

The POWER of CONNECTIONS



2008 Ryan White HIV/AIDS Program Progress Report







THE TRANSFORMATIVE POWER OF HEALTH CARE REVEALS ITSELF IN WONDROUS WAYS:

In a grandmother dressing her grandchild for school
In a middle-aged man living free of addiction
In a young person mentoring his peers.

Through the Ryan White HIV/AIDS Program, that power reaches underserved people living with HIV/AIDS by transcending barriers that often define access to health care in the United States. The program touches people who just happen to have been born on the wrong side of the poverty line: people in neighborhoods with too few health care providers or people whose most immediate emergencies may not be medical treatment but a place to sleep at night and food for their families.

THE RYAN WHITE HIV/AIDS PROGRAM REDUCES DISPARITIES IN ACCESS TO HEALTH CARE FOR MORE THAN HALF A MILLION PEOPLE EACH YEAR.

This strategic success is the result of many tactical successes: enrolling people in care—and keeping them there; paying for essential services; and reaching people whom other payors don't.

These successes offer lessons applicable far beyond HIV/AIDS. In them lies irrefutable evidence that we can provide health care to the poor and underserved. We can build capacity in communities with a shortage of health care resources. We can reach outside our own experience to understand and respect the perspectives, experiences, and values of the host of cultures that make America what it is.

OUR SUCCESSES ARISE FROM THE POWER OF CONNECTIONS.

Our successes arise from connections among providers who piece together a vibrant fabric of health care services; connections among government agencies, local organizations, and private citizens, debating yet always collaborating to fill holes in systems of care; and connections between providers and consumers working in concert to build better care and better lives.

LEARNING the ALPHABET

RYAN WHITE HIV/AIDS PROGRAM: FY 2007 Funding and Number of Grantees

PART A



Grants to Eligible
Metropolitan Areas
\$414,344,578
22 grantees



Grants to Transitional
Grant Areas
\$122,300,326
34 grantees

PART B



Care Grants to
States and Territories
\$405,954,000
59 grantees



Grants to
Emerging Communities
\$5,000,000
14 grantees



AIDS Drug Assistance Program Grants
to States and Territories
\$814,798,000
59 grantees

PART C



Early Intervention
Services
\$180,091,123^a
357 grantees



Capacity Development Grants
\$2,069,202^b
25 grantees

^aIncludes MAI funding.

^bRecommended funding level.

PART D



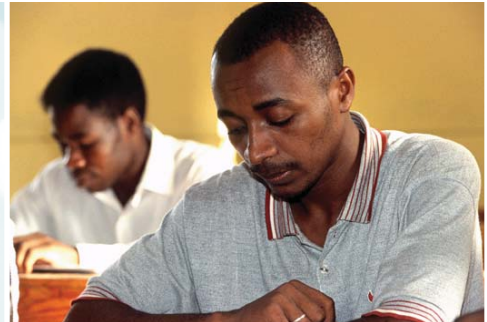
Services for Women, Infants, Children, Youth, and Their Families
\$67,996,135^a
90 grantees

PART F



Special Projects of National Significance
\$21,077,598 and 50 grantees
• • •
AIDS Education and Training Centers
\$33,177,624 and 15 grantees
• • •
Dental Programs:
Reimbursement Program
\$9,198,395 and 65 recipients
Community-Based Dental Partnership Program
\$3,319,803 and 12 grantees
• • •
Minority AIDS Initiative (MAI)
Part A: \$42,041,430 and 56 grantees
Part B: \$6,739,600 and 30 grantees
Part C: \$53,863,145 and 205 grantees
Part D: \$17,073,812 and 59 grantees
Part D Youth: \$1,430,541 and 10 grantees
Part F AETC: \$8,500,000 and 12 grantees

GLOBAL HIV/AIDS PROGRAM



Implements the international portfolio of the President's Emergency Plan for AIDS Relief (PEPFAR in collaboration with other U.S. agencies)
• • •
Supports organizations around the world in their efforts to
- Strengthen clinical systems
- Develop human resources for health
- Develop capacity
- Deliver HIV care and treatment
• • •
Funded through the PEPFAR legislation:
\$15 billion over a 5-year period from 2004 to 2009.



The depth of HIV/AIDS medical services at Albuquerque’s Truman Street Clinic “was a key factor in my decision to move,” says Kenneth, shown with Bruce Williams, M.D., a strong advocate for community-based, comprehensive care.

PART C EARLY INTERVENTION SERVICES, ALBUQUERQUE

UNIVERSITY/HOSPITAL MEDICAL CENTERS

FEDERAL/COMMUNITY MIGRANT HEALTH CLINICS

CITY/COUNTY HEALTH DEPARTMENTS

NONFEDERAL HEALTH CENTERS AND CLINICS

I. Reducing Health Disparities

KENNETH, 35, WAS DIAGNOSED WITH HIV/AIDS IN 1999, AFTER BEING tested while applying for life insurance. He says he was probably infected in 1997 but didn’t seek medical attention right away.

“I wasn’t avoiding talking about the ‘elephant in the room.’ I was dealing with other things I needed to deal with, because I wasn’t sick at that time,” he says. Kenneth says he spent his retirement and savings because he was sure he wouldn’t live long enough to need them. In 2002, when he did get sick, he found himself having to navigate the often cold waters of care and case management with no resources. “Even though I was so sick, I just kept going. Every day I just told myself to keep living,” he says of those trying times.

With his health rapidly declining, Kenneth decided that it was important to get quality care from providers who listened to him and responded to his needs. He researched his options and learned about the depth of HIV/AIDS medical

services provided by the University of New Mexico Health Sciences Center's Truman Street Health Clinic. "It was a key factor in my decision to move to Albuquerque," he says.

Because Kenneth had no health coverage, he was eligible for care through the Part C Early Intervention Services Program of the Ryan White HIV/AIDS Program. It's been 6 years since Kenneth enrolled in care at the Truman Street Clinic. Thanks to his care team, his determination to stay well, and a medication regimen that is working for him, his viral load is undetectable. He's also proud to say that he is working and has employer-sponsored health insurance. "I've come a long way," he says.

Results Out of Balance

Without the Ryan White HIV/AIDS Program, Kenneth might have become another person lost to health disparities. Uninsured, like 47 million other Americans, his lack of coverage could have led him and his health into a precipitous decline.¹

Health disparities in America are directly associated with health coverage. In her testimony before Congress on April 15, 2008, Diane Rowland, Sc.D., of the Henry J. Kaiser Family Foundation, captured the situation succinctly: "Having health insurance makes a difference in whether, when, and where people get needed care. The uninsured are more likely to postpone or forego needed care and preventive services than the insured."²

Study after study echoes Rowland's assertions. For example, a *Medscape Medical News* headline from April 11, 2007, reads, "Uninsured Have Higher Rates of Stroke, Death." The article cites a study in the *Journal of General Internal Medicine* confirming that "individuals without insurance are much more likely to forego routine physical examinations and are less likely to be aware they have high blood pressure, diabetes, or hypercholesterolemia."³

Tragically—and not unrelated to insurance—poor health in America is also predicted by race. The statistics are mind-boggling. African-Americans are twice as likely as their White counterparts to have a stroke; African-American men are 30 percent more likely to die from

ACCORDING TO THE INSTITUTE OF MEDICINE REPORT *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, health care disparities are defined as "differences in the quality of care received by minorities and non-minorities who have equal access to care . . . when there are no differences between these groups in their preferences and needs for treatment."⁴ In addition to differences in quality of care, minorities are disproportionately affected by a host of health care conditions, including heart disease, diabetes, and HIV/AIDS.⁵ In fact, despite continued efforts on the part of health care providers, "disparities are observed in almost all aspects of health care."⁶



Truman Street case manager Tyler McCormick (right) helps review paperwork for an insurance application.



Truman Street therapist Gail Jackson (left) says the clinic takes a holistic view of HIV/AIDS care, including the connections between physical and mental health.



New Mexico AIDS Services (NMAS) is housed in the same building as and partners with the Truman Street Clinic to offer clients a broad array of services. Among these is “Next Step,” shown above, a series of NMAS workshops for people living with HIV and their partners, families, and friends.

heart disease than non-Hispanic White men; Mexican-Americans, the largest share of the U.S. Hispanic population, suffer disproportionately from overweight and obesity.^{7,8} The list goes on to include infant mortality, many cancers, death by accident and, of course, HIV/AIDS.

A Complex Equation

The Ryan White HIV/AIDS Program and many other public programs, using a comprehensive approach to care, are successfully addressing health disparities among the underinsured; racial, ethnic, and sexual minorities; young people; and other populations. These organizations understand that tackling disparities is about more than opening doors to the disenfranchised. It is about what is on the other side of those doors—something embodied in the Truman Street Health Clinic’s approach to making health care more accessible.

The Truman Street Clinic has been providing Part C–funded services since 1991 and is the sole provider of Part D services for women, infants, children, youth, and their families in the entire State of New Mexico. Within its walls, consumers find passionate providers

who collaborate with patients to address the numerous problems that are associated with HIV/AIDS and that often coexist with health disparities.

In 2007, the clinic provided care, including a host of medical, case management, behavioral health, prevention, and social support services, to 881 people living with HIV/AIDS. Because it’s part of the University of New Mexico Health Medical Sciences Center, the team can initiate referrals for specialty care within the system. Eighty-six percent of the clients served are men, and 12.7 percent are women; the clinic also works with the transgendered population and has been successful in bringing young people into care. More than 50 percent of its clients are ethnic

minorities, primarily Hispanics and Native Americans.

Bruce Williams, M.D., has been at Truman Street since the beginning, pioneering the building of a community-based comprehensive care center for people living with HIV/AIDS. Dr. Williams says, “We’ve been able to provide overall unfettered access to care for patients living with HIV/AIDS without regard to gender, cultural differences, or ethnicity.”

The clinic offers a safety net for people who cannot afford care. “Forty percent of our patients are either uninsured or underinsured,” he says. With so many active patients in the case load, Dr. Williams says that he and the staff are starting to feel the strain of a growing demand for services but have nevertheless been able to meet consumer needs and even expand their programs.

For example, the Truman Street team understands the link between physical and mental health. In an effort to decrease all health disparities for which patients are at risk, the staff addresses disparities holistically. Clinic therapist Gail Jackson says that all clients get a

mental health and substance abuse assessment. “Nearly 85 percent of our clients said that they had issues with one or both,” she says. “Through Part C, we have been able to fund two new positions and establish a Behavioral Health Unit to help meet those needs,” Jackson adds.

The Truman Street Clinic shares a building with its partner agency, New Mexico AIDS Services (NMAS). Because NMAS provides testing, case management, and other support services, the shared location improves client access to those services. According to Dr. Williams, Truman Street has imminent plans to open a Youth Clinic to meet the needs of a growing population of young people living with HIV/AIDS in New Mexico. “We not only have young people coming into care because of their own diagnoses, but we also have kids coming from the pediatric clinic who have been positive since birth. As they get older, they need a place to get their primary care,” he says.

Consumers Helping Each Other—and Providers, Too

In December 2007, just months after her wedding, Katrina’s life changed. She was diagnosed with HIV. “Nobody knows,” she says. “Not my family or my husband’s. The stigma and blame [are] so real. We just didn’t want to deal with it.”

care at the clinic. “Older gay men have learned a lot about living with HIV and AIDS over the years. I wish there was a way that we could do more to get together with young women of color who are now dealing with the same issues,” he says. Teddy thinks that bringing the two groups together to discuss the issues would go a long way toward bridging health care disparities. “Sharing can be so important,” he says.

Consumer involvement in building care systems that mitigate health disparities goes beyond consumer-to-consumer relationships. Participating in program evaluation and adaptation to reflect changing needs is also an ideal consumer role. Without consumers’ willingness to give their time, energy, and expertise to address issues such as quality, accessibility, and cultural appropriateness, providers like the Truman Street Health Clinic would find their relevance to some consumers and their capacity to minimize health disparities compromised.

The Truman Street Clinic, like so many other Ryan White HIV/AIDS Program-funded organizations, has formalized a way of capturing consumer input by establishing a consumer advisory board. Dr. Williams and the treatment team depend on this board—whose

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At the Truman Street Clinic, Katrina has learned as much as she can about managing her treatment and the emotional stressors that go with living with HIV—from her providers and from other people who are HIV positive. Peer support among people living with a chronic illness has been shown to be a positive factor in helping them manage the physical and psychological manifestations of disease. It can also help them stay in care. Thus, peer support has a major role to play in reducing health disparities among people living with HIV/AIDS.

A shining example of this kind of support is Teddy. Now in his 50s, he has lived with AIDS for decades. He values the opportunities to share life’s lessons with young women like Katrina who seek their

membership reflects the clinic’s diverse client base—for valuable input on the quality and types of services they offer. In addition to working to help bridge gaps in care, clinic staff are investing in the future of quality care for people living with HIV/AIDS, says Dr. Williams. The staff nurture young physicians and other care providers by creating opportunities for them to work with patients in the clinic.

Dr. Williams says that the commitment of the clients, their work on the board, and the dedication of the staff and their partner organizations make it all come together. “We all work hard to translate what would otherwise be seen as issues into creative problem solving on behalf of our clients,” Williams says.



Brigette (left) and her daughter Melody receive congratulations from nurse practitioner Summer Nijem, as they learn that Melody’s viral load is undetectable.

PART D FUNDING,
ATLANTA

ATLANTA FAMILY
CIRCLE NETWORK

GRADY INFECTIOUS DISEASE
PROGRAM AND OB/GYN

AID ATLANTA

MOREHOUSE
DEPARTMENT OF PEDIATRICS

SISTERLOVE

2. Enrolling People in Care and Keeping Them There

AIDS TOUCHED BRIGETTE’S LIFE AT A MOMENT OF GREAT CELEBRATION—the birth of her daughter, Melody. Brigette, now 44, delivered her youngest daughter at Grady Health Systems in Atlanta, Georgia, more than 17 years ago. Three days later, she found out that her baby had been born with full-blown AIDS. Brigette was immediately tested and found out that she was HIV positive.

Brigette’s experience is like that of many women who lack good health insurance. She had poor prenatal care and was not screened for HIV during pregnancy. Consequently, she was not given the AZT regimen that makes the risk of HIV transmission from mother to infant plummet.

Melody spent most of her infancy in intensive care. “I prayed to God to not let me lose my child,” says Brigette. “I just wanted to fix it for her.” As she prayed for her daughter, Brigette kept putting off her own medical care.

Delay of entry into care is a frequent occurrence among poor and underserved women with HIV. It happens for many reasons, such as stigma, including being ostracized and even abused by friends and family, and the constant presence of more immediate problems, such as the quest for stable housing or the care of an aging parent. For Brigette, her daughter Melody—who has cerebral palsy as well as HIV—was her all-encompassing concern.

Unbroken Links

Brigette and Melody both receive medical care at Grady's Family Clinic. This public facility in the heart of Atlanta has treated HIV-positive patients since 1986. The Family Clinic is part of Grady Health System's Infectious Disease Program (IDP), which ensures access to the latest in HIV/AIDS care and treatment for people who need it.

Jacqueline Muther is Grady's Ryan White Part D project director. She reports an active roster of about 4,800 people receiving services throughout the IDP building. Services include primary and acute medical care, oral health care, mental health care, substance abuse treatment, social services, and nutritional support. Among the clients, more than 2,000 women and children are seen in the Family Clinic. "Because of this wide array of services, combined with a family-centered approach, we have been able to do a great job of not only getting people into care but keeping them in care," Muther says.

The Part D Program was first funded in 1998 and has provided scores of resources for medical care and the kinds of services that help people stay in care. Part D awards target women, infants, children, youth, and their families. In FY 2007, grants totaling \$68 million were distributed among 90 grantees across the country.

The Grady Family Clinic, under the medical direction of Emory University School of Medicine's Department of Pediatrics, is part of the Atlanta Family Circle Network, a group of Part D-funded service providers in the Atlanta area. The Network also includes Grady Obstetrics, AID Atlanta, SisterLove, and the Morehouse School of Medicine. The Network received a total of \$701,462 in Part D funding in 2008. These organizations use their relationships with one another to help women and their families face and overcome barriers that can make staying in care seemingly impossible.

THE PART D PROGRAM FOR WOMEN, CHILDREN, INFANTS, Youth, and Their Families is devoted to delivering family-centered comprehensive care and improving access to clinical trials and research. In FY 2007, 90 grants totaling \$68 million were awarded to providers through this program. Mirroring trends in the epidemic, most Part D clients in 2006 were minority women with heterosexual contact as their exposure category. Specifically, 86 percent of clients were racial and ethnic minorities, 69 percent of Part D clients were women, and 58 percent of clients listed heterosexual contact as their exposure category.



Grady clinicians confer before the day's appointments.



Bobbie, mother of three, lived in secrecy until March 19, 2008, her first day as a peer educator. "Speaking out is my chance to help somebody else overcome the fears you have when you get diagnosed," she says.



Rev. Lisa Diane Rhodes of Spelman College speaks at a recent symposium organized by SisterLove and other Atlanta Family Circle Network organizations to foster understanding of the scientific and social issues surrounding HIV vaccine research.

Building Trust

Being connected to one's provider is more than just a "feel good" proposition. Consider treatment adherence, which is an issue for more than just people living with HIV/AIDS. Research indicates that the average treatment adherence rate for chronic illnesses is about 40 percent. In a 2005 study, dietary adherence rates for people with type 1 and type 2 diabetes were 29 and 27 percent, respectively. It is also estimated that only 19 percent of patients in the general population can adhere to a 10-day course of antibiotics.^{9,10}

Self-reported adherence rates of most patients on highly active anti-retroviral treatment (HAART) are between 56 and 88 percent. Studies show that adherence of less than 95 percent has been linked to treatment failure among people living with HIV/AIDS.¹¹ The consequences of poor adherence to HIV drugs can include drug resistance, viral replication, opportunistic infections, and even death.^{12,13}

Research suggests that connectedness with health care providers, particularly those of the same sex, is important for women and influences the quality of their care.¹⁴ Trust in providers is associated with a number of positive health factors for people living with HIV/AIDS, including increased HIV-related outpatient clinic visits,

fewer emergency department visits, increased use of antiretroviral medications, and improved reported physical and mental health.¹⁵

Building Connections

Part D grantees across the country—and other organizations, too—will tell you that the single most important factor in keeping people in care is a comprehensive approach to what is often an overwhelming array of entrenched problems. No one with HIV/AIDS should have to go it alone—and no organization serving people living with HIV/AIDS should, either. More to the point, they can't. The problems are just too numerous, the needs too diverse.

Collaboration among Atlanta Family Circle Network members reveals a winning approach to keeping women, children, and youth in care. Using connections to draw on the strengths and abilities of a variety of players, the network creates a comprehensive approach to the interwoven challenges faced by underserved women, children, and families living with HIV/AIDS.

AID Atlanta, for example, provides medical case management to HIV-positive women served through the Atlanta Family Circle Network, linking them to social support services and primary medical providers

in and out of the Part D Network. It also assists clients in enrolling in the AIDS Drug Assistance Program (ADAP) and helps identify and address barriers to adherence.

SisterLove, another Family Circle provider, is the oldest community-based nonprofit in Georgia to focus on the needs of women at risk for HIV infection, particularly African-American women. “Our mission is simple to state but not simple to undertake,” says SisterLove founder, Dázon Dixon Diallo. “We strive to reduce the impact of HIV/AIDS and other reproductive health challenges on women and their families in the United States and around the world through education, prevention, support, and human rights advocacy.”

SisterLove supports the Atlanta Family Circle Network’s continuum of services by providing HIV prevention education to approximately 300 African-American women and adolescent men in metro Atlanta whose behavior places them at high risk of HIV infection. They

family to food, housing, and other supports that made care a reality. And powerful conversations between Brigette and caseworkers about the need to stay healthy and care for Melody finally got her to make the decision to start medication 14 years ago.

“At first,” Brigette recalls, “I was scared to start meds because I heard about some of the side effects.” Over the past 14 years, her providers have changed her regimen several times, but she says the course of therapy she is on now is working well for her. “I come in to see the doctors here every 2 months now and have an undetectable viral load,” she says with a mix of relief and pride.

And Melody? Brigette says that she is a typical teen with a mind of her own. “Melody loves going to school and interacting with her friends,” her mom says. “For a while, she went to the regular teen support groups here for kids with HIV/AIDS but decided that she really liked the camps and retreats the Family Clinic offers better.”

“Speaking out is my chance to help somebody else overcome the fears you have when you get diagnosed.”

also provide two annual clinical research trainings for providers and consumers to promote HIV testing, microbicide development, vaccine awareness, and clinical trials access.

Connecting With Brigette

The relationships among providers in Atlanta have been a solace for Melody since birth. Over time, the same kinds of connections among providers of all kinds of services have helped ensure that Melody’s mom is around to watch her grow up.

Without care for her daughter and without support in addressing her family’s basic human needs, it is impossible to know whether Brigette would have ever enrolled and stayed in care. But Part D of the Ryan White HIV/AIDS Program emphasizes care for the entire family, and people associated with Melody’s care never stopped working with Brigette to overcome her own barriers to care.

From almost the time that Melody was born, family members and Melody’s social worker encouraged Brigette to get into care and manage her own HIV disease. Melody’s caseworker helped link the



SisterLove workshops are dedicated to providing HIV prevention education and outreach programs for women, especially women of color, in metropolitan Atlanta.



Nina Kim, M.D., on board an early morning ferry from downtown Seattle, is a University of Washington physician who practices at a satellite clinic in Bremerton to ease the burden of travel for her HIV-positive clients.

PART B FUNDING,
WASHINGTON STATE

RURAL HEALTH

HARBORVIEW MEDICAL
SATELLITE CLINIC

WASHINGTON STATE/KITSAP
COUNTY DEPTS. OF HEALTH

UNIVERSITY OF
WASHINGTON

3. Reaching People Others Don't

ON A MISTY, CHILLY FRIDAY IN SEATTLE, WASHINGTON, NINA KIM, M.D., AN infectious disease physician, boards the Bremerton Ferry with the small orange biohazard cooler she uses to transport blood work across Puget Sound. She is headed to Bremerton, where she'll see patients in the satellite clinic of the Madison Clinic at Seattle's Harborview Medical Center.

Before the satellite clinic opened in late 2007, patients in Bremerton and surrounding areas found traveling to receive care a tremendous physical burden. Trips to the Madison Clinic in Seattle and back can take more than 8 hours, including two hour-long ferry trips, commutes to and from the dock to Harborview Medical Center, and the time spent in the Madison Clinic waiting and examination rooms. The intensity of the travel required to get to Seattle for appointments would take its toll on most healthy people, let alone those dealing with a complex disease like HIV/AIDS.

Dr. Kim says the new clinic has brought people back into care by easing the burden of travel. The satellite clinic is housed in the Norm Dicks Government Center in downtown Bremerton. It is a partnership of the Harborview Medical Center, the State of Washington, and Kitsap County Health District. "We do it all here," says Dr. Kim.

The Bremerton clinic was the brainchild of Bob Harrington, M.D., the medical director of the Madison Clinic at Harborview Medical Center (HMC), which is owned by King County and run by the University of Washington. Of the roughly 2,000 clients seen at the Madison Clinic, approximately 50 were traveling from the western part of Puget Sound before the establishment of the Bremerton clinic.

"We were already caring for people in that area, but transportation was an issue for them," says Dr. Harrington. "Our Bremerton patients would often miss appointments." Although the Bremerton Clinic was established as a 1-year pilot project, all involved are hopeful that the Washington State Department of Health (DOH) will continue its support. Dr. Harrington says that DOH and Ryan White Part B funding has "helped us bring established patients back into care by lifting their transportation burden." He adds, "It's also helped us reach HIV-infected people who previously had no care." (For more on Part B, see <http://hab.hrsa.gov/treatmentmodernization/partb.htm>).

Dr. Harrington explains that creating the satellite clinic required the DOH to establish contracts with the Kitsap County Health District and HMC. The clinic space, which is provided by Kitsap County, includes an examination room and conference room. Although the space is comfortable for patients, it was not set up for primary care, so staff have had to be creative in pulling resources together to create a functional primary care clinic—with some help from Ryan White HIV/AIDS Program Part B funding.

According to Dr. Harrington, "DOH and Ryan White funding helps us keep the lights on. It's allowed us to send University of Washington faculty physicians to Bremerton every Friday and to provide medical supplies, a computer, administrative support, maintenance, and a Kitsap County nurse's salary."

PART B AIDS DRUG ASSISTANCE PROGRAM (ADAP) CLIENTS

include people receiving at least one medication through ADAP and people receiving insurance services (premiums, co-pays, or deductibles) that provide access to medical care and medications. ADAP served a total of 157,988 clients in 2006: 84 percent (131,885 clients) received at least one medication through the ADAP, and 16.5 percent (26,103 clients) received insurance services.



Bremerton client Chad with nurse Ellen Arthur says, "It means a lot that I can come and get care minutes away from home . . . and that people here care about me."



Responsible for raising her great-granddaughter, Bremerton client Darlene stresses the role of personal connections in coping with HIV. "This little girl keeps me going," says Darlene. "She's just my joy."



Brian cooks a meal for his caregivers Kerry Dobbelaere (left) and Lisa Linden. “Cooking for people is my way of giving back for all the help I’ve received,” he says.

at Brian and know that just a few months ago, he wasn’t sure he’d survive. He lost his apartment and the ability to live independently when his housing assistance ran out, but he was able to move in with a friend. “It’s my connection to friends that is the biggest factor in my still being here,” he says. “They don’t tolerate silence; they check in to make sure I’m okay.” Brian’s friends have even become involved in his care by meeting his case manager and encouraging him to heed his doctor’s advice.

Brian also values having a network of people actively involved in his care as well as a doctor he can trust. “If I met someone who was recently diagnosed with HIV, I would steer them to this clinic, because being happy with your doctors, like I am, is really important. I’m lucky.”

People living with HIV/AIDS may be out of care for many reasons—from not qualifying for public programs like Medicare to needing services that local organizations don’t provide. But for HIV-positive people in Bremerton and the surrounding areas, the issue was limited HIV care providers in their region. Seattle has experienced HIV providers and support systems, but for people in Bremerton, the nearest specialist might be hours away. Of the nearly 200 HIV-positive people in Kitsap County, 60 had been traveling to Seattle for care, and many others had no HIV care at all.

Brian

Living with HIV since 1999, Brian stayed healthy without medication until 2007, when he became gravely ill with pneumocystic pneumonia and ended up in the hospital. “My doctors and friends were sure I wasn’t going to make it,” he says. He rallied, but he ended up in the hospital again, living on a health roller coaster.

Today, Brian is Dr. Harrington’s patient at the Bremerton satellite clinic. “Before I found out about this clinic, I spent 8 to 10 hours getting to Seattle on the ferry, waiting to be seen, trying to get my meds, and then getting back home,” he says. It’s hard to look

Life Changes in a Moment

Darlene is a great-grandmother raising her 2-year-old great-granddaughter. She is also HIV positive and, at 56 years of age, reflects the rise in HIV/AIDS prevalence among people age 50 and older. Darlene is a patient at the Bremerton clinic, where about one-third of all clients are women.

“Before my diagnosis, I didn’t have any of the things they tell you are risk factors. I wasn’t promiscuous; I didn’t use drugs,” Darlene says. After a divorce, she became involved with a man she met at work. “We stopped having protected sex, but we had ‘the talk’ about HIV status.” It was only after she found a pill belonging to her partner that she called the health department and found out the truth.

“They told me the pill was an antiretroviral. I thought that meant a drug to protect you from getting AIDS. I was shocked when they told me the drug was for people who had HIV or AIDS already.” She immediately was tested. “I waited 2 weeks to get the results—the longest 2 weeks of my life.”* Darlene soon found out that she was infected. That was in 1995. “The virus really knocked me down.”

*Today, the results of rapid HIV testing—administered by many HRSA-funded sites—can be delivered to the patient at the time of testing.

Like Brian, she had been making the trek to Seattle before the Bremerton clinic opened. The trip was long and exhausting, especially with her great-granddaughter, car seat, and stroller in tow. “It was overwhelming to go through traveling and waiting and more travel every time you needed to go to the doctor.” Darlene now only has to drive 15 minutes to get care at the Bremerton clinic.

No Valley Too Low

Nestled within Yakima Valley, celebrated for its fruitful vineyards and orchards, is the small city of Yakima, Washington. HIV-positive people here are surrounded by rich natural and other resources, but accessible and affordable health care is not among them.

With the Ryan White Part B Program, the New Hope Clinic in Yakima has served 254 patients. New Hope is located within the Yakima Valley Farm Workers Clinic, which provides medical and dental care, educational training, substance abuse treatment, nutrition counseling, and other services. It serves predominantly Hispanic, migrant, and seasonal farm workers in rural Washington and Oregon. The clinic is one of the largest of its kind in the Nation.

David Tucker, M.D., was serving those hard-to-reach patients when he was suddenly killed in a car accident in 2007. His death left a huge void for those living in this rural area. “There was no doctor set up to take his place and care for his patients,” says Debra

Adams, program administrator at the New Hope Clinic. Tom, age 57, depended on Dr. Tucker. “Although I was with him a short time, Dr. Tucker made me feel not just like a patient,” Tom says. “He gave me hope, encouragement, and treated me with integrity.” Since Dr. Tucker’s death, Tom and other former patients are being cared for by Neil Barg, M.D., medical director at New Hope Clinic, and his staff. “Dr. Barg has been able to pick up where Dr. Tucker left off. We’ve worked together on adjusting my treatment, something Dr. Tucker had planned to do, and now my virus load is undetectable and my T-cell count has never been this high,” says Tom.

Tom’s victories can be partially attributed to the AIDS Drug Assistance Program (ADAP), which is part of the Part B program. All U.S. States and Territories receive ADAP grants to provide HIV treatment for the underserved. ADAP funding can also be allocated for services that enhance access to, adherence to, and monitoring of drug treatments as well as to purchase health insurance for uninsured people living with HIV/AIDS who would otherwise lack coverage.

Since 1996, ADAP has been the single largest part of the Ryan White HIV/AIDS Program in terms of funding, providing services to an estimated 163,927 people in 2007. Nationally, more than 80 percent of ADAP clients have incomes at 200 percent or less of the Federal Poverty Level. (See also <http://hab.hrsa.gov/treatmentmodernization/partb.htm#ADAP>).



“Once I got my diagnosis, I wanted to go off somewhere so nobody would know,” says this farm worker and client at New Hope. When he found the courage to tell his family, they connected him to the clinic. Today, his viral load is virtually undetectable.



Workshops and conferences, teaching and training programs, formal and informal partnerships and agreements—these many varied interactions are integral to the Ryan White approach to care and help explain its history of success.

AIDS EDUCATION AND TRAINING CENTERS

REGIONAL AETCs

AETC NATIONAL RESOURCE CENTER

NATIONAL HIV/AIDS CLINICIAN CONSULTATION CENTER

NATIONAL MINORITY AETC

INTERNATIONAL TRAINING AND EDUCATION CENTER ON HIV

4. Teaching and Training

WHEN THE AIDS EPIDEMIC BEGAN, IT BROUGHT MANIFESTATIONS AND symptoms that most clinicians had never seen, opportunistic infections rarely encountered, and death rates among young people never witnessed in the industrial age except in war.

And so AIDS brought with it the need to learn . . . and that need continues today. The Ryan White HIV/AIDS Program responds to this need through the AIDS Education and Training Centers (AETCs), a series of regional and national centers that provide training to clinicians across the United States and beyond. (To learn more, see www.hab.hrsa.gov/treatmentmodernization/educating.htm and www.aidsetc.org.)

The magic of the AETCs isn't really magic at all. It is simply another manifestation of what we know about connecting people—in the case of the AETCs, connecting those who know about HIV/AIDS care with those who want to know. It is about interaction among people who are traveling a path of

service, although they may be at different places along that path. It is about the connections that occur among people united in a common cause.

AETC Provider Training Network

AETCs are a network of 11 regional centers and serve all U.S. States and territories. The AETCs and the connections built through them reach into small towns, suburban neighborhoods, and large cities to train clinicians who serve those most in need—minority populations, the homeless, rural communities, and people who are incarcerated. AETCs arm clinicians everywhere with the knowledge they need to educate, counsel, diagnose, treat, and medically manage people living with HIV disease.

During the 2006–2007 grant year, more than 128,000 participants attended AETC training events. Clinicians trained by AETCs have been shown to be more competent with regard to HIV issues and more willing than other primary care providers to treat people living with HIV disease. This knowledge has added enormously to our national capacity to screen for, help prevent, and treat HIV/AIDS.

Helen

Helen Miramontes is one of the world's first trainers of clinicians serving people living with HIV/AIDS. A nurse and mother of six, Helen lived and worked in Northern California when the "strange new disease" emerged. She worked in a hospital and, having two gay sons, stayed in tune with this issue affecting gay men.

"The outbreak of PCP (*pneumocystis carinii* pneumonia) among gay men in San Francisco was a baffling, scientific aberration," says Helen. "So I went to that first AIDS-related meeting in San Francisco in 1982. The big focus was PCP," she explains. "I remember driving to the airport Hilton where the meeting was convened wondering if many people would show up," she says. "Well, the meeting was packed," she remembers with excitement in her voice. "People were leaning against walls, or finding a place wherever they could.

"I knew then that God had led me to nursing because of this disease. I had an overwhelming mission: This is what I was meant to do."

WORLDWIDE, WOMEN ACCOUNT FOR ABOUT ONE-HALF of the 30.8 million HIV cases among adults.¹⁶ The feminization of HIV/AIDS is linked to poverty and other factors that can cause women to be more susceptible to HIV. The Health Resources and Services Administration (HRSA) has been at the forefront of delivering specialized, primary health care to women and educating clinicians about the needs of this population. HRSA's *Guide to the Clinical Care of Women With HIV/AIDS* has become the primary textbook on the subject worldwide. HRSA continues its knowledge-sharing role through the Global HIV/AIDS Program.



A client in Uganda holds a record of her hospital visits and medications received through PEPFAR-funded AIDS-Relief, a consortium led by Catholic Relief Services (CRS).



Once near death, Inongo Kokola recovered her health and now supports three children, receiving medication through CRS partner the Diocese of Mongu, Zambia.



The Ryan White HIV/AIDS Program community has a long history of sharing programmatic and technical know-how through teaching and training activities, like this Denver-based workshop convened last spring to improve program outreach and evaluation efforts.

Beyond Clinical Training

The quest for knowledge found at that conference in 1982 continues, not just for scientific understanding but for programmatic and technical know-how, too. In addition to clinical training through the AETCs, comprehensive technical assistance support—encompassing program design, implementation, and evaluation—is available to Ryan White–funded grantees, planning bodies, providers, affected communities, and people living with HIV/AIDS. To find out more about these services, see the Technical Assistance Resources, Guidance, Education, and Training (TARGET) Center Web site at <http://careacttarget.org>. The TARGET Center reflects the Federal commitment to strengthening local organizations and—through doing so—building better lives for people living with HIV/AIDS.

Experience at Home Helps Give Hope Abroad

Opportunities for learning and building capacity are rich in the United States, but in much of the world, resources are tragically limited and people too often die from entirely preventable conditions like malnutrition, malaria and of course, AIDS.

The United States has a long history of international development and, for decade upon decade, has been the world's leading donor Nation, providing assistance in various fields ranging from agriculture and animal husbandry to water management and energy development. Today, the United States is providing support to help countries address the HIV/AIDS epidemic.

PEPFAR

In 2003, President George W. Bush announced the President's Emergency Plan for AIDS Relief (PEPFAR), a 5-year, \$15 billion U.S. Government initiative (see www.pepfar.gov). PEPFAR aims to provide treatment to at least 2 million people infected with HIV; prevent 7 million new HIV infections; and provide care and support to 10 million

people living with and affected by HIV/AIDS, including orphans and vulnerable children. The annual funding for PEPFAR's efforts has steadily increased since its inception and rose to an all-time high of \$6 billion in FY 2008.

Today, more than 1.3 million men, women, and children in 15 focus countries in sub-Saharan Africa, Asia, and the Caribbean are getting lifesaving antiretroviral medications thanks to PEPFAR. This marks a dramatic increase from the rates of HIV treatment that existed prior to PEPFAR funding. In sub-Saharan Africa, for example, it was estimated that only 50,000 people were receiving treatment for HIV/AIDS when PEPFAR began its work in the region.

The Global HIV/AIDS Program of HRSA's HIV/AIDS Bureau (HAB) is taking the reins in implementing PEPFAR's international services, serving as the third-largest provider of PEPFAR funds to organizations in FY 2007. One of these organizations is the AIDSRelief Consortium, which provides HIV care and treatment at sites across nine countries in sub-Saharan Africa and the Caribbean, including Haiti.

“I had an overwhelming mission. This is what I was meant to do.”

Edna and Adam

Fifteen years ago, Edna and Adam Adnor were among the first people diagnosed with HIV in Fond-des-Negres, Haiti, a mountainous community. The news was nearly a death sentence for the parents of four children. Edna contracted tuberculosis. Adam, a carpenter, battled bouts of a skin disease that kept him out of work for months. “There were times we didn’t think we would survive,” Adam says.

Now Edna and Adam, as well as 2,559 other people living with HIV/AIDS, receive free, lifesaving antiretroviral medications thanks to the AIDSRelief Consortium, which is funded by PEPFAR and supported by the Global HIV/AIDS Program. People living with HIV/AIDS travel up to 75 miles to be seen at the Salvation Army Bethel Clinic in Fond-des-Negres, one of eight AIDSRelief clinical partners that provide voluntary testing and counseling, full medical care, medication, and support services in Haiti. In 2008, an estimated 200,000 people with HIV/AIDS were living in Haiti.

“It was difficult at first,” says Edna of the medication and side effects that made her ill. The AIDSRelief staff helped her cope with the medicines. A Bethel Clinic counselor made house calls to help her through that difficult period, providing support and advice for ways to deal with the illness. They also connected the Adnor family to monthly nutritional support from Catholic Relief Services’s Multi-Year Assistance Program.

It has been 4 years since Edna and Adam began receiving medications. Today, their family is thriving. All four children are in school. Their small, concrete house is filled with shiny pine furniture made by Adam. Edna is selling corn again at the local market. And last year the couple did something they’ve always wanted to do: They got married. “I had the white dress and the decorations and everything,” says Edna, pointing to the brass-framed wedding photo on her dining room hutch. “I know that I’m going to die one day,” she says, smiling. “But I know it’s not going to be HIV that kills me.”

The high quality of care that the Adnors experienced at AIDSRelief is no accident. The Global HIV/AIDS Program provides its grantees with an arsenal of technical assistance and support, and HRSA HAB staff regularly assist grantees with policy, funding, human resources, and outreach activities. This support ensures that the reach of PEPFAR and HAB extends beyond the sharing of financial resources to include the coveted resource of experience—experience gained from almost 2 decades of administering HIV services through the Ryan White HIV/AIDS Program. In this manner, the hard-won knowledge that comes from years of fighting the HIV epidemic on American soil can benefit a new, global audience. Because when it comes to fighting this deadly disease, we are all part of the same movement.



In 2006, after testing positive for HIV and seeing her CD4 count drop to 159 (from a normal level of about 1,000), Penina Petro started on the road to better health with the help of the medications she received from Sekoutoure Hospital, Tanzania, a partner of CRS, under Global HIV/AIDS Program funding.



Staff from local service agencies convene at a Denver coffee shop for the People of Color Retreat—an event devoted in part to building organizational ties to meet the needs of underserved people whether in or out of HIV care.

PART A FUNDING, DENVER
TRANSITIONAL GRANT AREA

MAYOR'S OFFICE OF HIV
RESOURCES & PLANNING COUNCIL

6 COLORADO
COUNTIES

15 SERVICE
PROVIDERS

4,493
CLIENTS

5. New Act Strengthens Local Ties

"I WAS 17 YEARS OLD AND NEWLY MARRIED WHEN I FOUND OUT THAT my husband had HIV and had infected me. A year later he was dead," says Luisa, a 24-year-old, soft-spoken mother of two. When she moved to Denver from Mexico, she connected with a social worker named Maria Lopez. "She was my first case," says Maria, "and we've become great friends." With Lopez's help, Luisa, who still speaks very little English, learned to manage her disease. In fact, she's never missed an appointment.

Today, Luisa is receiving care at La Clínica Tepayac, a Denver provider serving primarily Hispanic clients. In part because of the Ryan White HIV/AIDS Treatment Modernization Act of 2006, which created a new Part A Transitional Grant Area (TGA) program, Denver, a former Eligible Metropolitan Area, is able to continue to support not just a single organization like Clínica but a diverse set of organizations that together create a comprehensive system of care throughout the Denver region.

Service Offerings of the Denver TGA

The creation of TGAs is one of the most significant changes in the 2006 legislation compared with its predecessor, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. In 2008, there were 34 TGAs in the United States and Puerto Rico—in cities with a total population of at least 50,000 and between 1,000 and 1,999 AIDS cases reported in the past 5 years.

In Denver, the TGA program is coordinated by the Mayor's Office of HIV Resources (MOHR). Each year, the Denver HIV Resources Planning Council, appointed by the Mayor, develops a plan for the delivery of HIV/AIDS clinical and support services.

"We use CAREWare to tell us a lot of information about who is getting care and the quality of that care," says Lynn Hough, Program Director of MOHR (see the May 2007 *HRSA CAREAction* at <ftp://ftp.hrsa.gov/hab/may2007.pdf>). "CAREWare is just one of the tools the Planning Council uses to establish service categories, collect and review data to prioritize needs, and allocate and distribute resources," he adds.

The Denver TGA is always looking for innovative approaches to fulfilling the expanding needs of people living with HIV/AIDS. "We've created a type of 'insurance pool' in collaboration with our primary care providers for procedures that typically wouldn't be covered, such as ophthalmology, dermatology, and specialty care," Hough explains. "From the client standpoint, this improves their lives."

Similarly, organizations like Clínica are finding ways of improving health confidence and addressing worries of people like Luisa. "My biggest concern has always been how to care for and protect my children," she says.

Luisa is not alone. Lopez, who is now the project coordinator of the Planning Council, says that the concerns of the women who seek care at Clínica prompted them to conduct a series of workshops to give moms living with HIV/AIDS the parenting and disease management skills they need to care for their children.

KEY CHANGES IN THE RYAN WHITE HIV/AIDS TREATMENT MODERNIZATION ACT OF 2006:

- Required that Part A, B, and C grantees spend at least 75 percent of funds on "core medical services"
- Added or included HIV cases in funding formulas
- Codified the Minority AIDS Initiative in Part F
- Created TGA structure to fund midsized cities
- Provided authority to recover unobligated balance amounts and redistribute to areas most in need

See also www.hab.hrsa.gov/treatmentmodernization.



Planning Council member Christopher Smith (left) and coordinator Maria Lopez with MOHR's Lynn Hough.



In addition to its counseling sessions, Denver's Mile High Meth Project hosts informal get-togethers, including "coffee talks" in neighborhood gathering places.

Flexibility to Care for Patients

Mark Thrun, M.D., is co-chair of the Planning Council. He is also an infectious disease physician who is the director of prevention at Denver Public Health. Dr. Thrun says that one of the real powers of the Part A TGA-supported programming is that “it allows us to do what we really want to do—take care of these patients.”

Dr. Thrun understands the importance of getting people living with HIV/AIDS into care, and he and the other Planning Council members, many of whom are HIV positive, are passionate about keeping people in care. They do this by supporting linkages and building connections among organizations in the Denver TGA’s six counties. “Health is more than just coming into an office,” he says. “It extends into the community and into the home.”

When Epidemics Collide . . .

Bob Dorshimer is the executive director of the Council on Substance Abuse and Mental Health and founder of the Mile High Meth Project. He has seen the impact that the one-two punch of crystal methamphetamine (meth) addiction and HIV/AIDS has had on the gay community in Denver and surrounding areas.

While working in Denver’s Office of Drug Strategy, Bob discussed with Dr. Thrun the increasing incidence of HIV cases associated with meth in the Denver area. Soon afterward, Bob applied for Colorado Department of Public Health and Environment (CDPHE) funds to conduct evidence-based research about this burgeoning epidemic. He sent Rod Rushing, an HIV counselor and former meth addict, to study what other cities were doing to fight this new battle.

Bob has always worked to help others find renewed health and renewed hope. “I’ve been doing this work for 20 years. Social work is at the heart of my career,” he explains. And it is also at the heart of his home. Bob has adopted three sons, all from homes plagued by substance abuse.

When the CDPHE-funded study results came in, Bob and Rod went to the Denver Planning Council and MOHR with an idea—the Mile High Meth Project—which was soon approved for funding through Part A. Today, the Mile High Meth Project provides group and individual counseling services and support for men who have sex with men (MSM) and struggle daily with their meth addiction

“I remembered a time when care was more a family thing, and I wanted to bring that back.”

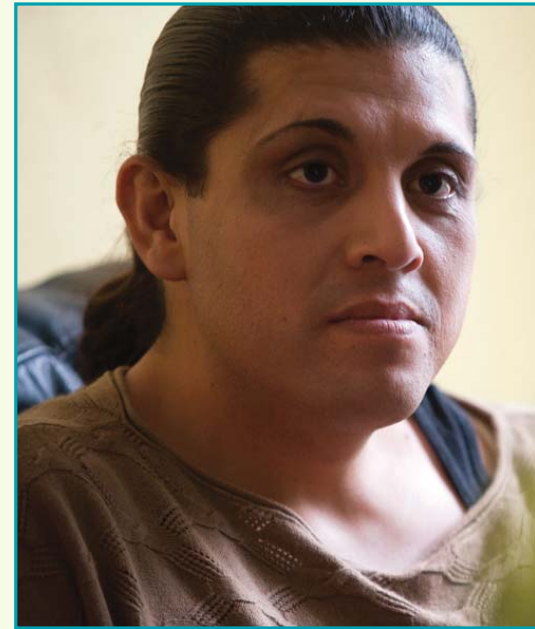
and HIV/AIDS status. Rod, now a counselor at the project, helps men battling many of the same demons he’s successfully overcome. “Once I found out that I was HIV positive in 1985, I started living like it was going to be over tomorrow. I was living on my 401k because I didn’t think I would be here long enough to need it.”

Many of the men in the program credit Rod with setting them on the course to recovery. Stephen gets emotional when he talks about Rod bringing him into the Mile High Meth Project. “I used meth every day for 15 years,” he says, fighting back tears. His rock bottom came when he was arrested for selling the drug in 2003 and landed in prison. Once he was released, he needed the skills to stay clean and to deal with his health issues. “It is a struggle, but the team at the Mile High Meth Project gave me the tools to make it work.” Stephen is proud to have his life on track and to be back in school because of this help.

The Mile High Meth Project is one of many initiatives that reflect what Dr. Thrun sees in today’s epidemic in Denver. Although medications have helped people do better in care, he adds that uncontrolled substance abuse such as meth addiction has meant more deaths because patients simply can’t manage their care sufficiently.

Unlocking the Key

When Imani Latif moved to Denver after many years in the New York City Health Department, she was burned out and convinced she’d never work in HIV care again. But then she had a vision. “I remembered a time when care was more a family thing and I wanted to bring that back. I also saw how some organizations were very afraid of working with people released from prison. But to us it’s not scary, because they’re our brothers, husbands, fathers, sisters, friends.”



“I collaborate with a lot of community agencies to help people coming out of prison. If they have to worry about where to sleep or if they’re going to eat, it’s hard to think about HIV,” says ITAV Caseworker Tonya Rozencwajg. Members of the ITAV family left to right are founder Imani Latif, Non-Medical Case Manager Hassan Latif, and client and community activist Monica.

It Takes a Village (ITAV) was built on the mantra that helping people living with HIV/AIDS takes the entire community. Caseworker Tonya Rozencwajg agrees with this principle:

“When I see people for the first time, they have no plan, no meds, and no support,” Tonya says. To help people living with HIV/AIDS transition from prison to community care, Tonya collaborates with many other players, including the case manager within the Department of Corrections, and links consumers into the Housing Opportunities for Persons With AIDS program. She also helps build relationships with organizations like Continental Divide Corporation, which hires ex-offenders who have successfully completed care programs at ITAV.

ITAV is a place where people of color with histories of incarceration can engage in care, find job training, access substance abuse and support services, and find hope for the future. It’s also a place where people can come and sit down on one of many couches and talk about their daily struggles or get clean clothes and a warm cup of coffee. ITAV is supported in part by Minority AIDS

Initiative (MAI) funds, which have helped reduce the impact of HIV/AIDS among minorities through research, prevention, care, and treatment since 1999. (To learn more, see www.hab.hrsa.gov/treatmentmodernization/minority.htm.)

Monica, a transgendered client, found hope and acceptance at ITAV. “Coming out of prison, you don’t get a plan,” she says. “They stay on me and are like a little family,” she says. Thanks to the hard work she has invested in stabilizing her life, and with the help of ITAV staff, she sees a bright future that might not have been possible otherwise. Characteristic of so many Ryan White organizations, ITAV is striving to expand care wherever it sees a need. Monica is helping to contribute to this expansion by establishing the TransAction program—designed to support transgendered and transsexual people living with HIV/AIDS like her—at ITAV.

Imani is proud of the organization she’s created and of the passionate providers like Tonya who have helped Monica and many others transform their lives and start anew. Imani says, “This is what’s possible when you get a vision in your head and don’t let go.”



Steven Toth, D.M.D. (right), looks on as dental patient Raymond Sanchez examines his new smile in the mirror. A former dental student recruited to treat people with HIV, Toth says, “It feels good giving back to the community.”

RYAN WHITE
AND DENTAL CARE

DENTAL REIMBURSEMENT
PROGRAM

COMMUNITY-BASED DENTAL
PARTNERSHIP PROGRAM

SPNS ORAL HEALTH
INITIATIVE

ORAL HEALTH CARE =
A CORE MEDICAL SERVICE

6. Using Innovation to Improve Health

INNOVATION HAS ALWAYS BEEN AT THE HEART OF THE RYAN WHITE HIV/AIDS Program. With a level of collaboration that seldom occurs in health care system design, the program was created by activists; clinicians; people living with HIV/AIDS; providers; and Federal, State, and local government officials. In a breathtaking departure from many initiatives, the program reflected from the beginning that the epidemic in suburban New Jersey, for example, was different from the epidemic in Miami. A cookie-cutter solution would not work.

Local constituencies have used innovation and unprecedented means to address HIV/AIDS since the Health Resources and Services Administration (HRSA) launched its HIV/AIDS programs in the mid-1980s (see <http://hab.hrsa.gov/livinghistory/>). The first Ryan White legislation brought novel solutions in areas such as community planning, consumer involvement, and resource allocation. Perhaps the most important innovation was so intrinsic that it's no longer regarded as innovative at all: the sheer breadth of ambulatory health care and essential support services provided through the legislation.

Innovation Creates Access

Dental care may not seem innovative in itself, but considering that approximately one-third of all Americans have no dental insurance at all, it demands an innovative approach to increase its availability and utilization.^{17,18} So perhaps it was indeed forward-thinking when in 1990 the Dental Reimbursement Program was made part of the Ryan White HIV/AIDS Program, in 2002 when the first Community-Based Dental Partnership Program (CBDPP) grants were awarded, and again in 2006 when oral health care was included as a “core medical service.” But the aim is not to be innovative for innovation’s sake; it is to create access to care for people living with HIV/AIDS.

The dental partnership program allows grantees like the University of Medicine and Dentistry of New Jersey (UMDNJ) to provide hands-on training for dental school students and residents in treating people living with HIV/AIDS in community-based settings. “The need for oral health professionals for HIV-positive people will only increase as consumers age,” says Jill York, D.D.S. She speaks from experience. In 2007, more than half of the HIV-positive people who received services at UMDNJ were between 45 and 64 years old.

“We were already seeing patients and training residents, but CBDPP funding made it possible to expand our community outreach. Since then we have grown dramatically,” says Dr. York. “We grew from nearly 300 patients in 2002 to more than 600 in 2007.” That kind of growth highlighted the need for more providers who understood the challenges of community-focused dental care. “In 2006–2007, we recruited 11 students from the dental school to train with us for a year,” says Dr. York. “Four of the 11 stayed on and have taken jobs with us, and 2 of the 4 are faculty members.”

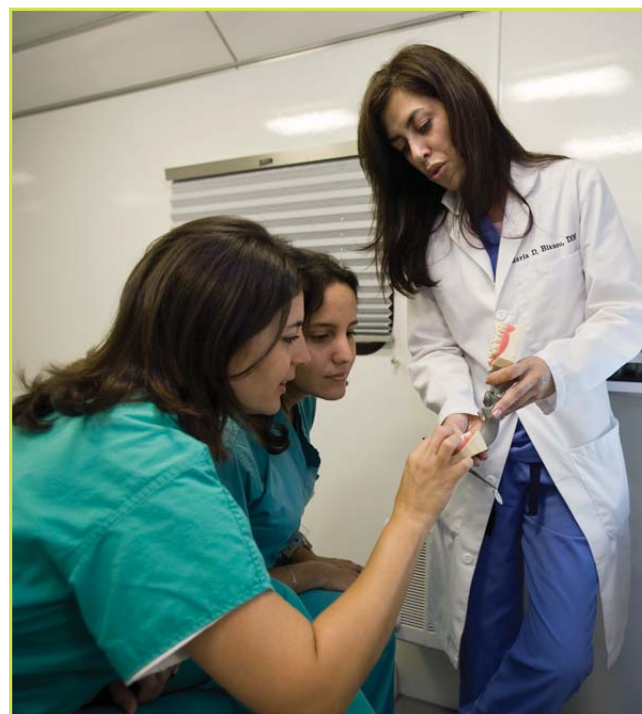
One of those past students is Steven Toth, D.M.D., who graduated in 2007 and is now working in the program. “It feels good coming from my background with no HIV experience to now really being part of this program and giving back to the community.”

It’s this sense of social responsibility that Dr. York tries to instill in students and that has driven her work since 1996, when an encounter with a young schoolgirl changed her life. “I was doing screenings for Head Start, and a 4-year-old girl came in with what

SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE PROGRAM: CURRENT INITIATIVES

- Improving linkages to HIV primary care and services in jail settings (2007–2011)
- Enhancement and evaluation of health information electronic network systems for PLWHA in underserved communities (2007–2011)
- Innovations in oral health care (2006–2010)
- Evaluation of innovative means to integrate buprenorphine opioid abuse treatment in HIV primary care (2004–2009)
- Outreach, care, and prevention to engage HIV seropositive young MSM of color (2004–2009)

See also <http://hab.hrsa.gov/special/evaluation2g.htm>.



Maria Blanco, D.D.S., originally from Colombia, treats HIV-positive dental patients in Miami’s mobile dental van. She also uses her experience to instruct the next generation of students who are performing their residency in the van in partnership with the University of Miami.

looked like thrush, a common symptom of HIV. The child had HIV and no one claimed to know," Dr. York says.

Connecting With Claire

The sun beams down on the Miami Dental Access Program (MDAP) mobile dental van parked at Jackson Memorial Hospital, and HIV-positive people are lining up to be seen. Dental care, like so many other health care services, is a luxury for the underinsured. But for uninsured patients like Claire, access to dental care is now a possibility, thanks to a Ryan White HIV/AIDS Program Special Projects of National Significance (SPNS) grant.

Claire started using drugs in her teens. "Drugs controlled my life," she says. Her drug abuse, coupled with her HIV-positive status, diagnosed during a stint in jail, threw her life into a tailspin.

"I lost connection with my family because I didn't think they could accept that I was living with HIV." At one point, Claire attempted suicide to end her isolation, addiction, pain, and shame. It has been a long battle, but she has been sober for 5 years. Part of her recovery has been getting care from MDAP for her teeth, which she neglected while using drugs and which had severely decayed. "Being able to have this dental care is like winning the lottery," Claire says. "If you have rotten teeth you have a rotten life."

equipment to expand the reach of care. MDAP grantees are the University of Miami Miller School of Medicine Department of Epidemiology and Public Health and the Jackson Memorial Hospital Division of Oral Surgery and General Dentistry. They took what had worked to engage and retain HIV-positive people in care and combined it with a new approach. The result was a mobile van like the ones used for HIV outreach but with a twist—a complete dental office capable of delivering oral health care services.

The Dental Access Program was conceived by principal investigator Lisa Metsch, Ph.D. The program was borne of the oral health linkages that Jackson Memorial Hospital had with three HIV/AIDS primary care clinics in Miami/Dade County that were unable to offer dental services. The team decided to use the van as one of the first transportable dental offices in the country, taking oral health services directly to people who needed them.

Today, patients can leave their primary care appointment at 1 of the 3 clinics and step aboard the van to get cleanings, oral exams, x-rays, and fillings. Those who need more extensive care are given referrals to complete their care.

Yves Jeanty, M.P.H., epidemiologist, is project director for the MDAP. He explains that Jackson Memorial Hospital, a program partner, is a

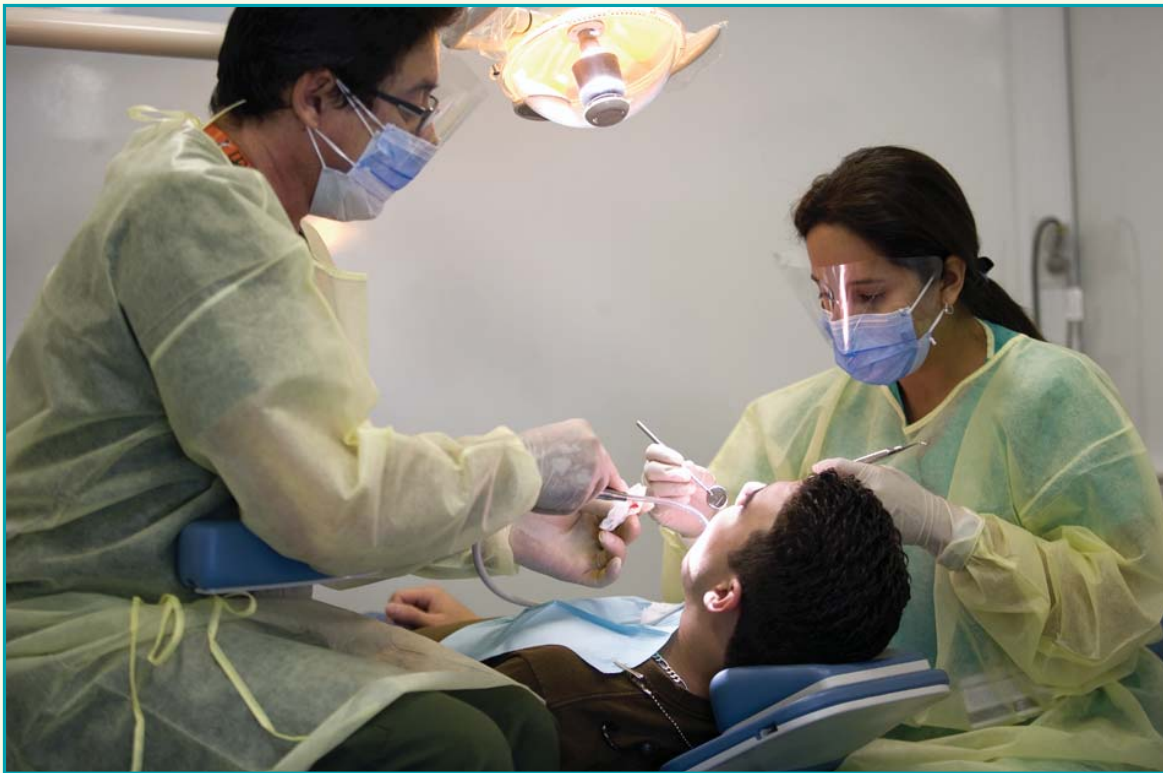
10,000 people have received dental care through the clinics and the van. Without the van, clients could wait up to 6 months to get the services they needed.

Making Innovation Happen

The Part F SPNS program creates and evaluates innovative approaches to care for people living with HIV/AIDS. Throughout its history, the SPNS program has examined issues like access to care for African-Americans, women, youth, and residents along the U.S.–Mexico Border, and now it is examining access to oral health care. (See <http://hab.hrsa.gov/treatmentmodernization/spns.htm>.)

The MDAP is 1 of 15 SPNS Oral Health Initiative grantees in the country, and 1 of only 3 using a mobile van outfitted with dental

principal provider of HIV/AIDS ambulatory care in the region. "Ninety percent of the patients who get their clinical care here are doing so because of Ryan White HIV/AIDS Program funds," says Yves. He adds that the hospital has built trust among the people it treats, but "even in a close-knit community like this, people living with HIV/AIDS still face stigma because of their illness. We use an innovative route to care by taking it to where people are." This approach appears to be working: 10,000 people have received dental care through the clinics and the van. "Without the van, clients could wait up to 6 months to get the services they needed," Yves observes.



“I see it on the van. There’s a dramatic difference once people start feeling taken care of. They become self-advocates for their health care,” says Maria Blanco, D.D.S.

Creating New Connections

It’s been 24 years since Henry Boza got his HIV/AIDS diagnosis. “I got my test results from a person dressed in what looked like an astronaut suit. He came into the room, dropped the diagnosis on the table and said, ‘Go home and die like the rest of you.’”

“I drove to the Golden Gate Bridge, in San Francisco, and got out of the car,” he recalls. “I was crying so hard that I couldn’t drive.” He says he never thought about ending his life, but he did think about all the people he had lost in the early years of the epidemic. “I felt like I had closed the eyes of everybody I loved.”

For Henry, that day proved to be cathartic. “There had to be a better way for people to get their diagnosis. I decided that individuals weren’t going to be treated like I was if I could help it.” Henry left San Francisco for Miami, and it wasn’t long before he made good on his pledge. He began his work in HIV first as a peer counselor and then by providing HIV counseling and testing. He says that his experiences have helped inform the way he provides health care support to clients. Today, he is project coordinator for MDAP.

Maria Blanco, D.D.S., is Henry’s colleague at MDAP. Her path to providing HIV/AIDS services was that of a dental student—a different journey from Henry’s but equally powerful and long lasting. As a University of Miami dental resident, Dr. Blanco was the first dentist to provide care in the van in December 2007. Dr. Blanco now works there 3 days a week, 1 day at each of the three clinic sites the van visits. “The mobile van offers a good way to reach people, especially ones who don’t know what services are available,” she says.

Dr. Blanco sees the van as a way to help patients be more proactive about their health. “We know that the cost of dental care and the fear of treatment are big challenges for people,” she says. She and Henry agree that the open, caring approach on the van helps clients get over their fears and seek out care. They have seen a big difference in patients and their outlook. “I remember a patient who had a bad smile,” says Dr. Blanco. “He always seemed sad. We did his dentures, which took about 3 or 4 months, but the day we delivered them he really smiled.” Dr. Blanco adds, “I feel I am doing something better than if I were in private practice. I enjoy coming to work knowing that I will change a patient’s life a little bit.”



Ryan White HIV/AIDS Program providers attended a Project ECHO telemedicine class in Albuquerque, New Mexico last spring, accessing expertise from all over the State, thanks to the latest in video conferencing technology.

7. The Ryan White HIV/AIDS Program: A Firm Foundation, a Shared Future

PROPOSALS COME FROM EVERY CORNER OF THE COUNTRY ABOUT HOW to fix a health care system that leaves millions of people without care. It remains far from clear how America will resolve its inequities in access to health care. What is far more clear are the issues that the HIV/AIDS services community must face as we near the end of the third decade of AIDS in the United States. Fortunately, America's response to AIDS thus far offers a firm foundation for addressing the epidemic in the future.

The Ryan White HIV/AIDS Program is improving the lives of people in ways that were unfathomable to the first patients and clinicians who encountered the "strange new disease" in 1980. Even the developers of the first HRSA AIDS programs in 1985 and the broad coalition associated with passage of the Ryan White CARE Act in 1990 must find the scope and reach of today's program more than most could have hoped for. To understand this amazing trajectory, we need look no further than the commitment of the Ryan White community to facing its challenges together.



It has been estimated that of the 1.04 to 1.19 million people living with HIV disease in the United States, between 24 and 27 percent don't know their serostatus (between 249,360 and 319,950 people).²⁰ It is not likely that everyone would enter care at the same time and in a single moment overwhelm HIV/AIDS services providers. Moreover, many of those who do enter care will elect to delay initiation of treatment.

However, many others—37,852 in 2006 alone—don't know their serostatus until they are diagnosed with AIDS.²¹ On top of that, nearly 2 out of 5 patients (39 percent) newly diagnosed with HIV progress to an AIDS diagnosis within a year's time.²² Clearly, they need treatment for their HIV infection and related AIDS-defining conditions. It is likely that they also need general primary care and services to help them overcome the barriers that led to a late diagnosis of HIV disease.²³

What is our capacity to handle a burgeoning patient census? How can we help providers and community-based organizations, many of whom are already reporting significant increases in client load, meet the need for growing demand? These are difficult questions. And there are no easy answers.

Is Anybody There? The Manpower Shortage

Decades ago, the U.S. Department of Health and Human Services defined regions where there are not enough clinicians to meet the



HRSA's efforts to bring clinicians to communities where they are in short supply includes this project in Yakima, Washington, where migrant workers receive comprehensive HIV/AIDS care.

primary care needs of the local community as "Health Professional Shortage Areas" (HPSAs). It is not lost on many people working in HIV/AIDS that the epidemic, like many diseases, has hit hardest in communities where there simply isn't enough health care to go around.

Where HIV/AIDS is concerned, the shortage of manpower in particular communities is compounded by other, more generalized developments: the aging of the first generation of HIV/AIDS services providers; a change in the role of the caregiver from palliation to treatment of a chronic disease; and, significantly, the burnout-causing sense that doing all that the patient needs and requires is simply impossible, given restrictions in time and money.

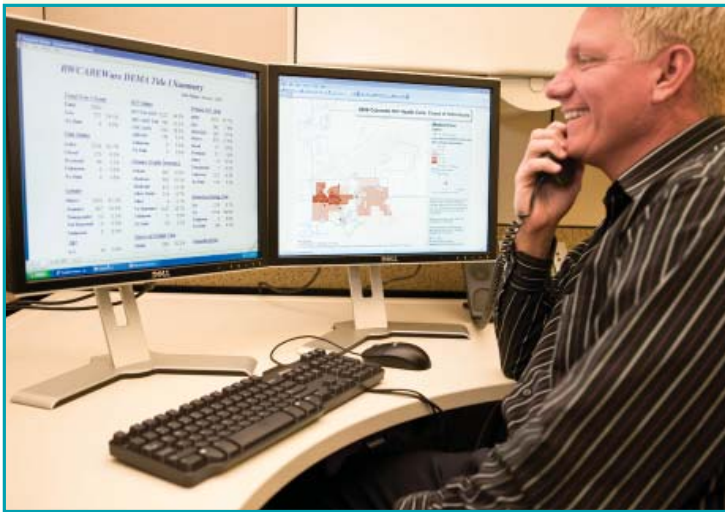
HRSA has done much to address the manpower shortage issue. The AIDS Education and Training Centers (AETCs) Program is using innovative approaches such as mapping to identify where the most significant shortages are and then taking training and engagement to those areas. Historically, the agency has administered programs that placed health professionals in HPSAs. Through its newsletter, *HRSA CAREAction*, HRSA has brought attention to the issue of burnout and has also helped identify tools that help forestall it (see <ftp://ftp.hrsa.gov/hab/march2007.pdf>).

But the looming manpower shortage is a complex problem caused by forces both internal and external to the AIDS epidemic. It will require a concentrated and synchronized response to deal with it.

Medicaid and the Deficit Reduction Act

Medicaid is the largest public health care program in the Nation and the largest payor of care for people living with HIV/AIDS by far. The program provides a full range of services to eligible persons, including case management, prevention services, hospice care, and prescription HIV drugs.²⁴ At \$6.3 billion, Medicaid accounted for 51 percent of all Federal HIV/AIDS spending in FY 2006, and more than 200,000 people living with HIV/AIDS are enrolled in the program.²⁵

In total, approximately 59 million people are enrolled in Medicaid, making the program necessarily complex. In February 2006, the Deficit Reduction Act of 2005 was signed, providing new regulations and cost-saving measures. Because these changes could potentially impede access to health care for some, it is incumbent on Ryan White



Left: CAREWare has enabled many organizations to improve clinical outcomes and efficiencies while reducing technical demands.



Right: Weekly Consumer Advisory Board meetings at Atlanta's Grady Family Clinic exemplify the commitment of Ryan White HIV/AIDS Program grantees to consumer involvement and collaboration.

HIV/AIDS Program providers to help clients overcome any barriers that arise, to ensure that their health is not negatively affected.²⁶

In fact, the Congressional Budget Office estimates that 13 million Medicaid recipients will face new costs, such as increased beneficiary copayments, and that 65,000 current Medicaid enrollees—60 percent of them children—will lose their coverage entirely by 2015.²⁷ This shift comes at a time when a graying HIV-positive population's needs for long-term health care are only increasing.

Fiscal Viability: Open for Business, or Closed Doors?

It is not the intent of the Ryan White HIV/AIDS Program legislation to support the financial viability of providers and grantees. The legislation, after all, funds services, not organizations. Yet, the legislative intent to serve as the payer of last resort for the underserved can't be realized unless providers are financially healthy.

If connectedness is the theme of HIV/AIDS service delivery in America, it is nowhere more apparent than between HRSA, which implements the legislation, and the grantees and providers who deliver mandated services. Neither can fulfill its role without the other.

Although the Ryan White HIV/AIDS Program does not directly address the financial viability of grantees and providers, its activities can have the effect of strengthening an organization's financial position. For

example, the AETCs and other HRSA-provided technical assistance help organizations operate more efficiently. The Special Projects of National Significance (SPNS) Program identifies approaches to care that offer the greatest return on programmatic investment. And tools like CAREWare and, more generally, the Federal emphasis on evaluation and data help organizations capture the results-oriented information that funders want to see.

These tools alone, however, cannot ensure the financial viability of organizations over time. To achieve that goal, we return once again to the theme of connectedness. Because it is by building a broad coalition of partners, each doing its part to respond to HIV/AIDS, that we share the financial burden—and strengthen the safety net for people who depend on it.

Client-Level Data: The Quest to Know More

The quest to know more is not new to the field of HIV/AIDS or, for that matter, the field of medicine. Science is always in search of more effective treatments, diagnostic tools, and health care practices. In today's health care field, the quest for continued learning increasingly extends to patients themselves. In recent decades, the power of computers and technology has made the search for knowledge more far-reaching and fruitful than could have been imagined before the Information Age. But the tools of this age are not distributed equally among all providers, which is why HRSA is heavily engaged



Client Curtis with his case manager Tonya Rozenwajg on the steps of It Takes a Village in Denver, Colorado.

in ensuring that HIV/AIDS program grantees and providers who may need assistance related to client-level data receive it.

With the reauthorization of 2006, the SPNS Program is mandated to fund special programs that expand capacity to develop client information systems and report client-level data. In 2008, 17 Part A and B grantees will receive funds through this program; Parts C and D are slated for funding in 2009. Over the past year, HRSA has collaborated with grantees and providers to build their client-level data systems. Working together, data elements have been defined and thoroughly vetted among grantees. Also in the spirit of collaboration, technical assistance is available as needed.

In 2008, the process of supporting grantees and providers in their efforts to gather and use client-level data will continue. Simultaneously, HRSA and its grantees and providers will be addressing this important question: With the gold mine of client-level data in place, how can the Ryan White HIV/AIDS Program maximize the utility of the data to improve client health?

Sunrise, Sunset: Preparing for Reauthorization

It hardly seems possible. Wasn't 2006 only yesterday? Isn't the ink on the Ryan White HIV/AIDS Treatment Modernization Act barely dry? Are we really preparing for the 2009 reauthorization hearings?

The implications of changes in the law have been center stage since 2006. The Ryan White community has been collaborating to implement changes in the legislation adopted to reach the neediest first and, more generally, increase access to life-changing care. Because of that collaboration, the implementation of new provisions has been extremely successful.

For most grantees and providers, 2006 wasn't the first reauthorized AIDS care bill—and everyone hopes that it won't be the last. The current Ryan White HIV/AIDS Treatment Modernization Act is set to expire on October 1, 2009. HRSA and its partners are already preparing for reauthorization hearings for a new bill. The agency's responsibilities are enormous. We must provide information that is as complete as possible on the successes—and shortcomings—of

our current programs. Even as a new administration takes over in January 2009, we must continue to respond quickly to policy makers' need for information. And while we are meeting those responsibilities, we must not lose sight of our true purpose: to reach the underserved.

The Power of Connections: Broad Coalition, United Force

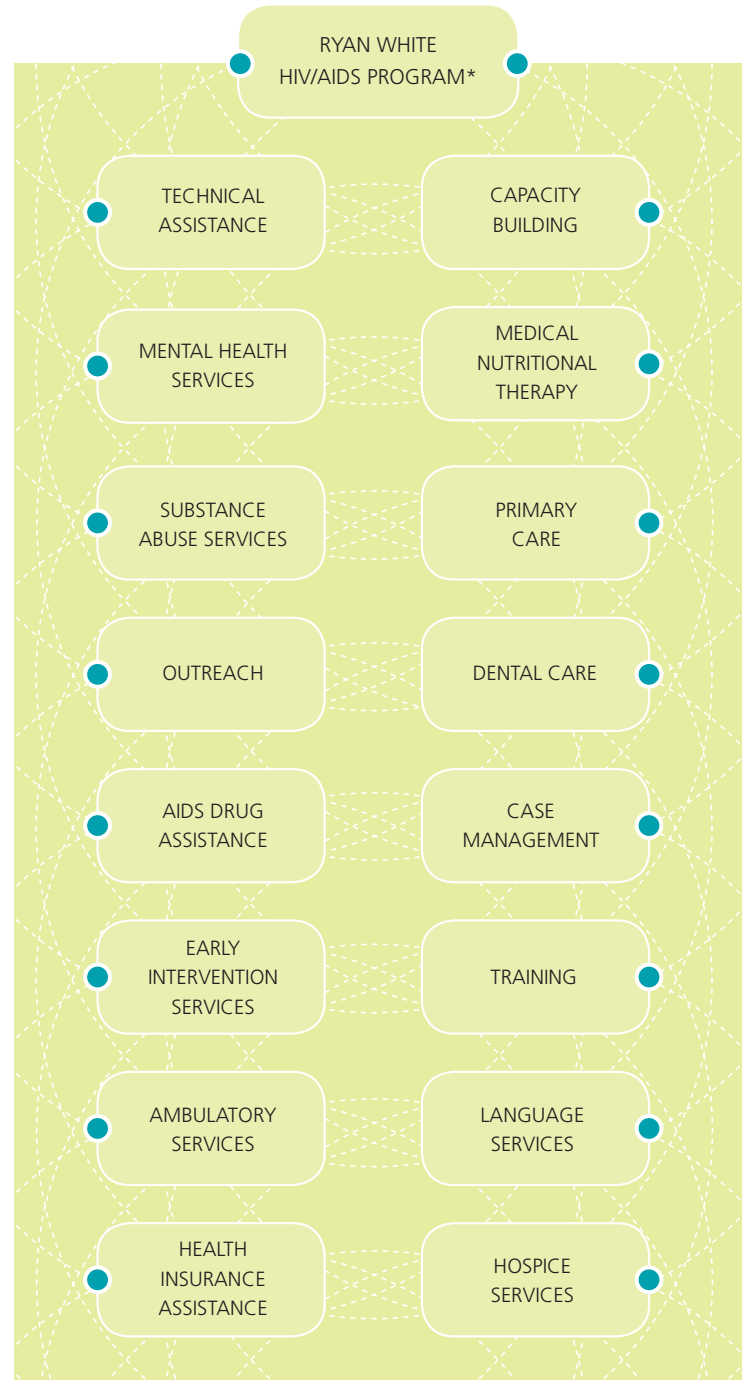
The interconnected force of everyone engaged in addressing HIV/AIDS can never be fully defined. Administrators and outreach workers, grantees and project officers, clinicians and case managers, clients and caregivers—all are stitched together like a patchwork quilt, inseparable parts of a whole, indivisible in their work.

We cannot know what the sunset of the current law will mean or the hoped-for rise of a new one will bring, but we do not enter a future full of unknowns. We go forward standing on the shoulders of those who dared to step into the fray before AIDS even had a name. We go forward with the knowledge gained from consumers and providers over almost 3 decades. We go forward knowing that the comprehensive, “wrap-around” services that we provide are, for many, the only thing standing between long life and early death. And we greet the future with the full knowledge that, regardless of the disease, health care is about more than a pill.

The Ryan White HIV/AIDS Program continues to grow and evolve because of the communities that have been built around care and support. Over the years, individuals, families, communities, health care institutions, and advocates have come together around a common goal: keeping people healthy. These communities have understood that people living with HIV/AIDS are deeply connected to friends and family as well as to a network of caregivers, case-workers, health care providers, and advocates, who have, in turn, connected to each other to improve the health care system.

The Ryan White HIV/AIDS Program is a model for the reduction of health care disparities in this country. Past successes have come not only from connections but also from a focus on what is possible. Each innovation began as a “What if?” Each HIV-positive person who benefited from the Ryan White HIV/AIDS Program did so because people connected, came to the table, and pondered the possibilities. In the end, they made each possibility a reality, using their collective power to break barriers that had once seemed insurmountable.

Who would have believed in the early days of the epidemic that years later, half a million people would be receiving vital health care services and medication? It has happened through funding and innovation—and the power of connections. As the projects highlighted in this report have shown, if we all use the lessons we have learned from one another; if we share and apply them in many different settings; and if we work together to provide compassionate, respectful health care for the country's poor and underserved—regardless of their ability to pay—then anything is possible.



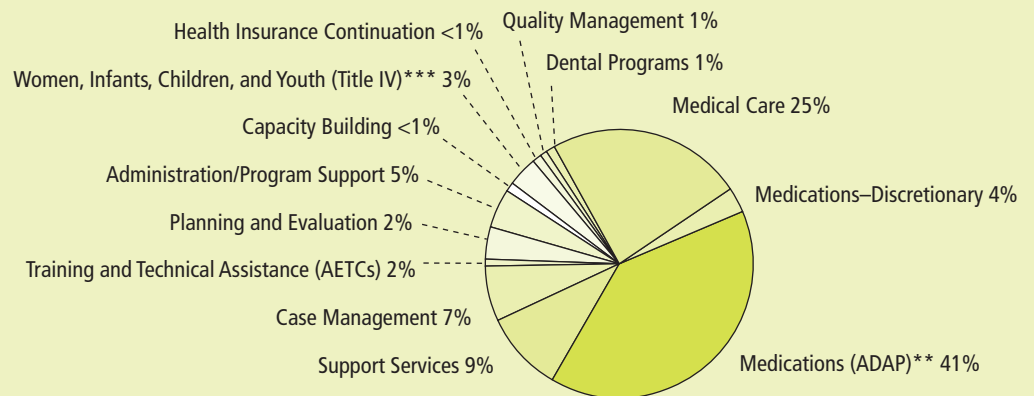
*This list of services is intended to be illustrative but in no way exhaustive.

8. What the Data Tell Us

THE QUEST FOR IMPROVED HIV DATA IS NOTHING NEW. THE RYAN WHITE HIV/AIDS PROGRAM is consistently fine-tuning the way in which data are managed and optimized. The more that we know about the services we are providing, who we are reaching, and how we are managing the care we offer, the better we are at providing care to those who need it most.

The data show that the Ryan White community has successfully been reaching the populations it has been charged to reach. It is enrolling people disproportionately affected by HIV disease—the under- and uninsured, the poor, ethnic and racial minorities, women, and people of all ages. As we move forward, we renew our commitment to improving the quality of our data and using it, in turn, to continue to improve the quality of HIV care that we are able to provide. And better care means better health and better lives for people living with HIV/AIDS.

CARE ACT SPENDING* FY 2006, N = 1.93 billion



Source: HRSA HIV/AIDS Bureau. *Allocation and expenditure reports, 2006*. 2006. [Unpublished data].

*Spending data in this chart are based in part on planned spending reported by grantees.

**Approximately 4 percent of Medications (ADAP) spending was for health insurance and adherence support.

***Title IV program reflects only a portion of spending for Women, Infants, Children, Youth, and Families.

Percentages may not sum to 100 due to rounding. Unknown or unreported responses are not included in percentage calculation.

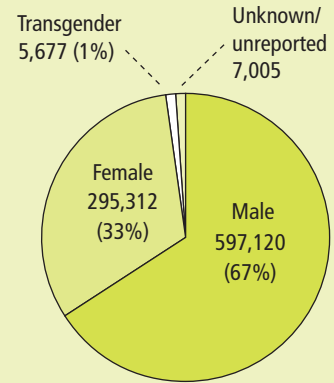
GENDER



Duplicated Ryan White HIV/AIDS Program Clients

2006, N = 905,114

Source: HRSA HIV/AIDS Bureau. 2006 CARE Act data report. 2008. Table 1. [In press]. Percentages may not sum to 100 due to rounding. Unknown or unreported responses are not included in percentage calculation.



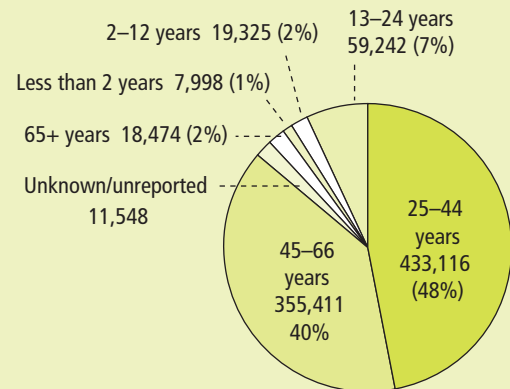
AGE



Duplicated Ryan White HIV/AIDS Program Clients

2006, N = 905,114

Source: HRSA HIV/AIDS Bureau. 2006 CARE Act data report. 2008. Table 1. [In press]. Percentages may not sum to 100 due to rounding. Unknown or unreported responses are not included in percentage calculation.

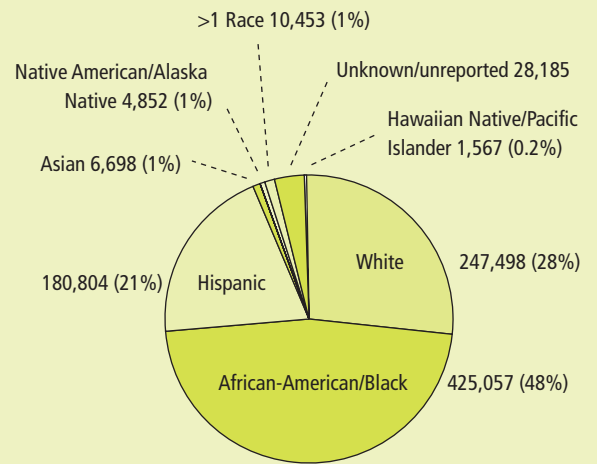


RACE/ETHNICITY

Duplicated Ryan White HIV/AIDS Program Clients

2006, N = 905,114

Source: HRSA HIV/AIDS Bureau. 2006 CARE Act data report. 2008. Table 1. [In press]. Percentages may not sum to 100 due to rounding. Unknown/unreported responses are not included in percentage calculation.

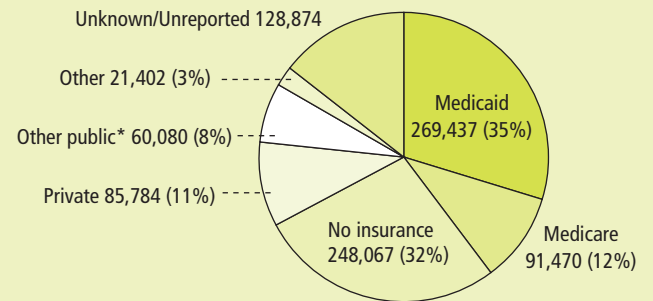


HEALTH INSURANCE

Ryan White HIV/AIDS Program Clients

2006, N = 905,114

Source: HRSA HIV/AIDS Bureau. 2006 CARE Act data report. 2008. Table 3. [In press]. *Includes State-funded plans, military health care (TRICARE/CHAMPUS), or care provided by the U.S. Department of Veteran Affairs (VA), Veterans Health Administration, the State Children's Health Insurance Program, and the Indian Health Service. Percentages may not sum to 100 due to rounding. Unknown/unreported responses are not included in percentage calculation.

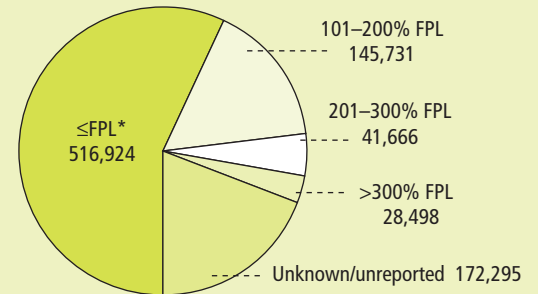


HOUSEHOLD INCOME

Ryan White HIV/AIDS Program Clients

2006, *N* = 905,114

Source: HRSA HIV/AIDS Bureau. *2006 CARE Act data report*. 2008. Table 2. [In press]. *FPL = Federal Poverty Level. Percentages may not sum to 100 due to rounding. Unknown/unreported responses are not included in percentage calculation.

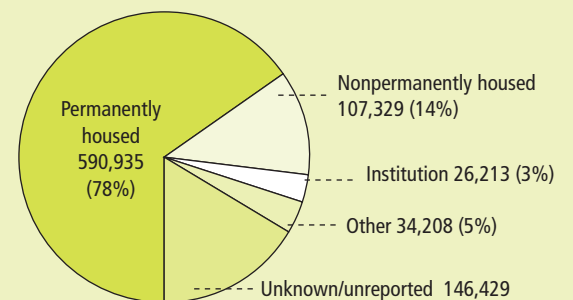


HOUSING ARRANGEMENTS

Ryan White HIV/AIDS Program Clients

2006, *N* = 905,114

Source: HRSA HIV/AIDS Bureau. *2006 CARE Act data report*. 2008. Table 2. [In press]. Percentages may not sum to 100 due to rounding. Unknown/unreported responses are not included in percentage calculation.

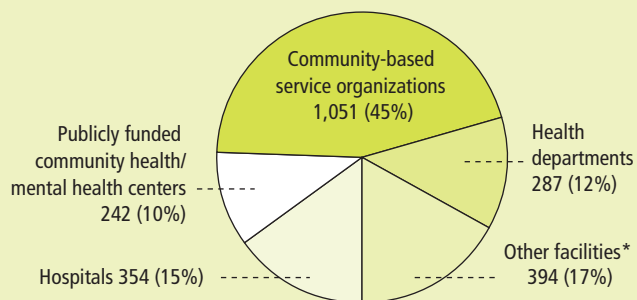


TYPE OF PROVIDER

Ryan White HIV/AIDS Program
2006, N = 2,328

Source: HRSA HIV/AIDS Bureau. 2006 CARE Act data report. 2008. Table 4. [In press]. Data on provider type were missing for 2 providers in 2006.

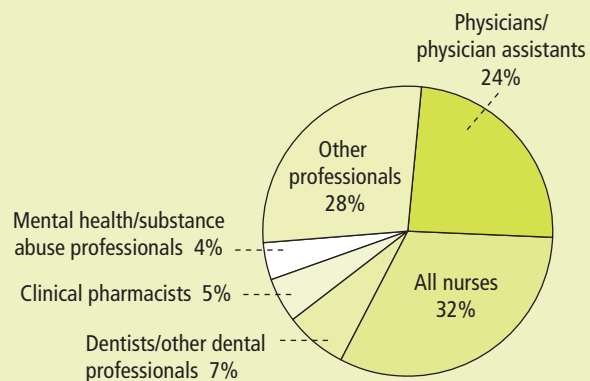
*Includes substance abuse treatment centers, solo/group private medical practices, providers reporting for multiple fee-for-service providers, coalitions of people living with HIV/AIDS, VA facilities, and provider type reported as 'other'. Percentages may not sum to 100 due to rounding.



AETC TRAINEES

Most Common Professions
2007, N = 73,157

Source: HRSA. 2007 AETC Report. 2008. [In press]. Data on the professions are missing for 1,346 trainees. All Nurses included nurses, nurse practitioners, and advance practice nurses. Percentages may not sum to 100 due to rounding.



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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 www.hab.hrsa.gov.

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