV disease in communities of color; the national headquarters and all regional sites are housed at minority-serving institutions. Increased funding was also made available to help all grantees expand services into minority communities, and grant applicants were required to illustrate their strategies for reaching underserved minority populations.

The attention brought to the national tragedy of AIDS among minorities in the late 1990s spurred renewed commitment to reaching minority populations. That commitment continues to this day. The high proportion of Ryan White HIV/AIDS Program clients who are racial or ethnic minorities reflects that commitment, but it also reflects persistent health care disparities and the continued necessity of finding new and more effective mechanisms for stemming the epidemic among the most vulnerable members of our communities. (See Figure 2, p. 43.)

2006: A New Age

The ability to rethink and reorganize as circumstances change is a hallmark of success in any pursuit. Ryan White HIV/AIDS Program communities nationwide have drawn on their capacity to innovate

and move forward to achieve better and better results for their clients.

The Ryan White HIV/AIDS Program and the legislation that authorizes it have never been static. First enacted in 1990 under the CARE Act, the Program was reauthorized in 1996 and again in 2000. Modifications by Congress over the first 10 years of the Program have often been substantial, reflecting changes in the epidemic itself, new approaches for addressing needs in underserved communities, and evolving Federal priorities.

For example, the 2006 reauthorized legislation reflected congressional emphasis on the Program's health care achievements. It renamed the CARE Act the Ryan White HIV/AIDS Treatment Modernization Act of 2006 and firmly positioned it as a major public health care initiative by adding a core medical services provision. (To find out more about the changes from the 2006 legislation, visit hab.hrsa.gov/law/leg.htm.)

The core medical services provision required that grantees under Parts A, B, and C use at least 75 percent of their grant funds, not including administration or quality management programs, to provide core medical services. In short, it called on grantees, once again, to be flexible and to adapt. This challenge was not without risks. Many in the Ryan White HIV/AIDS Program community were concerned, for example, that the new provision would ultimately deprive people living with HIV/AIDS of the essential support services necessary

HIV/AIDS care has experienced enormous change in 20 years. Providers like the Boriken Neighborhood Health Center (above and below) are often small in size yet able to offer a full array of medical and support services—including dentistry and digital record keeping of important client data.
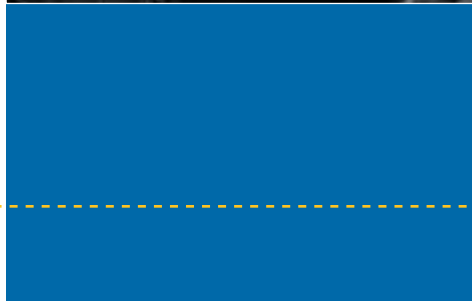
to facilitate their retention in care. But Ryan White HIV/AIDS Program grantees and providers rose to the challenge, as they had so many times before.

Supported by HAB, which worked to provide a framework for interpreting and implementing the core medical services provision, grantees quickly modified their spending to comply with the new requirements. Acting on concerns that the provision would reduce access to essential support services, grantees created new alliances with providers to whom they could refer their clients.

The determination, initiative, and resourcefulness demonstrated by grantees in rising to meet this challenge are just a few of the strengths that have always set our community apart. Although our 20-year quest has been marked by frequent and dramatic change, it's not simply the change that has been remarkable, but how we as a community have managed it and harnessed its potential.

We are not today, nor have we ever been, silent observers, and we are very good at responding to new developments. Those characteristics have enabled us to reach people whom, 20 years ago, no one was reaching. And our efforts are about not just reaching people but giving them the highest quality care—and keeping them in care on an ongoing basis.

It is because of those strengths—and so many others—that people today are living with HIV/AIDS rather than dying from it.

I got a PICTURE of RYAN WHITE

on one of my bookshelves.

If it wasn't for him...I'd probably be dead.

—Anthony Weldon
Member, Consumer Advisory Board
Bebashi health clinic, Philadelphia, PA

Nearly 25 percent of Philadelphia s
population lives in poverty.

The city s estimated rate of new HIV
infections is 5 times the national rate.

At the end of 2008, nearly 25,000
people in the Philadelphia Eligible
Metropolitan Area (EMA) were living
with HIV/AIDS.

Philadelphia was a recipient of
one of HRSA s first AIDS Service
Demonstration Grants.

Today, 10,000 unduplicated HIV
positive patients are receiving
primary care.

The EMA is part of a statewide
collaborative to strengthen quality
care.

Data-driven early intervention systems
are advancing local prevention efforts.

Case Study: Philadelphia Department of Public Health

"I was homeless. I was in jail for the second time. I had AIDS and thought I was going to die," says Willie, an HIV-positive patient who receives services funded through Philadelphia's Part A program. "Coming to ActionAIDS changed my life. I knew HIV existed, but I never thought it could happen to me," Willie explains. "I said, 'I don't want to die.' And the doctor said, 'You don't have to,' and she told me about this place."

ActionAIDS was one of the first agencies in Philadelphia to address HIV. Today, it is one of more than 100 organizations funded through the Part A grant to the Philadelphia Eligible Metropolitan Area (EMA).

Philadelphia's role as a HRSA grantee is as longstanding as the epidemic itself. In the mid 1980s, the city was a recipient of HRSA's first AIDS Service Demonstration Grants, a predecessor to the Ryan White HIV/AIDS Program.

"We really used the AIDS Demonstration Project as a model," says Matthew McClain, a consultant for the Philadelphia Department of Public Health's AIDS Activities Coordinating Office (AACO) and longtime HIV advocate. "Even though our first-year grant was tiny, at the time we just thought it was an incredible victory, [and] we saw an immediate impact on the community."

Because there were no treatments for HIV in the early years, most Ryan White money was used to increase capacity and provide palliative care to dying patients. The grant monies also created a system of care linking community-based organizations and hospitals.

"Ryan White money helped provide whatever the state-of-the-art treatment was at the time," explains McClain. "In the beginning, it was compassionate care, but then we got AZT, and then in 1996 we got antiretrovirals. As a system, we had to grow up fast. . . but it meant we [could] implement findings from ACTG–076 and HAART quickly and adapt to other changes in the epidemic.

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Ihojanna Santos (left) connects a patient to primary medical care and case management services through AACO's Client Services Unit. Les Riley (right) tracks incoming HIV testing surveillance data to ensure that the EMA's outreach efforts are targeting communities most in need.

We took the E in CARE Act—the emergency part—seriously to get the money out fast, so organizations could immediately treat and respond to HIV."

Director Jane Baker says AACO has always sought to keep pace with the epidemic. For example, the service system now includes 52 HIV medical care sites and 75 medical case management sites to serve more than 10,000 people. Providing services is no easy feat. The EMA covers 3,855 square miles and 9 jurisdictions in 2 States (Pennsylvania and New Jersey) and treats an incredibly high-need consumer base. Among the 10 largest cities in the United States, Philadelphia ranks first in the number of people living in poverty (25 percent). Camden, New Jersey, also part of the EMA, ranks first among similar-size cities: 44 percent of its residents live below the Federal Poverty Line.

To address unmet needs and reach people who are unaware of their HIV status, the EMA developed an extensive early intervention system coordinated with HIV prevention efforts. Quality management, data collection, and surveillance activities have grown with this expansion, as has the use of sophisticated performance measures.

"We want to be very data driven, so we can see what's going on in the community and address changes," says Coleman Terrell, health program administrator at AACO. "We're constantly trying to improve what we do here, and providers [welcome] being held to a higher level because they know we're truly interested in bettering services." An important part of these improvements is Philadelphia's participation in a HAB-sponsored statewide quality management collaborative.

Although the EMA's approach to HIV care has become increasingly strategic over the past 20 years, the demographics of the epidemic have remained relatively unchanged and tell administrators what providers have long seen in the City of Brotherly Love—that the face of HIV in Philadelphia is, and has always been, predominantly African-American.

On the national scale, the epidemic shifted from what had been known as a White, gay disease to one increasingly ravaging minority communities. As McClain explains, however, "The epidemic here in Philadelphia has always included a lot of African-Americans. That's how it looked in the beginning, and that's who we're still treating today."

Baker is quick to point out that although Philadelphia's HIV efforts have always targeted minorities, today's clients are not the same as yesterday's. "Patients today are more often tri-diagnosed with HIV, substance abuse issues, and mental illness," she explains. To address the increasing client needs, AACO created a Client Services Unit to link clients to primary medical care and medical case management services and provide referrals to a host of other core and supportive services.

"Patients not only have a range of competing health and social service needs," says Baker, "they're also living longer today. This is a good thing, but it also creates strains on the health system as we care for people into old age."

Kathleen Brady, Philadelphia Department of Public Health medical direc-

tor, agrees. "Now we have patients on a number of medications, from HIV to high blood pressure to diabetes. We need to address interactions and adherence to all of these medications. We also have to do things that were previously ignored or left to a later date in the early years, like colonoscopies."

Advances in HIV care have not only extended people's lives but greatly improved their health outcomes. "I'm aggressive. . . . I can remember how many times people said, 'Isn't it time for hospice?' and I said 'no' and kept pushing," says Brady. "Over the last couple of years, with the new drugs available, it's really given people who were on the last leg of a salvaged regimen new hope. Now they're undetectable."

Baker explains that the city's response has changed as the epidemic has evolved. "We've moved from an acute illness to a chronic disease model. We fund different services than we used to because of where the epidemic is. We now fund support services to keep patients in core medical services because no matter how wonderful the medical care is, if patients can't access it, then it's not conducive to getting them the treatment they need."

Consumers like Willie testify to the critical importance of support services and the effect they've had not only on their health but on their life. "I don't have family around here," Willie says. "I stay in Philadelphia because of ActionAIDS. They took me to get transitional housing, they take me to every appointment, and they give me support. If it wasn't for them I'd think nobody cared, but here they do."

Willie adds that, thanks to ActionAIDS, he's encouraged about his health and well-being. "I've met so many people with HIV who are doing well. I consider them my mentors because they saved me, and now I want to be involved," he says. "I want to be in a clinical trial where I can help be part of the solution. I want to help save people, too."

In Philadelphia, we were the role model for other cities on how to empower consumers, read grants, and make good decisions, not just rubber-stamp.

—Roy Hayes
Bebashi consumer and
26-year HIV/AIDS survivor

V I S I O N

2. Clearing Major Hurdles:
Our Greatest Successes

A Jubilant Clinician Delivers Long Awaited News

"Your virus is undetectable," she declares, as tears of joy and relief stream down her patient's face. An HIV/hepatitis C (HCV)-positive parent of three is finally home from work after another evening's long commute and now it's time for homework with the children. A long-term survivor is more than surviving—he is thriving—because the clinic that gives him care is reaching further into the corners of his underserved urban community.

Are successes like these the most important achievements of the Ryan White HIV/AIDS Program, or is it that exemplary HIV/AIDS care is now available in rural areas far away from AIDS epicenters? Is it that children born to HIV-positive mothers in our care almost never become perinatally infected with HIV? Or is our greatest success that, at the end of life, our clients are surrounded by top-quality care and unparalleled compassion? If those isolated souls who took up the fight against AIDS in those early years in places like the Castro District in San Francisco and Greenwich Village in New York could have time-traveled forward to 2010, they might very well have said that you—the person reading these words today—reflect one of the movement's

greatest successes. Why? Simply because you—and thousands upon thousands of others like you—have been brave enough to step into a stigmatized field, courageous enough to fight a powerful foe, and daring enough to believe that we can eradicate the ravages of one of the most serious illnesses known to people in our time. Without you—whether you are a clinician, patient, volunteer, caregiver, or simply someone who understands the importance of public health programs and support services—there would be no Ryan White HIV/AIDS Program. There would be no decline in AIDS morbidity and mortality among the underserved. And there would be no health care equity for people living with HIV/AIDS.

What would you say if someone asked you, "What are the greatest successes of the 20-year old Ryan White HIV/AIDS Program?" How would you answer if you were told that you could list only four achievements? We at HAB asked ourselves the same questions in preparing for the 2010 All-Grantee Meeting. And in looking at our answers, we think you'll agree: We have come a long, long way.

Making Comprehensive Care a Reality

According to Columbia University's Mailman School of Public Health, comprehensive care is "a 'basket' of services that are linked together through active organizational efforts to facilitate patient/client access to these services." Behind this concise definition lies an extraordinary amount of work, collaboration, and commitment, because comprehensive care is something that we—the community of people concerned with addressing HIV/AIDS—have to make happen. Comprehensive care to address complex medical and essential social service needs does not occur naturally.

HOW
DO WE DO IT ▪

We fund a wide variety of services and deliver them in ways that create maximum access.

We continually build and strengthen referral networks and partnerships with many different medical and social services providers.

We ensure that consumers and their advocates are key players in designing HIV/AIDS care programs.

We invest heavily in training and education to meet multiple and ever evolving provider needs.

Comprehensive care has to be *designed*. Partnerships must be created, and a complete understanding of patients' needs has to be acquired. Systems of care that reflect those needs must be implemented and made accessible in a culturally competent way, especially for underserved populations. And then there is the issue of funding: Without it, services cannot be provided at all.

By the time it became clear that HIV/AIDS was an epidemic, it was also clear that fighting the disease required a multitude of services. By the late 1980s, for example, a few highly committed clinicians began to create compassionate inpatient services within institutions that had first treated dying gay men with disapproval. This far-reaching achievement in hospital settings expanded to improved diagnostic services in the community. Simultaneously, physicians serving at-risk populations gained access to the very first training on what was known about the disease, and hard-hit communities were busy weaving together the social and palliative supports that were so critical to patients struggling to meet their subsistence needs.

In the first years of AIDS, we were still in "react mode," and the first efforts to address HIV/AIDS were not always a coordinated, or easy, endeavor. Yet it was during this time that the community's core value of compassionate, comprehensive, and coordinated care was born. The first responders to HIV/AIDS were bound together by this vision—which lives on as the foundation of HIV/AIDS care today.

Reaching People Others Don't

In the past 20 years, the Ryan White HIV/AIDS Program community has taken on many of the most formidable challenges in health care. No challenge has been more daunting than reaching people other programs don't, and none has been met more successfully.

Unconditional Love, Inc., in Melbourne, Florida, now stands alone as the only HIV disease management clinic in the area. While resources are dwindling, the number of HIV patients in care continues to increase, from 375 clients served by 31 full-time employees in 2000 to 678 clients served by 21 full-time employees in 2009. Unconditional Love provides multiple services at a single location, from primary care and nutritional counseling to hepatitis and TB testing. In addition, the clinic offers a suite of support services. Without Unconditional Love, who would serve these people?

The HIV Clinic of the University of Kansas School of Medicine/Wichita Medical Practice Association is the only HIV primary care provider in Kansas outside of Kansas City. The Wichita clinic treats 850 clients and counting. It has also created a partnership with the United Methodist Mexican-American Ministries Health Center in rural Garden City, Kansas, to bring care services to the many impoverished Latino workers who are at risk of or infected with HIV but who have nowhere to turn for care. If this provider went away, where would its patients go?

Throughout the history of HIV/AIDS, social and economic impediments have formed a chasm separating people living with the disease from care. Bridging that divide was the goal of the HIV/AIDS pioneers, and we rely on the same kinds of forward-thinking, determined people to bridge that gap in 2010 and beyond. Largely as a result of their commitment, creativity, skill, and judgment, we succeed in reaching clients who not only have insufficient health care coverage or financial resources for coping with HIV but also face social, physical, psychological, and historical barriers that keep them from seeking care.

Arising out of the extraordinary AIDS activism of the 1980s, Consumer Advisory Boards (CABs) have been a feature of the Ryan White HIV/AIDS Program from the outset. Most grantees today face their health care challenges with the active collaboration of their CABs. Shown here is Mariksa Nieves from the Boriken Neighborhood Health Center CAB.

Think about it: Minority populations account for an estimated 55 percent of Americans with no private health insurance,[5] yet 73 percent of Ryan White HIV/AIDS Program clients are minority. (See Figure 2, p. 43.) Sexual minorities report discrimination and stigma in many health care settings, yet our programs reach them in high numbers. Eighty-eight percent of our clients have no private health insurance. (See Table 7, p. 46.)

Our success in reaching people who need what we offer is a reflection both of who we are and of who we wanted to become. We wanted to acquire the cultural competence needed to reach marginalized communities, and we made it happen. We knew that alliances with others were vital to meet clients' complex needs, so we built those alliances. There is no question, however, that many people living with HIV/AIDS are in dire need of our services but remain tangentially in care or not at all. Perhaps stigma keeps them away. Perhaps they are unaware of their status. Or perhaps HIV services are hours away from their rural home.

In today's environment of increasing needs and stagnant funding, we remain committed to achieving continual enhancements in the way we do business. Communication among partner agencies needs to increase to ensure they better coordinate service offerings, reduce duplication of services and, ultimately, improve targeted financial resources. How else can we do more with less?

The shortage of providers in rural and southern States may mean turning to technology to help close the gap. For instance, Oklahoma State University administers the State's largest telemedicine network. The university has connected with more than 20 sites statewide to share HIV primary care information. The network exemplifies the efforts of the Ryan White HIV/AIDS Program to improve client services wherever those clients reside.

In the early 1980s, the first responders to the HIV/AIDS epidemic opened doors to people who had often found them shut. Thirty years later, we continue that legacy. In our success lies the promise of better health for the people we serve and a lesson for the country at large: If you want to reach the underserved, you can.

Reaching People Others Don't

HOW
DO WE DO IT ▪

We develop skills and resources in cultural competency.

We enlist allies such as communities of faith and social services providers to reach the underserved.

We create outreach tools to connect with clients facing barriers to care.

We reward innovation in caring for the people most in need.

Adapting to Change

Nolan Ryan, one of the greatest pitchers ever to have thrown a baseball, once said, "Enjoying success requires the ability to adapt. Only by being open to change will you have a true opportunity to get the most from your talent."

We have shown our capacity to adapt throughout our movement's history. By retraining when needed and by maneuvering and changing when warranted, we have used our talents, knowledge, and capabilities to achieve astounding results. Just look at the cutting-edge, community-led responses to AIDS that we built in the early 1980s. Look at how our ability to rethink and retrench led to the creation of HRSA's first AIDS programs in 1986 and to the Ryan White HIV/AIDS Program itself a short time later.

After the 1994 ACTG–076 results and the HAART breakthrough in 1995, we brought the power of treatment advances to our patients by adapting our programs, shifting resources, and recruiting people with essential skills and talents for treating HIV/AIDS today. And we have continued to hone and modify our clinical programs, perfecting them for today's epidemic and beyond. Our aggressive attack on HIV/HCV co-infection and our recalibration of clinical care programs to address the needs of an aging population are but two examples.

Our extraordinary capacity to adapt in times of promise is matched by an equal capacity to adapt in times of difficulty. Over the past 15 years, we have made far-reaching changes in almost every aspect of our Program to fight the epidemic among racial and ethnic minorities. For women and youth, we have built programs and clinical approaches that accommodate their unique needs. As needs have increased, we have built stronger partnerships with allies outside the Ryan White HIV/AIDS Program that offer services patients need.

This has not been easy work by any means. For the past 20 years, the Ryan White HIV/AIDS Program community has unflinchingly faced down a nimble, resilient, ever-evolving disease. During

Adapting to Change

HOW
DO WE DO IT ▪

We understand that the world—and the virus—never stands still.

We observe and study, using the latest research to inform all our efforts.

We learn from people living with HIV/AIDS and their providers to help us keep pace with evolving needs.

We train and disseminate, creating access to cutting-edge knowledge.

We promote increased effectiveness as a primary goal of our Program.

those two decades, almost every aspect of the epidemic has shifted, from its geographic reach to its demographic impact, from the promise of new treatments to AIDS' effects on aging. Using vigilance and foresight to anticipate new challenges—and the vision and drive to respond to them—means that we are continually improving the quality of our response to the HIV/AIDS epidemic. This track record can give our clients confidence as we enter the next decade of AIDS in America.

Providing High Quality Care

If compassion is the heart of the Ryan White HIV/AIDS Program, quality care is its driving force. In the first years of AIDS response, the insistence that people living with AIDS deserved high-quality health care brought health care and social services professionals into the fray.

Over the 20-year history of our Program, our commitment to quality has become more formalized. Since the 2000 reauthorization, grantees have carried out quality management programs that enable them to track and improve the quality of their services to enhance clients' quality of life. Quality management is implemented through continuous quality improvement and data tracking programs like CAREWare (free software from HAB, accessible at hab.hrsa.gov/careware/) and other software.

HAB and its partners developed these tools to achieve several important goals. They include making sure that services adhere to U.S. Department of Health and Human Services, Public Health Ser-

HOW
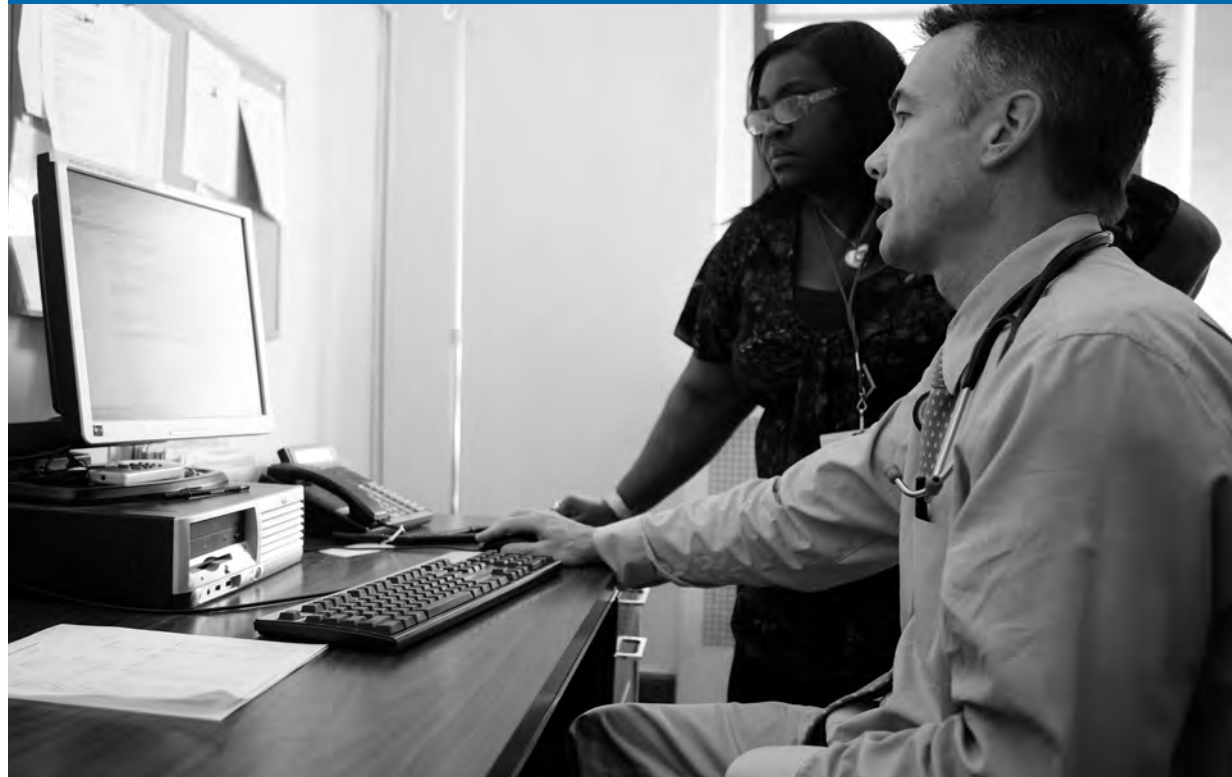### DO WE DO IT ■

We identify and fund organizations with a track record for performance.

We put tools in place to capture and analyze data on health outcomes.

We set a high bar for ourselves and grantees by reporting which interventions work and which do not.

We firmly believe that there are no second-class citizens and no one should receive second-class care.

Peter Gordon and associate Paula Merricks-Lewis discuss a SPNS-funded program that empowers clients to access their health information via a continuity of care record (CCR) wherever they have Internet access.

vice guidelines and established clinical practices; that improvements include support services to increase access, retention rates, and treatment adherence; and that demographic, clinical, and utilization data are used to address characteristics of the local epidemic.

HAB's quality management expectations appear in its grantee program guidance. HAB has created performance measures for clinical care, oral health, medical case management, and ADAP. Systems-level and pediatric performance measures are scheduled for release in 2010. Performance measures allow grantees to track data on their capacity to provide a specific service, treatment, or level of care and to identify trends. The result-

ing data help grantees set targets and compare those targets with actual care delivered. And the process of analysis allows providers to evaluate—and learn from—successes and short-comings. Ultimately, performance measures help ensure that we fulfill our pledge that people living with HIV/AIDS receive the highest quality care possible. (For more on HAB performance measures, see hab.hrsa.gov/special/habmeasures.htm.)

Finally, HAB has created HIVQUAL, a national project to build capacity and capability among Ryan White HIV/AIDS Program Part C and D grantees to sustain quality improvement. Early findings are cause for celebration. Among the results, in 2007

- an average of 93 percent of eligible patients were on HAART;
- approximately 90 percent of HIV patients knew their HCV status; and
- an average of 90 percent of HIV patients had been screened for substance abuse.[6]

HAB's continued quality management efforts have been so successful that of the 1,016 Federal programs rated by the Office of Management and Budget in its 2007 Program Assessment Rating Tool, the Ryan White HIV/AIDS Program was 1 of 7 programs to receive a score of 100 percent in the area of "program results and accountability." Truly, that is success we can celebrate.

When I tell people I was PRENATALLY INFECTED, they say, "You look wonderful for someone who [has been living with HIV] for 22 years."

—Angel Jenkins, Consumer
Bronx–Lebanon Hospital Center
Bronx, NY

The Bronx has the lowest per capita income ($10,514) and lowest median household income ($24,769) of any New York City borough.

In the South and Central Bronx, more than 95 percent of people with HIV/AIDS are African-American or Latino.

The estimated HIV rate in the Bronx (67.6 per 100,000) is the highest of all New York City boroughs.

From January through June 2009, Bronx–Lebanon served 1,856 people living with HIV/AIDS.

Bronx–Lebanon offers wrap-around, co-located primary care and support services in addition to clinical trials.

HIV/AIDS prevention and education programs targeting high-risk populations exceeded their targets in 2009.

Quality improvement initiatives have led to improved and expanded services tailored to client needs.

Case Study: Bronx–Lebanon Hospital Center AIDS Program

Synonymous with sky-high buildings, world-class culture, and fashion, Manhattan ranks as America's most visited metropolitan area.[7] Across the river, however, is New York's 16th Congressional District—the South Bronx. It is the country's poorest district: Approximately 42 percent of residents live below the Federal Poverty Level,[8] and nearly 37 percent struggle to buy food.[9] It is, quite literally, a tale of two cities.

"The South Bronx is the epicenter of many epidemics in this country," explains Edward Telzak, chief of infectious diseases and director of the AIDS program at Bronx–Lebanon Hospital Center, a Part C grantee. He adds, "Our community has some of the highest rates of HIV, hepatitis C, diabetes, and heart disease."

Bronx–Lebanon Hospital Center's Division of Infectious Diseases has 1,856 HIV-positive patients, up to one-third of whom had an AIDS-defining condition when they entered care. Many factors can cause people to delay diagnosis and treatment. "In high-poverty areas like ours, there are high rates of alcoholism and substance abuse; diagnosed and undiagnosed mental health issues; homelessness and substandard housing; issues related to hunger and nutritional status; and a hierarchy of needs, like providing clothing for your children, that can make accessing medical care seem less important," says Telzak. "There are also high levels of HIV stigma in the populations we serve," he notes. The South Bronx has high concentrations of West African immigrants, Hispanics, Caribbean-Americans, and African-Americans.

The South Bronx is a federally designated Medically Underserved Area as well as a Health Professional Shortage Area, meaning that there aren't enough health services or health providers there to meet the community's needs.* Against this backdrop the Bronx–Lebanon Hospital Center shines like a beacon of hope for the underserved, including people living with HIV/AIDS. The hospital opened its

*A "Medically Underserved Area" is an area in which residents have a shortage of personal health services. A "Health Professional Shortage Area" has a shortage of medical care, dental, or mental health providers.

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doors more than 100 years ago with a commitment to community service and high-quality health care to those in need, regardless of the ability to pay. Bronx–Lebanon is, in short, the consummate Ryan White grantee.

"We deliver first-rate care in a high-need community," says David Ferris, a Bronx–Lebanon internist who provides medical care to many people living with HIV/AIDS who come into the hospital. "It's all here, everything a patient needs. It's a one-stop shop."

The hospital has worked hard to provide comprehensive services, but for many staff that goal feels like a moving target. Because effective antiretrovirals are keeping people healthier longer, the population of clients has aged. So not only is Bronx–Lebanon meeting the treatment needs of people living with HIV/AIDS, it has made the decision to add

new services and specialties for its older patients, such as gastroenterology and otolaryngology (ear, nose, and throat).

Over time, hospital staff saw patient trends that were affecting care. One of those trends was lack of access to specialized care outside the Bronx–Lebanon Hospital Center system. Many medical specialists do not accept uninsured or Medicaid-insured clients, making it difficult for patients to get services. Another trend was in no-show rates for scheduled appointments. "What we've learned over the years," says Telzak, "is that the more services we can co-locate, the more comprehensive our offerings are in one location, the more likely patients are to make use of them."

Addressing those needs meant the Bronx–Lebanon team had to establish a large mental health program and create services for HIV patients such

as pain management and intensive case management. The addition of "patient navigators" who accompany clients to appointments has also helped retain people in care.

To serve other specialized client needs, the hospital has brought on an obstetrician and nurse–midwife specialized in high-risk pregnancies, as well as a dermatologist and a neurologist. Moreover, Bronx–Lebanon offers opportunities for all of its HIV patients to participate in cutting-edge clinical research, an area of medicine that has historically had low minority participation. And to ensure a constant pipeline of prepared doctors ready to step up, the hospital has a teaching component to address the special needs of people living with HIV/AIDS.

"We use the strengths around us," says Ferris. The team also has built strong

The Bronx–Lebanon team has gone to great lengths to build up service offerings and create a comprehensive care program under one roof. Because antiretrovirals are keeping patients healthier longer, the hospital has added new specialties to meet the needs of aging clients, like Jose Febus (left with Jennifer Marciano), and Clarence Collins with clinician Eugenie Joseph (right).

relationships with visiting nurses, the health department, and community-based organizations that provide housing. "We don't have a cookie-cutter approach. We create a program and adapt it to fit the particular needs of our clients," Ferris adds.

In addition, the hospital's prevention and outreach workers have ventured into more than 1,000 locations across the Bronx, where—based on internal reporting over a 6-month period—they distributed some 740,000 condoms and conducted more than 800 HIV tests. "We have a real presence in the community," says Telzak.

Talk to anyone on the hospital's infectious disease team, however, and it quickly becomes clear that their presence is not limited to the community. It also extends into the lives of the patients they treat. "We have an HIV-positive patient who has had the disease for 21 years," explains Jennifer Marciano, administrative director of the AIDS program. "During that period he has gotten cancer. He was struggling as a single man with no family, so our clinic became his family." Marciano adds, "He's found support through our programs, where he's met other men and women who have HIV. They may not have family, but [here] they're not alone."

There is a true sense of pride among the team at Bronx–Lebanon in the work being accomplished on behalf of people living with HIV/AIDS. Ferris says, "When I graduated from Columbia University and had to cross the river into the Bronx, I wasn't sure what I was going to find." But he is quick to add that "patients would be hard-pressed to find better care and support services than those offered at Bronx–Lebanon Hospital Center."

"Despite a resource-strapped community outside this hospital, our team has made the program resource rich," Ferris says. "All the tools I need to succeed are here [, and] HIV patients have access not to one doctor but to an entire team."

It's this reality—an extensive group of providers creating a full continuum of care—that Telzak touts as one of the hospital's greatest accomplishments and one of HIV care's most powerful lessons. He would know. Telzak has been at Bronx–Lebanon for more than 20 years and has helped build the AIDS program from the ground up.

"In the outpatient clinic, patients aren't just living—they're thriving," says Ferris, "[and] we're grateful to HRSA and Ryan White, because I don't know how we would provide care to this population without them."

I was really sick, but I came to Boriken, and THEY WERE PATIENT WITH ME, and I thank God for that.

—Richard Colon
President, Consumer Advisory Board
Boriken Neighborhood Health Center
East Harlem, NY

Thirty-nine percent of residents in East Harlem live below the Federal Poverty Level; 63 percent live below 200 percent of the poverty level.

Thirty one percent of people living with HIV/AIDS in East Harlem report a history of injection drug use.

Forty-two percent of HIV patients at Boriken are also diagnosed with hepatitis C.

Although relatively small, the Boriken Center offers fully bilingual medical and support services.

Through a phased-in capital renovation project, Boriken is on target to expand its support services; pediatric care; and Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program.

One-hundred percent of Boriken HIV patients are screened for hepatitis.

Monthly patient education sessions focus on the importance of treatment adherence.

Case Study: The Boriken Neighborhood Health Center

East Harlem, in New York City, is also known as "El Barrio" (the neighborhood). Once largely Puerto Rican, the community is now becoming gentrified. Small, family-run shops are being replaced by chain stores and restaurants. Tenements are being refurbished as condominiums, and new, luxury buildings have supplanted vacant lots. While roughly 60 percent of all area residents will continue to live in public housing, the influx of upper middle-class residents is starting to dilute the community's unique cultural feel.

Some landmarks, however, have remained longstanding. For example, the Boriken Neighborhood Health Center has been in this community for the past 36 years. The name "Boriken" is the indigenous word for Puerto Rico and signals both the clinic's culturally competent approach and its bilingual services.

In addition, Boriken has had very little staff turnover. When patients come for care, they see the same faces over and over. There's comfort in going to a place where people know you and your history. That is why clients like Richard travel across the city to receive care at Boriken. He grew up in this neighborhood. The staff who treat him today are the same people who supported him during a long battle with substance abuse and who gave him aggressive and, ultimately, successful HCV treatment.

"I didn't know what I was going to do," says Richard. "I was really sick, but I came to Boriken, and they were patient with me, and I thank God for that." Richard has also helped bring his wife Isabel into care here at Boriken. "I see the dentist, the OB/GYN, the nutritionist, and I see Dr. Milano for my HIV," says Isabel. "It's beautiful. You're not going to find a place like this. Everything I need is here and I'm feeling good; I'm getting healthy, and I have my husband by my side."

Richard and Isabel are two of just over 200 HIV-positive clients who receive their services at Boriken. And those services extend far beyond HIV to include everything from geriatrics to pediatrics to dental care to dermatology. For example, East

PERSEVERANCE

The outreach program run by the Boriken Neighborhood Health Center distributes health and HIV testing information throughout Harlem. Outreach workers re engage out of-care patients and help educate new contacts about the wide array of services available at the center.

Harlem residents have the highest asthma diagnosis rates in the United States and are disproportionately affected by diabetes and heart disease. To address those conditions, Boriken established asthma and diabetes education services and hired a nutritionist.

"A lot of our patients have issues with disclosure of their HIV status," says Danielle Milano, Boriken's HIV clinical services director. "They come here because they feel safe; people don't know what they're here for because there's no mention of HIV anywhere in the clinic." Patients at Boriken include not only Puerto Ricans but also large numbers of Mexicans, Dominicans, African-Americans, and African immigrants.

"The patients here are representative of the trends in HIV," says Milano. "Our newly diagnosed HIV patients are young African-American or Hispanic MSM [men who have sex with men] and very young African-American women. This is the face of the epidemic in America."

Milano explains that most patients at Boriken are poor and have low levels of educational attainment. "Many can't read or write," she says. To address the issue of health literacy, staff review all information with each client in his or her preferred language.

Issues related to poverty plague the patient population here. As a result, Milano describes the case managers as the most important members of the team. "We have good linkages," explains Crimilda Rivera, Boriken's director of social services. "Patients let me know what they need, and I work to ensure that they have access to it. We have connections to family shelters, substance abuse counseling, and food pantries. If our HIV patients don't have insurance, then we get them on ADAP so they can get on their meds and stabilize their health."

Maria Delgado, a Boriken social worker, agrees. "Between our services and our referral system, it's truly comprehensive care, and we work hard to keep patients in those services. We have an outreach

program that's focused on letting people know we exist and educating them about health issues. We've also found that patients lost to follow-up will see our outreach team and come back to us."

Boriken's outreach workers distribute condoms and pass out pamphlets about the clinic and its services as well as information about sexually transmitted infections including HIV. Outreach workers conduct presentations in community areas frequented by high-risk populations and alert community stakeholders about HIV testing days.

Recently, Boriken hosted its annual "Livin' La Vida Sana Health Fair," attended by several thousand community residents who benefitted from not only health education but also dental, weight/body mass index, and blood pressure screenings; referrals to services; and rapid HIV testing. In addition, Boriken collaborated with other community partners for a forum on health advocacy and client access to free and low-cost medications.

Boriken has also created tailored approaches to particular subpopulations. For women, for example, Boriken has collaborated with the Latino Commission on AIDS Latinas Por La Salud Project to offer a series of educational interventions to meet the particular needs of this population. In addition to bilingual services, Boriken offers child care and transportation assistance to ensure attendance of interested clients. The center also offers pediatric care and support services such as the WIC program.

As part of a continued effort to evolve with the changing and growing needs of its clients, Boriken is in the process of relocating to a renovated building just across the street. This move will enable the clinic to expand its services. To date, Boriken has already received approximately $4 million in support for the new site through Federal, State, and local sources.

The clinic has also adopted a walk-in policy so that if patients fall ill, they can get in to see a doctor. If they need to talk, then case managers like Crimilda are around to listen. "I try to be that friend that they've been looking for," says Crimilda. "I listen with my heart as well as my ears," she says. One look in Crimilda's office and it's easy to understand why patients feel at ease here. Plastered across a large corkboard are inspirational quotes and stories that are meant to empower patients to reclaim their health. What Crimilda has found, however, is that her work has also inspired many patients to reclaim their lives.

"Some of my patients are going back to school," says Crimilda. "One of my patients opened their own business, and another came by yesterday to tell me she got a promotion."

It's the health care services that get patients in the door, but the clinic's self-described family and community-driven mission is what keeps people coming back. "Patients know they can count on us, and we're persistent," says Crimilda. "We're not going to give up on them, and that means a lot."

Boriken clients Anibal Beltran (R) and Victoria Lazu (L) on a neighborhood street near the health center.

Innovative Models of Care: Our Latest SPNS Initiatives

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Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color

O

Innovations in Oral Health Care

L

Enhancing Linkages to HIV Primary Care and Services in Jail Settings

V

Enhancement and Evaluation of Existing Health Information Electronic Network Systems for PLWHA in Underserved Communities

E

Funding Our Future

2010 Ryan White HIV/AIDS Program Appropriations (in $ millions)

Part A	679.1
Part B	1,253,800.0
(State Formula Grants)	(418.8)
(State ADAP)	(835.0)
Part C	206.8
Part D	77.8
Part F: AETCs	34.8
Part F: Dental	13.6
Part F: SPNS	25.0
Total Funding	2,290,900.0

3. Our Quest Continues

The Challenges We Still Face

The Ryan White HIV/AIDS Program enters a new decade stronger and more vibrant than ever. Our team stands on the shoulders of those who fought AIDS with few resources at a time when the path was much less clear. Yet make no mistake, many hurdles are ahead of us:

- There is still no vaccine or cure for HIV disease.
- Approximately 56,000 new HIV infections occur in the United States each year.[11]
- Roughly 1 in 5 HIV-infected people are unaware that they have HIV.[12]
- Treating HIV patients who are aging is becoming increasingly complex and costly.
- Although we distributed more than 175,000 medications through ADAP in 2009, and although it is the largest financial component of our program, some States continue to have waiting lists.[13]

Our team, however, is as strong and committed as ever to addressing these and other challenges. We go into neighborhood after neighborhood to reach the underserved. We unite with consumers to break through impediments

HRSA IS LEADING THE WAY

IN SETTING THE STANDARD FOR

THE KIND OF CARE AMERICANS SHOULD GET.

Peter Gordon, Medical Director
SelectHealth, New York, NY

to progress and health. We constantly reassess how we work and perform, looking for even the smallest improvements and for the next big breakthrough.

The $2.29 billion Ryan White HIV/AIDS Program comprises many different initiatives, hundreds of grantees, thousands of provider organizations, and an ever-stronger multitude of people determined to face down America's AIDS crisis. With our services, we touch an estimated 529,000 people living with HIV/AIDS every year. The results are clear: We are running the good race, but there are many miles to go.

Capturing the Promise of Technology

The promise of technology for HIV/AIDS care is extraordinary in our age, and in many ways, our community is out in front. By the mid-1990s, the Ryan White HIV/AIDS Program was using telemedicine to train clinicians in remote locations across the country. In 1997 and 1998, we combined audio and video conferencing capabilities and satellite broadcasting to train thousands of clinicians on the applications of HAART. Since then, we have used technology in a range of applications, all for the purpose of building a more efficient, responsive, and successful program.

We are only just beginning. Throughout the private sector and government, major investments are being made to advance the development and use of technology in health care. The SPNS Program is conducting an initiative called Enhancement and Evaluation of Existing Health Information Electronic Network Systems for PLWHA in Underserved Communities (see hab.hrsa.gov/special/itplwha_index.htm). And on April 2, 2010, HHS Secretary Kathleen Sebelius announced 28 grants totaling $267 million to establish Health Information Technology Regional Extension Centers.

One of the most powerful weapons in our HIV/AIDS care delivery system is the use of peer educators like Intake Coordinator and former Peer Graduate Yvonne Gooden of the AIDS Service Center NYC. Peers teach, counsel, and reach out to clients. They help counter shortages of health care professionals. And they influence the direction of future programs through insights into what works and what needs to be changed.

In 2004, the national health care bill was estimated at $1.79 billion; an estimated 31 percent of those costs were administrative.[14] As in other industries, technology has the power to improve service and efficiency, decrease the amount of time in which we are able to respond to need, and reduce errors and administrative costs associated with health care delivery. The new HHS centers will help expand health information technology and support the use of health information technology in local communities. (See www.hhs.gov/news/press/2010pres/04/20100406a.html.)

The power of technology reaches far beyond administrative tasks to the very heart of our work—to the lives of people living with HIV/AIDS. Although technology brings new challenges, such as issues of confidentiality, synergy across data collection software, and provider capacities in technology development, there remains much promise.

In our transient society, personal electronic health records allow patients to store their health information, keep it with them, and share it with a range of providers. Technology can strengthen adherence and can be used by patients to monitor their health at home rather than at a clinic. Health information technology can improve provider communication and accuracy of information to ensure that programs achieve their objectives and patients receive the highest quality care.

Building Our Team

Every team is quite naturally engaged in competition for talent, expertise, commitment, and vision. In the health care industry, competition is intense, and acute shortages of physicians, nurses, and other health care professionals are projected to continue in the coming years. In HIV care, shortages are a confluence of three key factors:

- An increase in the demand and scope of HIV services
- Declining supply of experienced HIV clinicians and primary care physicians willing to treat HIV
- Flat or falling reimbursement rates and public funding.[15]

According to a 2008 survey of Ryan White–funded clinics, 69 percent of clinics reported difficulty recruiting HIV clinicians and 51 percent of clinics reported up to a 25 percent increase in caseloads.[16,17] These difficulties are particularly acute in some areas. The number of Health Professional Shortage Areas now totals 13,725 (including primary care, dental, and mental health care). Underserved areas have an estimated shortage of 7,000 primary care physicians.[18,19]

Once people decide to enter the health care profession, in many areas of specialization they find themselves in high

demand. They also encounter many communities in need of their skills or clinics that are at or above capacity in the number of patients they treat. These circumstances can lead HIV professionals to burn out, causing staff turnover and exacerbating clinic needs. In this environment, we know that our large Ryan White HIV/AIDS Program team will not naturally rebuild itself.

HRSA has undertaken several initiatives to address this issue. It has increased HIV management curricula and training opportunities for providers; convened an HIV/AIDS workforce meeting with clinicians, researchers, State health department officials, and health care funders to develop a plan of action; and funded a health information center that features news on upcoming trainings, funding opportunities, and State and other resources (see healthworkforceinfo.org).

In addition, HRSA is funding a quantitative assessment of the supply of clinicians and other key personnel in the Ryan White HIV/AIDS Program and the impact of supply on the delivery of services. The data from this assessment will further assist HRSA in proactively addressing the workforce shortage so that people living with HIV/AIDS have access to high-quality care today and well into the future.

Continuing Our Pursuit

The demand for excellence was innate in HIV/AIDS care pioneers. At first they addressed simple, yet horrible, problems, like replacing staff who refused to bathe AIDS patients with those who would. When intensive care unit staff balked at caring for AIDS patients, the pioneers built inpatient units staffed by people who provided the kind of care that patients deserved.

The demand for excellence in AIDS care is not merely something that funders and administrators require of us. It is something that we have always demanded of ourselves and *for* those in our care. Ara Parseghian, the former University of Notre Dame football coach, once said, "A good coach will make his players see what they can be rather than what they are." Visualizing what we can become—and then becoming it—will be a prime determinant of our future success.

Decades into the AIDS epidemic in America, we're not an inexperienced team any more. We are time tested and proven, having journeyed through many years of learning and growth. We have the wisdom and know-how that come from study and hands-on experience. We have the cohesiveness that comes from long-term collaboration. We are strengthened by diversity and breadth in our skills and perspectives.

Our journey has toughened us, and we have the capacity to both foresee obstacles on the horizon and respond to changes that no one saw coming. We have been trained to address the challenges posed by AIDS today, and we have the mechanisms in place to retool and retrain as circumstances demand. We have displayed the determination to *be* more for our patients as well as to *do*

more. We have accomplished our goals by broadening the array of partners with whom we work and deepening our commitment to address the many critical issues that affect the health and well-being of the patients in our charge. And we continually reassert our commitment to *do* more and to *be* better.

One way in which we're fulfilling this promise is through leadership in helping to implement *Healthy People 2010,* an ambitious Federal collaborative to address the Nation's most pressing health issues, including substance abuse, mental health issues, access to health care, and responsible sexual behavior (see www. healthypeople.gov/lhi). We also stand poised and ready to adapt to the changes that a national HIV/AIDS strategy and health care reform will bring.

With HIV disease, there's no certainty where the road will lead. We know only that our work is not done. Addressing HIV/AIDS is difficult but that's also why we've become so strong as a program and as providers. Despite constant barriers, we've managed to achieve miraculous victories. We have never chosen what is easy—rather, we've chosen what is right. We have been, and will continue to be, emboldened. So as we enter our third decade together, in providing care and treatment for people living with HIV/AIDS, we stand committed to meet both today's challenges and tomorrow's unknown demands. And we will continue our pursuit of the same mission that drove the enactment of this program 20 years ago: delivering the highest quality care for people living with HIV/AIDS.

I'm my own HEALTH ADVOCATE....I have ACCESS to some of the BEST HEALTH CARE.... [and] I have this program. This is THE FUTURE.

—Danny, NYPS SelectHealth Client
with Esmerlin Valdez, Continuity of Care
Record (CCR) Project Community Coach
New York, NY

Fifty percent of SelectHealth s target population is Latino, and 43 percent is African-American.

Coordinating hospital information technology with regional health information exchange networks is a complex undertaking.

Access to core health information via My Health Profile is now available to nearly 1,300 SelectHealth patients, care providers, and case managers.

 Computer 101" and "Introduction to My Health Profile classes are offered to all patients to improve computer and self-efficacy skills.

The project is already demonstrating better patient care coordination and communication among providers.

Case Study: SelectHealth, New York–Presbyterian Hospital System

"A [client] of mine ended up in the emergency room and couldn't speak because his asthma was so severe," says Esmerlin Valdez of New York–Presbyterian Hospital System's SelectHealth program. "He pulled out his My Health Profile card and they could look up his information on any computer with an Internet connection." Valdez explains that because of this access, "they didn't have to run unnecessary lab tests, and during his stay in the hospital, they knew exactly what medications he was on so they were able to keep him on the correct antiretrovirals without interruption."

My Health Profile transmits, via a secure Internet connection, patient core clinical, demographic, and care coordination data to provide "a snapshot in time." The technology making this possible is a Continuity of Care Document (CCD), which SelectHealth created for its HIV patients under a HRSA SPNS grant and implemented into an existing health information network.

"Unlike a comprehensive electronic medical record, a CCD isn't exhaustive," explains Peter Gordon, medical director of Select-Health. "It isn't always necessary to see everything about a patient. What a CCD does is aggregate a patient's critical information." An important part of the My Health Profile project includes allowing patients, in addition to providers and case managers, to access their CCD, thereby promoting patients' self-efficacy as they negotiate the health care environment.

To access their health information, however, many patients must first learn how to operate a computer. "I was computer illiterate before," explains Bobby, a member of SelectHealth, "but then I went through the training and it was so easy." The project has found that it is increasing computer and health literacy, resulting in a more educated and engaged patient population.

"We thought the project would empower patients, and it has. Patients are learning to use the computer, and they're learning about their own health," says Eli Camhi, executive director of Select-Health. "It's changed the patient's role in health care. Instead of being reactive, they're proactive."

INNOVATION

Danny, a SelectHealth patient, agrees. "I'll go in there and say, 'You gave me medicine with these side effects. What else is out there?' I've built a doctor–patient relationship. I'm not intimidated to ask questions because he's in a white coat. . . . [I] have the confidence now to ask those important questions and make changes to better my health."

According to Gilad Kuperman, who oversees NYCLIX, a health information organization working with SelectHealth, "The goal of [this system] is to make data more broadly available. As a health provider, you usually only have access to your own data, but now you have a more complete picture of care services being accessed across the care spectrum."

Explains Camhi, "Most doctors think they're the sole provider, but looking at a CCD built upon a functioning health information exchange, they can see that the patient has many different doctors and case managers. It can be a catalyst for stimulating all participants involved in a patient's care."

One of the promises of the system is that it can help improve quality and coordination (e.g. reduce duplication of servic-

es). Another is the ability of providers to see what medications are being prescribed—including prescriptions written by other practitioners—and what medications patients are actually filling. CCD is more than living up to its promise.

Through shared data, the system offers increased ease and effectiveness of outreach and retention efforts. "If a patient's address is wrong or their phone number has changed," says Valdez, "we can update it, which is great, because if someone in the system is looking for them but unable to reach them, now they can."

And patient access to this information has correlated to improved—and expedited—enrollment in support services. "Patients will say, 'I needed housing and I had to show documentation of my HIV status. They had a computer, and I could show them right there and get my benefits,'" says Camhi.

SelectHealth's ability to use the promise of technology to improve care standards symbolizes, in many ways, how the Ryan White HIV/AIDS Program has evolved. One Ryan White component that has never changed, however, is its

approach to treating the whole person. SelectHealth shares in this belief, and it partners with community organizations like the AIDS Service Center NYC to ensure that patients feel confident not only in their health care but in their lives.

Whereas SelectHealth offers HIV care, the AIDS Service Center NYC (ASC)—one of SelectHealth's many partners in the community—offers case management, mental health services, and other resources for people living with HIV/AIDS. At ASC, clients like Bobby enroll in a 6-month peer training program. Through paid internships, they become community leaders, performing outreach work to educate others about HIV testing, prevention, and care.

The center also sponsors a creative writing support group, where the participants get together to discuss their work. They also give poetry readings at a local bookstore and see their writing published in a periodical that is produced by the center.

ASC Executive Director Sharen Duke observes, "Our partnership with Select-Health is a powerful testament to the impact of medical care by HIV spe-

ASC, a SelectHealth partner, promotes many forms of client empowerment, including a creative writing support group. Shown here are ASC clients reading their work at a local bookstore.

cialists [in conjunction with] the [support services] work that we do in the community, on the streets, and in clients' homes to help keep individuals in care." Taken together, the array of services that HIV-positive patients are able to access within this network have much to teach the rest of America about what is possible in health care.

And if the innovative work of SelectHealth and its community partners like ASC is any indication of what's to come, Danny says, "The future is going to include better managed patient care." He leans into his chair, shakes his head, and explains, "I'm my own health advocate. I have a good patient–doctor relationship. I have access to some of the best health care there is [and] I have this program. This is the future [and] it's bright."

GARY SNEED AND VANESSA SULLIVAN ARE TRAINERS FOR ASC'S ACTIVE PEER PROGRAM, WHERE PEOPLE LIVING WITH HIV/AIDS REACH OUT TO THE COMMUNITY TO EDUCATE OTHERS ABOUT THE DISEASE.

4. Ryan White HIV/AIDS Program
Data Summary*

On October 30, 2009, Title XXVI of the Public Health Service Act was amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111–87). The legislation was first enacted in 1990 as the Ryan White CARE Act and was amended and reauthorized in 1996, 2000, and 2006. The Program is administered by HAB, and its goal is to improve the availability and quality of health care and supportive services for low-income and medically underserved individuals and families living with HIV/AIDS.

Ryan White HIV/AIDS Program services are intended to reduce the use of costly inpatient care, increase access to care for underserved populations, and improve the quality of life for people affected by the HIV/AIDS epidemic. The Program works toward these goals by funding local and State programs that provide HIV primary medical care, medications, and support services; health care provider training; and technical assistance to help funded programs address implementation and emerging HIV care issues.

This section of the Progress Report focuses on the services Ryan White–funded grantees and their providers organizations delivered in calendar years (CYs) 2007 and 2008, the most recent years for which complete data are available. It emphasizes 2008 data and highlights any notable changes from 2007. Readers are referred to the tables and figures accompanying this report for detailed information on both years.

Background

In 2007, HAB implemented the standardized Ryan White HIV/AIDS Annual Data Report (RDR), formerly known as the Ryan White HIV/AIDS CARE Act Data Report (CADR), to collect comprehensive information from all Ryan White HIV/AIDS Program grantees and service providers. The data allow HAB to examine and understand how Program funds are being used to deliver health care services to people living with and affected by HIV.

All Ryan White HIV/AIDS Program grantees and service providers are required to submit an RDR to HAB in March of each year. Like its predecessor the CADR, the RDR collects data from service providers on the following areas of interest:

- Characteristics of provider organizations
- Number and characteristics of clients
- Types of services provided and the number of clients receiving those services as well as the number of client visits by type of service.

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* In years past, the Ryan White HIV/AIDS Program Data Summary Report has appeared as a separate document.

Agencies and organizations that provide HIV counseling and testing services report on the number of people receiving those services. Since 2005, AIDS Drug Assistance Program (ADAP) grantees have reported data on ADAP clients, medications purchased and dispensed, funding received, drug pricing, and expenditures. This information is provided to HAB on a quarterly basis.

Data Limitations

Given the structure of the RDR, the specific Ryan White HIV/AIDS Program that funded a particular set of client services cannot be determined. Although service organizations may be funded by multiple Ryan White HIV/AIDS Program parts, providers are required to complete only one RDR that includes information on all services provided, regardless of the funding source. In addition, the utility of RDR data is limited by duplicated client counts: Because the RDR does not collect client-level data with unique identifying information, it cannot be determined whether clients served by one provider are included in the counts of other service providers. Thus, aggregating the provider data to the national level, as in this summary, results in duplicated client counts.

Providers, Clients, and Services Received

Each year, nearly 550 Ryan White HIV/AIDS Program grantees and more than 2,100 service providers submit reports on the services they provided to people living with HIV/AIDS during the previous year. These data provide insight into the broad impact of the Ryan White HIV/AIDS Program. In CY 2007, 881,700 duplicated clients received one or more Ryan White HIV/AIDS Program–supported services and a total of 892,673 duplicated clients received Program-funded services in 2008. The data in this report describe the HIV primary medical care and support services provided through the Ryan White HIV/AIDS Program, the types of organizations providing the services, and the demographic characteristics of people receiving services in CYs 2007 and 2008.

The RDR provides important insights into the populations served by the Ryan White HIV/AIDS Program grantees and providers. A total of 2,234 Ryan White-funded service organizations reported data for 2007, and 2,157 organizations reported data for 2008.* The data are presented in the sections that follow.

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* The number of organizations vary from year to year as a result of changes in grantee contracting.

Types of Organizations Funded

In 2007 and 2008, a variety of organizations provided Ryan White HIV/AIDS Program services (Table 1 and Figure 1). A majority of providers in both 2007 and 2008 (43 percent) were community-based service organizations (CBOs). The next most common provider types were hospitals and State and local health departments, followed by other facilities and publicly funded community health centers. The remaining provider types, none of which exceeded more than 4 percent of the total, consisted of substance abuse treatment centers, and publicly funded community mental health centers.
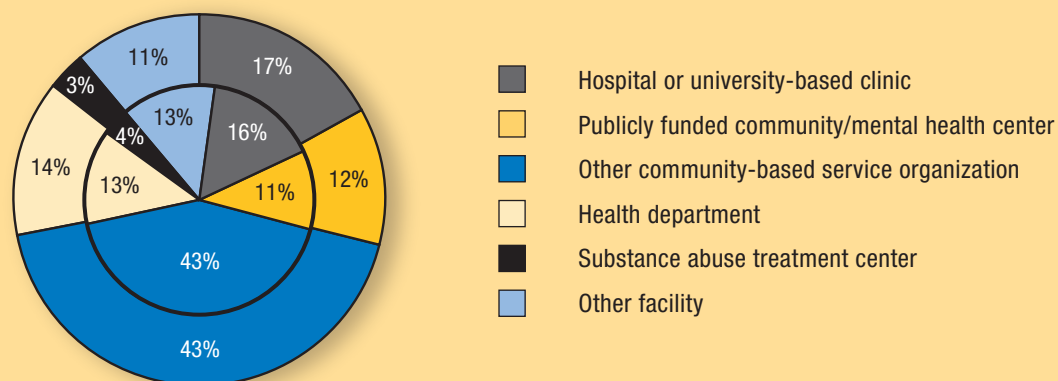
TABLE 1. TYPES of PROGRAM PROVIDERS*

Provider Type	2007		2008	
	Total	Percentage	Total	Percentage
Hospital or university-based clinic	355	16	370	17
Publicly funded community health center	226	10	234	11
Publicly funded community mental health center	23	1	25	1
Other community-based service organization	953	43	923	43
Health department	298	13	297	14
Substance abuse treatment center	85	4	71	3
Other facility	294	13	237	11
Total	2,234		2,157	

* Percentages may not total 100 due to rounding.

FIGURE 1. TYPES of PROVIDERS: 2007 and 2008 COMPARISON*

Inner Circle = 2007; Outer Circle = 2008
2007 *N* = 2,234; 2008 *N* = 2,157

- Hospital or university-based clinic
- Publicly funded community/mental health center
- Other community-based service organization
- Health department
- Substance abuse treatment center
- Other facility

* Percentages may not total 100 due to rounding.

Ownership Status

Ryan White HIV/AIDS Program providers include public and private organizations (Table 2). Approximately two-thirds of providers (67 percent in 2007 and 68 percent in 2008) are private, nonprofit organizations, and approximately one-quarter are publicly owned (local, State, or Federal).

TABLE 2. OWNERSHIP STATUS of PROGRAM PROVIDERS*

Ownership Status	2007		2008	
	Total	Percentage	Total	Percentage
Public, local	331	15	335	16
Public, State	203	9	200	9
Public, Federal	16	1	15	1
Private, nonprofit	1,503	67	1,464	68
Private or profit	134	6	94	4
Unincorporated	8	—	4	—
Other	39	2	42	2
Total	2,234		2,154	

— = Less than 1 percent.
* Percentages may not total 100 due to rounding.

Source of Program Funding

Organizations completing an RDR were asked to indicate which Ryan White HIV/AIDS Program Parts funded the services that they delivered. Organizations may receive funding directly from the Federal government as a Ryan White HIV/AIDS Program grantee, through a subcontract with a Ryan White HIV/AIDS Program grantee, or through Program Part B funding from a consortium agency. Providers frequently receive funds from more than one Part, and they often receive funds from additional, non-Ryan White sources. Of the 2,157 providers submitting data for 2008, 1,213 received Part A funds; 1,160 received Part B funds; 444 received Part C funds; and 263 received Part D funds. Of the 2,234 providers that submitted data for 2007, similar proportions reported receiving each type of funding (Table 3).

In 2008, 24.5 percent of providers received funds from two Program sources; 6.8 percent ($n = 147$) received funds from three Program sources, and less than 2 percent ($n = 35$) received funds from all four Program sources. More than two-thirds of providers in both years (68.2 percent, $n = 1,523$ in 2007, and 67.1 percent, $n = 1445$ in 2008) received funds from a single Program source. (Data not shown.)

TABLE 3. SOURCE of PROGRAM FUNDING*

Source	2007		2008	
	Total	Percentage	Total	Percentage
Part A	1,237	55	1,213	56
Part B	1,202	54	1,160	54
Part C	448	20	444	21
Part D	276	12	263	12

* Percentages may not total 100 due to rounding.

Provider Staffing

Many Ryan White HIV/AIDS Program providers rely on both paid and volunteer staff (Table 4). In 2007, 1,992 providers reported that a mean of 7.4 paid, full-time equivalent (FTE) staff were funded by the Program, and 613 providers reported a mean of 15.7 volunteer FTE staff. In 2008, 1,894 providers reported a mean of 7.6 paid FTE staff, and 572 providers reported a mean of 14.9 volunteer FTE staff. Providers reported a small decline in volunteer staffing from 2007 to 2008.

CLIENT INFORMATION

(Duplicated) Clients Served

In 2007, Ryan White HIV/AIDS Program providers served 881,700 duplicated clients, including 230,821 duplicated new clients (Table 5). In 2008, providers served 892,673 duplicated clients, including 245,292 duplicated new clients. In both 2007 and 2008, 90 percent of the clients served were HIV-positive clients, and 10 percent were HIV affected. HIV-positive clients include those diagnosed with HIV or AIDS as well as children under age 2 for whom HIV status is indeterminate. HIV-affected clients include affected family members who are HIV negative as well as clients whose HIV status is unknown.

The term "duplicated" reflects the circumstances under which providers report data for services that clients receive. Many clients receive services from more than one provider during the reporting period and, as a result, may be represented more than once in the report. The aggregate data that service providers and grantees are mandated to report to HAB annually also limit the ability to assess quality of care.

TABLE 4. PROVIDER STAFFING

	Number of Providers	Mean FTEs* per Provider	Range
2007 Staffing			
Paid	1,992	7.4	.01–128.30
Volunteer	613	15.7	.04–4500.00
2008 Staffing			
Paid	1,894	7.6	.01–114.00
Volunteer	572	14.9	.05–5000.00

* FTE = full-time equivalent.

TABLE 5. CLIENT GENDER, AGE, and RACE/ETHNICITY*

	2007		2008	
Characteristic	N = 881,700	%	N = 892,673	%
Gender				
Male	581,457	66	591,299	67
Female	287,333	33	291,195	33
Transgender	5,702	1	6,328	1
Unknown/unreported	7,208	—	3,851	—
Age (years)				
<2	7,815	1	7,383	1
2–12	15,971	2	14,462	2
13–24	60,176	7	60,069	7
25–44	406,401	47	393,559	45
45–64	362,393	42	386,409	44
≥65	19,823	2	21,893	2
Unknown/unreported	9,121	—	8,898	—
Race/Ethnicity				
White (not Hispanic)	239,281	28	236,775	27
Black or African-American	413,262	48	408,125	47
Hispanic or Latino(a)	175,583	21	194,492	22
Asian	6,907	1	9,279	1
Native Hawaiian/other Pacific Islander	1,613	0	2,014	<1
American Indian/Alaska Native	4,597	1	7,320	1
More than one race	13,862	2	11,657	1
Unknown/unreported	26,595	—	23,011	—

* Unknown/unreported is not included in percentages. Percentages may not total 100 due to rounding.

Gender

In both 2007 and 2008, 67 percent of duplicated Ryan White HIV/AIDS Program clients were male, 33 percent were female, and less than 1 percent were transgender (Table 5). For both years, the gender distribution varied by HIV status: Among duplicated HIV-positive clients, more than two-thirds were male and just under one-third were female (68 vs. 31 percent). In contrast, 51 percent of HIV-affected clients were male, and 48.5 percent were female.
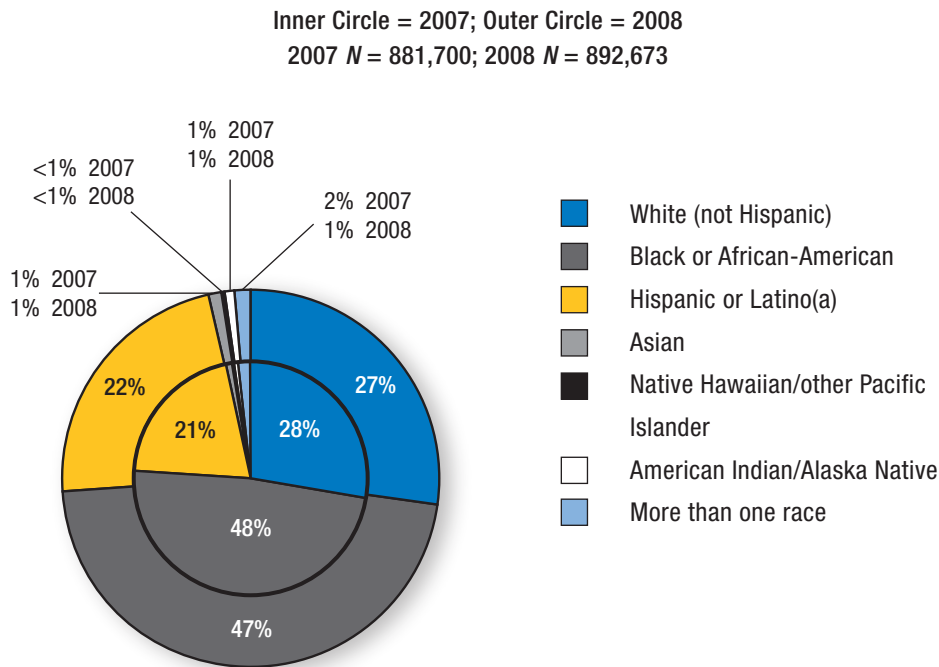
Race and Ethnicity

Seventy-two percent of clients in 2007 and 73 percent of those seen in 2008 self-identified as racial or ethnic minorities. As seen in Figure 2 and Table 5, a majority of HIV-positive clients in 2008 (47 percent) were African-American/Black, and 22 percent were Hispanic/Latino(a); 27 percent of clients were White. One percent of clients self-reported more than one race in 2008. Proportions were similar for 2007.

Differences were noted in racial/ethnic composition among HIV-positive and HIV-affected clients. Whites composed 27 percent of the HIV-positive clients in 2008 but only 19 percent of the HIV-affected clients. (Proportions are nearly identical for 2007). In 2007, 48 percent of HIV-positive clients and 56 percent of HIV-affected clients were African-American/Black. In 2008, however, African-American/Black clients made up 47 percent of the HIV-positive clients and 48 percent of the HIV-affected clients.

In 2007, 21 percent of HIV-positive clients and 22 percent of HIV-affected clients were Hispanic or Latino(a). In 2008, 22 percent of HIV-positive clients and 29 percent of HIV-affected clients were Hispanic or Latino(a). (Affected clients not shown.)

FIGURE 2. RACE/ETHNICITY: 2007 and 2008 COMPARISON of HIV-POSITIVE CLIENTS*

Inner Circle = 2007; Outer Circle = 2008
2007 *N* = 881,700; 2008 *N* = 892,673

1% 2007
1% 2008

<1% 2007
<1% 2008

2% 2007
1% 2008

1% 2007
1% 2008

22%

21%

27%

28%

48%

47%

- White (not Hispanic)
- Black or African-American
- Hispanic or Latino(a)
- Asian
- Native Hawaiian/other Pacific Islander
- American Indian/Alaska Native
- More than one race

* Unknown/unreported is not included in percentages. Percentages may not total 100 due to rounding.

As seen in Table 5, the majority of clients are 25 to 44 years old (2007 = 47 percent; 2008 = 45 percent) and 45 to 64 years old (2007 = 42 percent; 2008 = 44 percent).

The trend toward an increasing number of older clients ages 45 to 64 continues. From 2004 to 2008, a marked decrease in the number of clients ages 25 to 44 occurred along with a corresponding increase in the number of clients ages 45 to 64 (Figure 3). Whereas 34 percent of clients served in 2004 were ages 45 to 64, this age group grew to 44 percent of clients in 2008. In the same period, the percentage of clients ages 25 to 44 declined from 53 percent to 45 percent. The increase in the percentage of clients in the older age group may reflect that HIV-positive people are living longer because of antiretroviral treatments. Less than 3 percent of clients in 2007 and 2008 were age 12 or younger, and youth ages 13 to 24 constituted 7 percent of all clients.

FIGURE 3. AGE of CLIENTS, by YEAR, 2004–2008
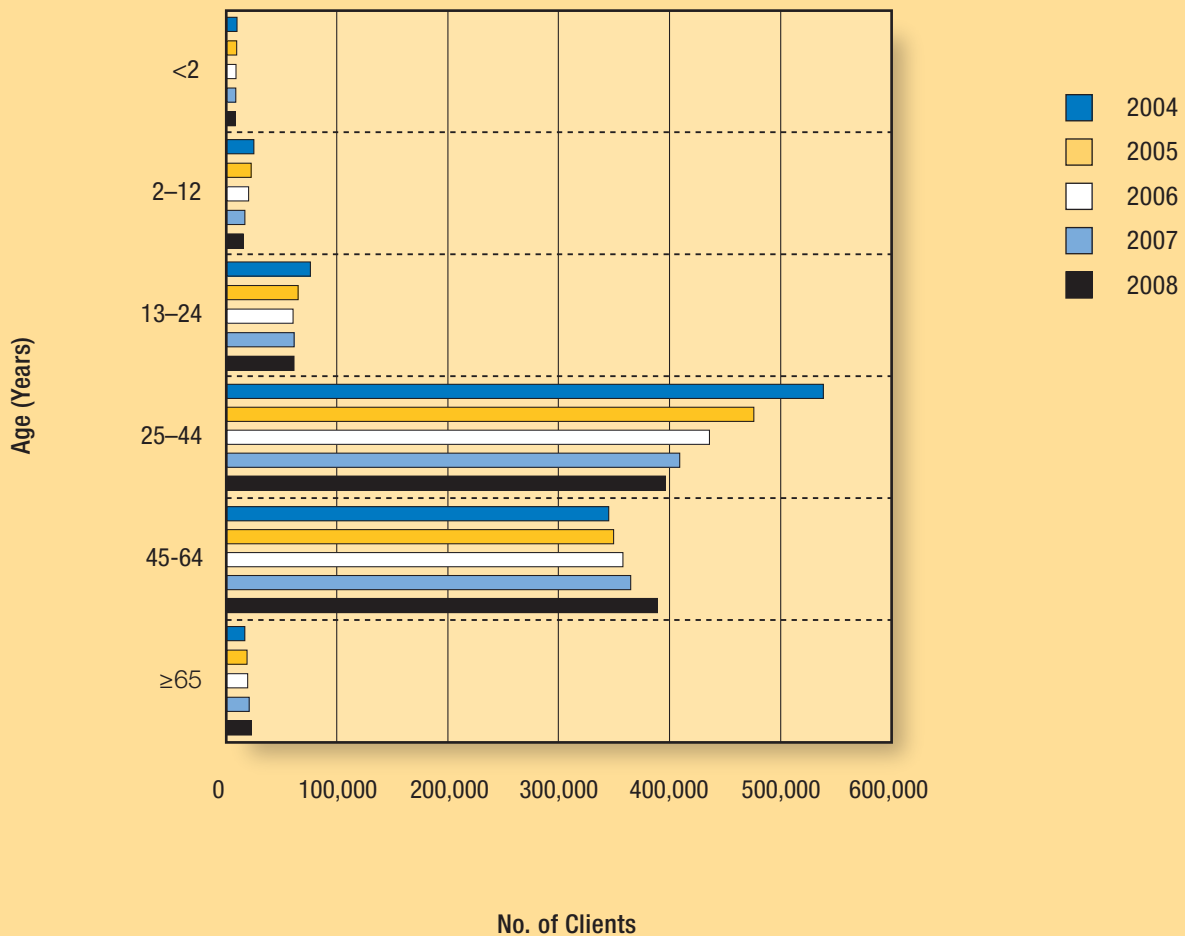
No. of Clients

Household Income

The percentage of clients with income at or below the Federal Poverty Level (FPL) was 68 percent in 2008 (Table 6). Twenty-two percent of HIV-positive clients reported household income between 101 and 200 percent of FPL in 2008; 70 percent of clients reported household income at or below FPL; and 20 percent had income between 101 and 200 percent of FPL in 2007.

Housing Arrangements

Providers reported that among all Program clients in 2007 and 2008, 79 percent had permanent housing arrangements and 14 percent were nonpermanently housed (Table 6). Just over 3 percent of all clients lived in institutions. The proportion of clients reporting "other living arrangement" increased from 3 to 4 percent between 2007 and 2008. HIV-positive clients were more likely than HIV-affected clients to be permanently housed.

TABLE 6. CLIENT HOUSEHOLD INCOME and HOUSING ARRANGEMENTS*

Client Characteristic	2007 N = 881,700	%	2008 N = 892,673	%
Household Income				
Equal to or below FPL[†]	497,339	70	493,432	68
101–200% FPL	142,917	20	157,396	22
201–300% FPL	42,752	6	45,764	6
>300% FPL	25,125	4	26,499	4
Unknown/unreported	173,567	—	169,582	—
Housing Arrangements				
Permanently housed	565,337	79	586,238	79
Non-permanently housed	103,215	14	105,791	14
Institution	24,596	3	24,252	3
Other	24,477	3	29,476	4
Unknown/unreported	164,075	—	146,916	—

* Unknown/unreported is not included in percentages. Percentages may not total 100 due to rounding.
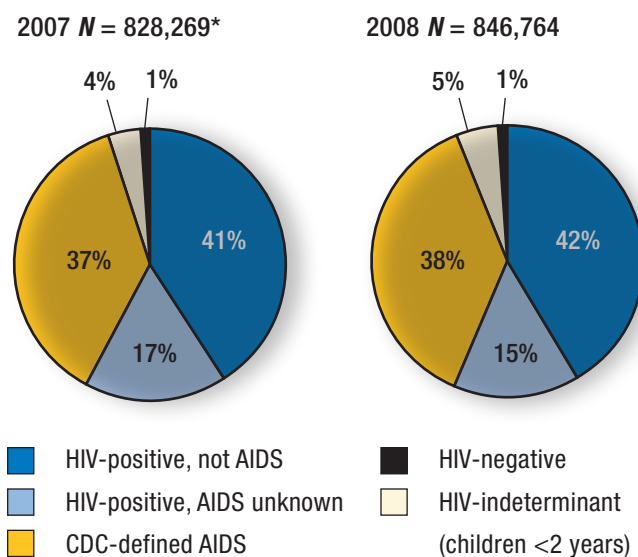[†] FPL = Federal Poverty Level

HIV/AIDS Status

Most clients receiving Ryan White HIV/AIDS Program services in 2007 and 2008 were in one of three HIV/AIDS status categories (Table 7 and Figure 4):

- HIV-positive, not AIDS (42 percent in 2008)
- CDC-defined AIDS (38 percent in 2008)
- HIV-positive, AIDS unknown (15 percent in 2008, a decrease of 3 percentage points from 2007).

Five percent of clients in 2008 were HIV negative, and HIV status was unknown for another 5 percent of clients in 2008.

FIGURE 4. CLIENT HIV STATUS*

2007 N = 828,269*
4% 1% 41% 17% 37%

2008 N = 846,764
5% 1% 42% 15% 38%

- HIV-positive, not AIDS
- HIV-positive, AIDS unknown
- CDC-defined AIDS
- HIV-negative
- HIV-indeterminant (children <2 years)

* Unknown/unreported is not included in percentages. In 2007, there were 53,431 clients whose HIV status was unknown/unreported; in 2008, there were 45,909. Percentages may not total 100 due to rounding.

Health

In 2008, the proportion of Ryan White HIV/AIDS Program clients providers covered by publicly funded medical insurance was 55 percent: 34 percent of clients were Medicaid recipients, just over 12 percent were covered by Medicare, and 9 percent had health care coverage through other public programs (Table 7; note that response categories are not mutually exclusive, a client may report more than one type of insurance). In 2008, 30 percent had no medical insurance, and 12 percent of clients had private medical insurance. Similar health insurance status characteristics were reported for 2007.

TABLE 7. CLIENT HIV STATUS and HEALTH INSURANCE STATUS*[†]

	2007 N = 881,700		2008 N = 892,673	
	n	%	*n*	%
HIV/AIDS status				
HIV-positive, Not AIDS	340,825	41	359,498	42
HIV-positive, AIDS unknown	140,868	17	123,979	15
CDC-defined AIDS	306,541	37	318,211	38
HIV-negative	33,903	4	38,852	5
Unknown/unreported	53,431	—	45,909	—
Health insurance and coverage status*				
Private	84,870	11	94,491	12
Medicare	92,445	12	98,278	13
Medicaid	254,871	34	262,076	34
Other public	57,952	8	67,297	9
No insurance	239,731	32	234,004	30
Other	19,002	3	21,327	3
Unknown/unreported	132,829	—	115,200	—

*Response categories are not mutually exclusive.
[†] Unknown/Unreported is not included in percentages. Percentages may not total 100 due to rounding.

SERVICE UTILIZATION

Health Care Service Utilization

The most frequently utilized Ryan White HIV/AIDS Program services in both 2007 and 2008 were case management and ambulatory/outpatient medical care services (Table 8). Program case management providers reported serving 309,824 duplicated HIV-positive and HIV-affected clients through more than 2.65 million client visits in 2008. Case management services include initial assessment of service needs; development of a comprehensive, individualized service plan; coordination of client services; and periodic reevaluation and adaptation of the individualized service plan over the life of the client.

TABLE 8. NUMBER of DUPLICATED CLIENTS SERVED and VISITS for HEALTH CARE and CASE MANAGEMENT SERVICES

	2007 N = 881,700		2008 N = 892,673	
	Duplicated clients, *n*	Total Visits	Duplicated clients, *n*	Total Visits
Core health services				
Ambulatory/outpatient medical care	371,187	2,183,627	384,990	2,150,715
Mental health care	81,576	477,554	84,722	556,971
Oral health care	80,601	243,421	86,446	285,380
Substance abuse services, outpatient	37,074	407,745	31,557	388,783
Home health care	3,260	48,615	2,915	43,568
Home and community-based health services	3,422	137,349	3,147	138,985
Medical case management	279,867	2,347,537	309,824	2,651,246

Providers reported serving 384,990 duplicated HIV-positive clients through more than 2.15 million outpatient/ambulatory medical care services client visits in 2008. In addition to HIV primary care, this category of service utilization includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, and other related activities.

Clients frequently used three other health care service categories: mental health, oral health, and outpatient substance abuse treatment services (Table 8). Outpatient substance abuse services are defined as medical treatment and counseling to address substance abuse problems provided by or under the supervision of a physician in an outpatient setting. For 2008, the following utilization statistics were reported:

- 84,722 clients utilized mental health services in 556,971 visits.
- Service agencies provided oral health care services to 86,446 clients in 285,380 visits.
- Outpatient substance abuse treatment services were used by 31,557 clients in 388,783 visits.

Visits per Client by Service Category

In 2007 and 2008, substance abuse and medical case management services had the highest average number of visits per client* (Table 9). In 2008, providers of outpatient substance abuse services reported an average of 17.3 visits per client, and medical case management providers reported an average of 11.0 visits per client. Ambulatory/outpatient medical services clients averaged 5.7 visits in 2008, and clients of mental health care services averaged 6.8 visits. Finally, for oral health care services, the average number of visits per client was 2.5 in 2008. The proportions are similar for all service categories for 2007.

TABLE 9. VISITS per CLIENT by TYPE of SERVICE

Type of Service	2007				2008			
	Number of Providers	Average Visits per Client	Median Visits per Client	Range	Number of Providers	Average Visits per Client	Median Visits per Client	Range
Ambulatory/outpatient medical care	870	5.9	4.6	1–97	861	5.7	4.8	1–73
Mental health care	772	6.0	4.2	1–52	769	6.8	4.3	1–153
Oral health care	568	2.4	2.0	1–22	556	2.5	2.1	1–17
Substance abuse services, outpatient	413	18.4	6.1	1–365	401	17.3	6.0	1–350
Medical case management services	931	10.8	6.9	1–277	1,016	11.0	7.4	1–178

* Visits for substance abuse treatment services may be higher as a result of daily administration of treatments such as methadone.

Ryan White HIV/AIDS Program providers deliver an array of supportive services to HIV-positive and HIV-affected clients to promote entry into and retention in HIV primary medical care. The total number of duplicated clients receiving supportive services declined in the reporting period (Table 10). In 2008, providers delivered the bulk of support services (duplicated client counts) to HIV-positive clients in the following service categories: nonmedical case management (n = 187,748 clients), health education/risk education (n = 118,103 clients), psychosocial support services (n = 99,064 clients), food bank/home-delivered meals (n = 97,791 clients), and treatment adherence counseling (n = 95,042 clients). Utilization of support services was somewhat different among HIV-affected clients than among HIV-positive clients in 2007 and 2008. Most support services (duplicated client counts) delivered to HIV-affected clients included outreach and nonmedical case management services and services to assist in preventing further transmission of HIV. For all categories of supportive services except outreach, Ryan White HIV/AIDS Program providers reported serving more HIV-positive clients than HIV-negative clients.

TABLE 10. NUMBER of DUPLICATED CLIENTS RECEIVING SUPPORT SERVICES by HIV STATUS

Support Services	2007 N = 881,700		2008 N = 892,673	
	HIV-Positive, n	HIV-Affected, n	HIV-Positive, n	HIV-Affected, n
Case management (nonmedical)	191,836	12,353	187,748	8,064
Child care services	2,132	1,457	1,582	836
Pediatric development assessment/early intervention services	1,925	714	1,887	560
Emergency financial assistance	46,643	2,734	39,361	2,853
Food bank/home-delivered meals	103,612	6,803	97,791	4,776
Health education/risk reduction	122,137	7,780	118,103	7,061
Housing services	35,229	2,085	32,944	1,385
Legal services	19,362	769	18,969	550
Linguistic services	4,702	413	4,755	426
Medical transportation services	79,267	2,152	86,435	2,250
Outreach services	31,658	36,659	32,855	31,458
Permanency planning	4,104	503	1,198	434
Psychosocial support services	102,332	9,317	99,064	7,086
Referral for health care/supportive services	79,544	4,063	81,870	2,112
Rehabilitation services	3,281	48	2,670	69
Respite care	1,635	70	448	11
Substance abuse services, residential	3,067	32	3,082	35
Treatment adherence counseling	94,611	1,738	95,042	1,509

Provider Related Data

In 2008, 731 Program–funded organizations provided HIV counseling and testing services, which include pretest counseling about the benefits of testing, HIV antibody testing, and posttest counseling (Table 11).

Counseling includes providing information on the medical benefits of early HIV diagnosis and treatment. The proportion of providers who used Program funds to support counseling and testing services increased from 57 percent in 2007 to 59 percent in 2008. In 2008, 41 percent ($n = 293$) of providers offered partner notification services, an increase from 2007 (33 percent, $n = 241$). A total of 25,099 infants were tested in 2007; 12,786 infants were tested in 2008 (Table 11).

TABLE 11. HIV COUNSELING and TESTING SERVICES AMONG PROVIDERS

	2007		2008	
Program Characteristic	*n*	%	*n*	%
Program provided HIV counseling and testing services				
Yes	761	37	731	37
No	1,312	63	1,260	63
Total	2,073	100	1,991	100
Program funds supported HIV counseling services				
Yes	433	57	430	59
No	328	43	301	41
Total	761	100	731	100
Program offered partner notification				
Yes	241	33	293	41
No	494	67	422	59
Total	735	100	715	100
Program tested infants				
Number of infants tested during reporting period	25,099	—	12,786	—

Not everyone who receives an HIV test receives pretest counseling. Ryan White HIV/AIDS Program providers delivered pretest counseling services to 1,002,900 people in 2007 and 1,151,100 in 2008 (Table 12). This growth was an 8 percent increase in the number of people receiving pretest counseling from 2006 to 2007 and a 12.9 percent increase from 2007 to 2008. The number of people who re-ceived pretest counseling increased 24 percent from 2006 to 2008. Concurrently, the number of people who were tested for HIV in Ryan White–funded settings in-creased significantly. From 2007 to 2008, the number of people receiving HIV tests from Ryan White-funded providers in-creased 15 percent. More significantly, the number of people tested for HIV in Ryan White–funded settings grew 35 percent from 2006 to 2008. In 2008, 18,489 of peo-ple who received HIV pretest counseling (1.6 percent) tested positive; among those testing positive, more than 90 percent (n = 16,699) received posttest counseling (Table 12).

Ryan White HIV/AIDS Program providers also offered prevention and treatment services to people after testing.

TABLE 12. CLIENTS WHO RECEIVED HIV COUNSELING and TESTING FROM PROGRAM PROVIDERS*

Counseling Status	2007		2008	
	n	%	*n*	%
Received pretest counseling	1,002,900	—	1,151,100	—
Received HIV test with or without pretest counseling	1,021,963	—	1,186,241	—
Positive HIV test	18,099	1.8	18,489	1.6
Positive HIV test; received posttest counseling	15,801	87.0	16,699	90.0

* Percentages may not total 100 due to rounding.

AIDS DRUG ASSISTANCE PROGRAM

Clients

The AIDS Drug Assistance Program (ADAP) provides HIV/AIDS medications to low-income individuals living with HIV dis-ease who have little or no coverage from private or third party insurance. ADAP reported serving 163,925 clients in CY 2007 and 175,194 in CY 2008. As shown in Table 13, the number of clients increased by 11,267 (6.9 percent) over the previous year. The ADAP client population is made up of two components: (1) clients who re-ceive at least one medication and (2) cli-ents who receive insurance to purchase medications. A noticeable increase in both components occurred from 2007 to 2008. The largest increase (16.8 percent) was among clients who were receiving services for the first time.

TABLE 13. COMPONENTS OF ADAP CLIENT POPULATION*

Component	2007	2008	% Change
Total number served	163,927	175,194	6.9
Served for the first time (new clients)	24,079	28,123	16.8
Received at least one medication	135,233	144,615	6.9
Received insurance service	28,694	30,579	6.6

* Categories are not mutually exclusive

Gender

Most clients in 2007 were male (about 78 percent); about 21 percent were female (Table 14). Less than 1 percent were reported as transgender or of unknown or unreported gender. Although the number of clients across gender categories increased notably, the proportions were nearly identical in 2008.

Age

The proportions of the different age groups served by ADAP were roughly identical in 2007 and 2008. Nearly all ADAP clients (about 95 percent) were between 24 and 64 years old. Approximately 50 percent of clients were between ages 25 and 44, and approximately 44 percent were between ages 45 and 64 in 2008.

Race/Ethnicity

About 63 percent of ADAP clients in 2008 were racial/ethnic minorities. Nearly 37 percent were White, 32 percent were Black or African-American, and 27 percent were Hispanic. Racial or ethnic minorities served by ADAP grew 2 percent from 2007 to 2008, largely attributable to a 17.8 percent increase in Hispanics served (Table 14).

TABLE 14. DEMOGRAPHIC CHARACTERISTICS of TOTAL ADAP CLIENTS SERVED*

Characteristic	2007 N = 163,935		2008 N = 175,194	
	n	%	n	%
Gender				
Male	128,526	78	136,606	78
Female	35,059	21	38,155	22
Transgender	296	<1	365	<1
Unknown/unreported	44	—	68	—
Age (years)				
<2	91	<1	66	<1
2–12	285	<1	277	<1
13–24	4,403	3	5,704	3
25–44	84,667	52	88,260	50
45–64	70,604	43	76,809	44
≥65	3,859	2	4,070	2
Unknown/unreported	16	—	8	—
Race/Ethnicity				
White (not Hispanic)	62,623	39	63,727	37
Black or African-American	52,648	33	54,415	32
Hispanic or Latino(a)	39,261	24	46,251	27
Asian	2,070	1	2,198	1
Native Hawaiian/other Pacific Islander	785	<1	282	<1
American Indian/Alaska Native	988	<1	833	<1
More than one race	3,175	2	3,021	2
Unknown/unreported	2,374	—	4,467	—

* Unknown/Unreported data are not included in percentages. Percentages may not total 100 due to rounding.

Funding

ADAP is funded through many sources (Table 15). In addition to Part B ADAP earmark funds (the largest component of Ryan White HIV/AIDS Program appropriations) and ADAP supplemental funds, State ADAPs may receive funds from Parts A and B and other Program sources. In addition, total ADAP funds may include non-Program sources such as Medicaid; Medicare; other Federal, State, or local government funding; other public payments; manufacturer rebates; private contributions; and client payments.

As reported by Part B grantees, ADAPs together received slightly more than $1.5 billion in CY 2007, more than half of which (52 percent, or $775 million) came from the ADAP earmark. During CY 2008, all ADAPs received $1.8 billion in total funding, an increase of more than 20 percent over the previous year.

TABLE 15. ADAP FUNDING SOURCES, 2007–2008

Source	2007 $ Total	2008 $ Total
EMA	16,952,364	29,404,693
Part B Base	155,211,969	317,499,337
State contribution	273,610,088	248,708,459
Carryover	6,907,008	14,782,901
Other funding*	265,239,315	—
Manufacturer rebates*	—	318,355,423
Insurance reimbursements*	—	55,870,768
Earmark	775,320,700	774,025,042
Supplemental	39,477,300	39,718,776
State match	4,648,077	2,564,830
Totals	1,537,352,969	1,800,930,229

* In 2008, the funding source category "other funding" was eliminated and replaced with "manufacturer rebates" and "insurance reimbursements."

Expenditures

States and Territories reported total ADAP expenditures of nearly $1.3 billion in CY 2007 and slightly more than $1.4 billion in CY 2008 (Table 16). The largest part was for the purchase of pharmaceuticals: 89.6 percent in 2008. A sizeable proportion also was used to pay insurance premiums, co-pays, and deductibles for clients. Expenditures also paid for grantees' administrative costs and fees for dispensing medications. In addition, funds were used for activities to enhance the ability of eligible people living with HIV/AIDS to gain access to, adhere to, and monitor their progress in taking HIV-related medications. This policy is referred to as the ADAP Flexibility Policy.

TABLE 16. ADAP EXPENDITURES*

Source	2007		2008	
	$ Total	%	$ Total	%
Pharmaceuticals	1,166,544,563	90.7	1,294,704,727	89.6
Administration and dispensing fees	29,222,746	2.3	33,884,538	2.3
Insurance	84,242,247	6.6	108,208,192	7.5
Adherence	2,318,612	<1	4,258,475	0.3
Accessibility	577,681	<1	1,332,104	0.1
Monitoring	3,033,228	<1	2,225,056	0.2
Total	1,285,939,077	100.0	1,444,613,092	100.0

* Percentages may not total 100 due to rounding.

Notes

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For more information

The Ryan White HIV/AIDS Program is administered by the U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. To find out more about the Ryan White HIV/AIDS Program and for access to tools that support providers of HIV/AIDS services, visit hab.hrsa.gov.

Free copies of this report are available online or from the HRSA Information Center, 1-888-ASK-HRSA.

"The AIDS battlefield is so large and yet these doctors, my case manager, they go to battle for me. This is a small clinic, but they do the job of a large hospital. They gave me good care when I had nowhere else to go. They treated me like family."

—Ronald, Consumer,
Philadelphia Fight, Philadelphia, PA