

// AHEAD OF THE CURVE //



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This publication lists non-Federal resources in order to provide additional information to consumers. The views and content in these resources have not been formally approved by the U.S. Department of Health and Human Services (HHS) or the Health Resources and Services Administration (HRSA). Listing these resources is not an endorsement by HHS or HRSA.

On August 18, 1990, the Ryan White Comprehensive AIDS Resources Emergency (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. The program is up for reauthorization in 2013.

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, and the Community-Based Dental Partnership Program was included in the 2000 legislation. 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 grantees include both large Eligible Metropolitan Areas (EMAs) of which there are 24 grantees funded at a total of \$499.8 million and smaller Transitional Grant Areas (TGAs) of which there are 28 grantees funded at a total of \$137.7 million. 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. In 1995, the AIDS Drug Assistance Program (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. In FY 2012, 59 Part B grantees were awarded a total of \$1.2 billion, of which \$868.4 million was ADAP and ADAP Supplemental 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. The largest—and first—Part C program provides early intervention services (EIS) grants. Planning grants and capacity development grants were added in 1996 and in 2000, respectively. In FY 2012, \$192.2 million was awarded to a total of 356 Part C EIS grantees and \$1.2 million was awarded to 15 Part C capacity building grantees.

### 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 previously housed in HRSA's Maternal and Child Health Bureau. In FY 2012, \$68.3 million was awarded to a total of 114 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, it 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 5 national centers (including 2 focused on minority and multicultural health) 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 (DRP) 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 (CBDPP). First funded in 2002, this program supports collaborations between dental education programs and community-based dentists and dental clinics. In FY 2012, \$9.01 million was awarded to 56 DRP grantees and \$3.8 million to 12 CBDPP grantees.

#### ***Minority AIDS Initiative***

The Minority AIDS Initiative (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.

To learn more about the history of the Ryan White HIV/AIDS Program, visit [www.hab.hrsa.gov/livinghistory/](http://www.hab.hrsa.gov/livinghistory/).

*1. THE RYAN WHITE HIV/AIDS PROGRAM: HRSA LEADS BY EXAMPLE*



*BECAUSE OF RYAN WHITE, I'M ALIVE.*

*RYAN WHITE HIV/AIDS PROGRAM PATIENT*

The Ryan White HIV/AIDS Program was built on forward thinking. At a time when AIDS was feared and misunderstood, activists, providers, people living with HIV/AIDS (PLWHA), and their advocates reached beyond stigma and inadequate care systems to serve some of the most marginalized people in the United States.

The Ryan White HIV/AIDS Program is overseen by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) and provides funding to clinics, training institutions, health departments, and health care providers across the country. Today, this comprehensive, \$2.35 billion program serves as the payor of last resort for more than 529,000 patients across the country. Since its enactment in 1990 it has evolved in response to the changing epidemic service needs and clinical paradigm. Over its 22-year history, the Program has led the Nation's response to AIDS care through innovation, discovery, and breakthrough after breakthrough. Along the way, the Ryan White HIV/AIDS Program has reminded America of its own greatness and taught us much about what can be achieved when we move past today's barriers and dream of a better tomorrow.

In this seventh edition of the HHS, HRSA, HAB Progress Report, we examine how HRSA is paving the way towards the future. Now, more than ever, we're tapping into the promise of technology, health care advancements, and innovative research to reach, engage, and retain vulnerable PLWHA in care. We've built a strong public health infrastructure and are meeting the goals of Healthy People 2020.

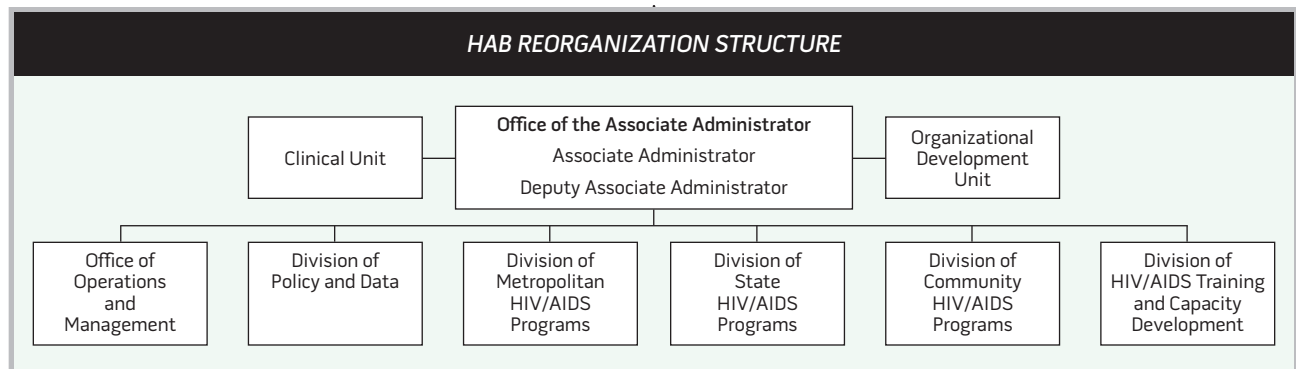
As we move into the next phase of HIV care and a new era at HRSA, we remain dedicated to staying ever vigilant and, as always, ahead of the curve. One example is HAB's recent reorganization—the first since HAB's

founding in 1997. Since that time, the external environment including the face of the HIV epidemic and the health care system itself, have changed. Additionally, with each Ryan White HIV/AIDS Program reauthorization, the complexity of the Program as well as HAB's work load have significantly increased. The reauthorization was done in order to:

- > better position HAB to respond to health care system and HIV/AIDS epidemic changes,
- > further our technical assistance and information dissemination efforts,
- > enable HAB to hire additional staff, and
- > allow project officers to have smaller portfolios enabling them to spend more time with each grantee.

The figure below illustrates the new HAB organizational structure. We believe this will make the Ryan White HIV/AIDS Program even stronger.

Since our last progress report in 2010, we've had other milestones. Some include the creation of our in+care Campaign, which focuses on retention in HIV primary care and reflects our values. It also marks HAB's first health campaign run entirely online and through phone and Webinars. The Campaign is focused on increasing provider readiness and working to bring patients back into care to access all that the Ryan White HIV/AIDS Program has to offer. Other recent HRSA successes are outlined as follows.



## HRSA RECENT SUCCESSES

### Early Intervention Training and Services

We know that improving care strategies involves effective patient engagement and critical early intervention services (EIS). Some parts of the country, however, continue to be impacted by the HIV epidemic at a rate that outpaces available resources. HRSA has heard this call for action and, in 2011, directed \$4.6 million dollars to fund up to 10 new Part C EIS grant programs. In 2012, HRSA's Division of Community Based Programs, in partnership with the Bureau of Primary Health Care, also launched the Increasing Access to HIV Care and Treatment supplemental funding opportunity, an approximately \$12 million effort for current EIS grantees to increase HIV care and treatment access for patients most in need.

HRSA's EIS efforts are also extending to a newly launched peer-based early intervention program. Through a cooperative agreement, tools have been developed to provide guidance, a readiness checklist, recommended intervention and planning strategies, and suggested timetables. This is all being done to help Part A and B programs effectively engage consumers and reduce their unmet needs. Tools are available at the Technical Assistance Resources, Guidance, Education & Training (TARGET) Center Web site, a technical assistance site funded by HRSA through a cooperative agreement. The Web site includes capacity building and technical assistance tools found at: [www.careacttarget.org](http://www.careacttarget.org).

### Shifts in the Epidemic

Increasing HIV infections coupled with workforce shortages underscores the need for new strategies and innovative thinking.

To ensure the Ryan White HIV/AIDS Program public health infrastructure remains ever strong, HRSA is working diligently to increase the HIV workforce capacity by expanding HIV management curriculum and training opportunities, holding a HRSA workforce strategy meeting, and launching the HRSA-funded Health Workforce Information Center (found here, [www.hwic.org](http://www.hwic.org)). These efforts will help achieve the National HIV/AIDS Strategy's (NHAS's) goal of increasing access to care.<sup>1</sup>

HRSA has also created and expanded data and information systems, and focused on proper planning, delivery, and evaluation of HIV care.

In 2011, HRSA launched three AIDS Education and Training Center (AETC) telehealth center awards for \$599,924 to provide education, training, and clinical consultations by utilizing the power—and promise—of technology. Programs funded through this work include the Pacific AETC HIV Learning Network, the Telehealth Appalachian AETC Program, and the Northwest (NW) AETC Project Extension for Community Healthcare Outcomes (ECHO). (To learn more about these efforts and what they're doing to assist providers in low prevalence and often rural pockets of the country, see Chapter 6 of this report, where the NW AETC Project ECHO is discussed in detail.)

HRSA's programs also reflect shifts in HIV epidemiology, and these shifts are mirrored in the NHAS's call for comprehensive health-care services for women, infants, children, and youth in those areas of the country with

<sup>1</sup> The National HIV/AIDS Strategy was released on July 13, 2010 and provides a clear and comprehensive roadmap toward mitigating the impact of HIV on people living with and affected by HIV/AIDS and, ultimately ending the HIV epidemic. To learn more, visit: [www.whitehouse.gov/administration/eop/onap/nhas](http://www.whitehouse.gov/administration/eop/onap/nhas).



the greatest need for services. To help achieve this goal, HRSA's Part D Program was recompeted to ensure more equitable funding. HRSA has also launched a Special Projects of National Significance (SPNS) initiative to address the disproportionate impact of HIV among women of color. In this way, HRSA is reducing HIV-related health disparities concurrent with NHAS strategy. (To learn more about this initiative see Chapter 5 of this report and visit: [www.hab.hrsa.gov/abouthab/special/womencolor.html](http://www.hab.hrsa.gov/abouthab/special/womencolor.html).)

### Pilot Projects

#### *AETC Expanding HIV Training into Graduate Medical Education Program*

In 2011, HRSA, for the first time, created a 4-year pilot project (funded at \$450,000) to expand opportunities for academic health science centers to train medical residents in HIV/AIDS primary care and treatment. This developmental work seeks to expand upon existing accredited primary care residency programs to

include an HIV focus. Currently three programs are participating in the project, including Yale University AIDS Internal Medicine Infectious Disease Division; Family Medicine Residency of Idaho; and the Research Foundation of the State University of New York (SUNY) Downstate Medical Center.

### HRSA Goes High Tech

HRSA is investigating the potential role of social media in health care. In 2006, HRSA released a *What's Going on @ SPNS* bulletin on social media outreach geared towards young men of color who have sex with men, available at: [www.hab.hrsa.gov/abouthab/files/cyberspns\\_outreach.pdf](http://www.hab.hrsa.gov/abouthab/files/cyberspns_outreach.pdf). In 2011, HRSA devoted an entire *HRSA CAREAction* newsletter on the topic of social media and HIV, available here: [www.hab.hrsa.gov/newspublications/careactionnewsletter/june2011.pdf](http://www.hab.hrsa.gov/newspublications/careactionnewsletter/june2011.pdf). HRSA also has its own YouTube channel at [www.youtube.com/user/HRSAtube](http://www.youtube.com/user/HRSAtube), Twitter account at [@HRSAgov](http://twitter.com/HRSAgov), Target



NW AETC staff regularly meet to discuss new HIV developments.

Center Twitter account at [@ryanwhitecare](https://twitter.com/ryanwhitecare), and provides social media and health care resources along with other Federal agencies at [AIDS.gov](http://AIDS.gov). In FY 2012, HRSA successfully competed for Minority Aids Initiative (MAI) funding from the HHS Secretary to support the Text4Care project. This two-year \$750,000 project will use mobile texting to improve retention in care and medication adherence in youth and adult minorities living with HIV in Southern States. These social media outreach efforts represent an exciting time at HRSA.

### Special Projects of National Significance

Pilot projects at HRSA are nothing new. SPNS is built around the goal of research and replication. These SPNS projects align with the NHAS and, in fact, the *HHS Operational Plan: Achieving the Vision of the National HIV/AIDS Strategy* identifies the creation of buprenorphine training materials (outlined below) as one way HRSA can further Federal HIV efforts. In recent years, many successful SPNS projects have come to an end yielding promising results for the greater HIV community. Some recent SPNS achievements include:

- > **Oral Health Initiative (2006–2010).** Oral health is often one of the most unmet needs among PLWHA. This initiative promoted the development and evaluation of successful models in overcoming this challenge, particularly in communities where public HIV oral health services either did not exist or were severely inadequate.
- > **Electronic Networks of Care Initiative (2007–2011).** This initiative funded six demonstration sites to enhance existing electronic information technology systems to facilitate health information exchanges among providers.
- > **Enhancing Linkages in Jail Settings (2007–2012).** As a follow up to the successful HRSA–U.S. Centers for Disease Control and Prevention (CDC)-funded Correctional Demonstration Project focused on people with HIV in prisons, this initiative identified how best to promote integration of services and create a continuum of care for people leaving jail settings.

- > **Integrating Buprenorphine into HIV Primary Care Settings Monograph (2012).** A monograph was created based on the results of the SPNS Innovative Methods for Integrating Buprenorphine Opioid Abuse Treatment in HIV Primary Care initiative. The buprenorphine monograph can be found at [www.careacttarget.org/content/integrating-buprenorphine-therapy-hiv-primary-care-settings](http://www.careacttarget.org/content/integrating-buprenorphine-therapy-hiv-primary-care-settings).

These resources are just one of many efforts HRSA is taking to improve information dissemination to grantees, arming them with the resources they need to bolster their HIV efforts. Marrying SPNS best practices with training and technical assistance (TA), HRSA has launched the Integrating HIV Innovative Practices (IHIP) project. This project creates an online community where providers can share their experiences



Good oral health is important for medication absorption and nutrition in people living with HIV.

and learn from one another and which also houses an implementation training manual, curriculum, frequently-asked questions resource, and educational Webinars that can be accessed at [www.careacttarget.org/library/integrating-hiv-innovative-practices-ihip](http://www.careacttarget.org/library/integrating-hiv-innovative-practices-ihip).

Other ways SPNS is meeting public health objectives is with its new Hepatitis C Treatment Extension Initiative (<http://hab.hrsa.gov/about/hab/special/spnshepatitisc.html>). Although research is still underway, we know that PLWHA are disproportionately affected by viral hepatitis—including hepatitis C—which can lead to

adverse health outcomes. This work aligns with the HHS action plan to combat viral hepatitis (To learn more, visit: [www.hhs.gov/ash/initiatives/hepatitis/actionplan\\_viralhepatitis2011.pdf](http://www.hhs.gov/ash/initiatives/hepatitis/actionplan_viralhepatitis2011.pdf)). Other ways this work is being advanced is through the inclusion of hepatitis screenings in HIV performance measures, detailed here: <http://hab.hrsa.gov/deliverhivaidscares/habperformmeasures.html>.



### Oral Health

Ryan White medical providers offer an opportunity to serve as the first line of defense in preventing oral health issues. As such, HAB's chief dental officer has created the first oral health assessment for the Ryan White medical community. This work was informed by a meeting of medical and dental experts who discussed training and education needs of primary care providers; the meeting was followed by a national Webinar on performing oral health exams in primary care settings.

Often, PLWHA must take their antiretroviral medications with food—a challenging directive for a person with missing teeth or who suffers from painful oral infections

such as mucositis that can make chewing painful and difficult. As a result, lack of proper dental care can lead to poor nutrition and decreased medication adherence, creating additional health complications.

HRSA's Part F Dental Reimbursement Program assists institutions by defraying unreimbursed dental treatment costs for PLWHA. In addition, HRSA has the Community-Based Dental Partnership Program to provide education and clinical training to dental providers, ensuring that dentists are ready to meet mounting needs. (To learn more about these programs, visit [www.hab.hrsa.gov/abouthab/partfdental.html](http://www.hab.hrsa.gov/abouthab/partfdental.html).)

In an effort to increase awareness around oral health, HAB's Division of Community Based Programs helped create HRSA's first-ever HIV and Oral Health Webpage, which can be accessed at: [www.hrsa.gov/publichealth/clinical/oralhealth/index.html](http://www.hrsa.gov/publichealth/clinical/oralhealth/index.html). *The Ryan White HIV/AIDS Oral Health Program Fact Sheet*, available at [www.hab.hrsa.gov/abouthab/files/oral\\_health\\_fact\\_sheet.pdf](http://www.hab.hrsa.gov/abouthab/files/oral_health_fact_sheet.pdf), was recently produced to educate grantees and includes resources on oral health offerings and questions to work through when integrating these services into primary care settings.

### Fiscal Responsibility and Funding

As part of the Ryan White HIV/AIDS Program Parts A and B National Monitoring Standards, HRSA has sought to increase communication with grantees and improve transparency regarding specific requirements. In doing so, HRSA has released a packet of materials consolidating:

- > the minimum expectations for programs,
- > required fiscal monitoring,
- > management policies,
- > conditions of award, and
- > HRSA and HAB guidelines.

These materials can be found at [www.careacttarget.org/library/monitoring-standards-ryan-white-part-and-b-grantees-universal-standards](http://www.careacttarget.org/library/monitoring-standards-ryan-white-part-and-b-grantees-universal-standards).

This was a joint effort on behalf of HRSA's Division of Service Systems, Grants Management Office, the HHS Office of General Counsel, and the Office of Communications. For Part A and B grantees, particularly new grantee staff, there was a training in Rockville, Maryland on June 6–8, 2011 and June 13–15, 2011 to engage with HRSA staff, watch presentations, and

participate in open dialog about monitoring standards. HRSA's goal is, and always has been, to ensure grantees are armed with what they need to succeed; these materials and meetings are just two more ways we're ensuring this happens.

Through a national TA cooperative agreement, we're further bolstering the fiscal skills of grantees and providers by providing trainings across four U.S. cities on grants compliance, preparation for audits, and other fiscal needs.



"My greatest accomplishment is hearing people," says Brian Fisher (featured here). Fisher is a long-time advocate and is served through the Marion County Health Department in Indianapolis, a Ryan White Part A grantee.

*Thanks to advances in HIV care and programs like Ryan White, "Every day I wake up, no matter how I feel, I know it's a good day: I'm still alive."*

KELLEY, AN HIV PATIENT AT BOSTON MEDICAL CENTER, A RYAN WHITE HIV/AIDS PROGRAM PART B SUBGRANTEE

### Increasing Capacity at Home and Abroad

It's a demand HRSA is more than happy to fill: helping grantees increase their capacity and achieve the vision of the NHAS. Through the TARGET Center Web site ([www.careacttarget.org](http://www.careacttarget.org)), we're routinely updating the HIV community with new resources, Webinars, journal articles, and manuals. New sections have been devoted in the TA library to those issues grantees and providers tell HRSA are most pressing.

HRSA has also entered into a cooperative agreement with the University of Medicine and Dentistry of New Jersey. Through this partnership we're assisting Ryan White providers in becoming patient-centered certified medical homes, a process that will enable them to



HRSA continues to educate providers across the country and, indeed, the world about HIV care and delivery.

benefit from Affordable Care Act reimbursement policies. The medical home model is one the Ryan White HIV/AIDS Program has helped spearhead and it's an issue discussed in one of this year's *HRSA CAREAction* newsletters, found at: [www.hab.hrsa.gov/newspublications/careactionnewsletter/habcareactionmarch2012.pdf](http://www.hab.hrsa.gov/newspublications/careactionnewsletter/habcareactionmarch2012.pdf).

Grantees and providers seeking additional training resources to ramp up their patient service delivery systems also can turn to HRSA's new ADAP quality management tutorials. Created in partnership with the National Alliance of State and Territorial AIDS Directors (NASTAD), the tutorials provide ADAP coordinators information and guidance around the implementation of HRSA and HAB clinical performance measures for ADAPs. (Visit [www.careacttarget.org](http://www.careacttarget.org) and search "ADAP Quality Tutorials" to learn more.)

### National Lessons Learned Get a Global Spin

The Ryan White HIV/AIDS Program has a lot to teach not only the Nation, but also the world, about delivering comprehensive health care. Delivering effective care requires clinicians to be educated, not only about the myriad changes in the HIV landscape, but also about lifesaving—and life-extending—treatment. Ensuring PLWHA have access to this informed care and treatment drives the Ryan White HIV/AIDS Program. ADAP, which connects PLWHA with HIV medications, accounts for the largest investment of Program funds. Translating Ryan White HIV/AIDS Program successes abroad, HRSA's President's Emergency Plan for AIDS Relief (PEPFAR)-funded Global HIV/AIDS Program, in conjunction with the U.S. Centers for Disease Control and Prevention (CDC), Catholic Relief Services/AIDSRelief Consortium, and Harvard School of Public Health, has embarked on the Track 1.0 care and treatment program designed to kick-start large-scale antiretroviral programs.

The Track 1.0 care and treatment program has delivered antiretroviral therapy (ART) to more than 1.5 million patients in 13 resource-constrained countries. Ryan

White providers and grantees have learned that long-term solutions to local problems often lie within those communities. In this vein, HRSA's capacity building activities are enabling local clinicians to step into more active roles in delivering ART and, now, into managing patients themselves. HRSA's work is creating a stronger workforce and an improved health-care system.

HRSA's Global HIV/AIDS Program is also supporting PEPFAR efforts to increase the number of health care workers by 140,000. One such example is HRSA's work with the University of the West Indies in Kingston, Jamaica, to implement Caribbean HIV/AIDS Training Initiative (CHART-II). In 2010, the U.S. Government signed the Caribbean Regional Partnership Framework with 12 countries in the Caribbean: Antigua and Barbuda, the Bahamas, Barbados, Belize, Dominica, Grenada, Jamaica, St. Kitts and Nevis, St. Lucia, St. Vincent and the Grenadines, Trinidad and Tobago, and Suriname. This work is currently being transitioned to full country ownership.

In Africa, HRSA's Global HIV/AIDS Program created the Medical and Nursing Education Partnership Initiatives (MEPI and NEPI, respectively). In collaboration with the National Institutes of Health, the MEPI provides up to \$130 million in grants over 5 years to African institutions in 12 countries, to develop or expand models of medical education, research, and retention of medical school faculty. The NEPI addresses the severe shortage of nurses and midwives in the areas of recruitment, training and education, and retention.

## LOOKING AHEAD

HRSA's recent achievements serve as stepping stones toward a higher level of care, a more comprehensive health-care system, and a healthier planet. Because of HRSA, communities in severe need are receiving an influx of resources. Clinicians interested in HIV care, whether in medical residency programs in rural America or in Africa, are receiving the training they need to deliver the care their patients deserve. We are not reinventing the wheel, but reimagining what's possible. It's dreaming big that enabled passage of the Ryan White HIV/AIDS Program all those years ago and what's inspired the work outlined in this chapter. This aspiration for increased health-care coverage for the underserved is what's also driven the seminal passage of the Affordable Care Act (ACA). Together with the Ryan White HIV/AIDS Program, the health-care landscape looks bright. (To view a copy of the *HRSA CAREAction* newsletter on the ACA, visit [www.hab.hrsa.gov/deliverhivaids/careactionnewsletter.html](http://www.hab.hrsa.gov/deliverhivaids/careactionnewsletter.html).)

There is and will continue to be a need for the Ryan White HIV/AIDS Program today and well into tomorrow. And as always, HRSA will rise to the charge and will continue to ensure PLWHA have healthier lives and brighter futures.

To provide a glimpse of some of the exciting work and success stories realized on the ground, each forthcoming chapter includes a grantee case study from each Ryan White HIV/AIDS Program Part.

2. PART A PROGRAM: ELIGIBLE METROPOLITAN AREAS (EMAS) AND TRANSITIONAL GRANT AREAS (TGAS)

WHETHER YOU'RE ON THE FRONTLINES OR NOT, YOU  
DO THIS WORK BECAUSE YOU REALLY WANT  
TO MAKE A DIFFERENCE.

RYAN NIX, STEP-UP, INC.



Part A of the Ryan White HIV/AIDS Program provides assistance to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs). To qualify for EMA status, an area must have reported at least 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. To be eligible for TGA status, an area must have reported 1,000 to 1,999 AIDS cases in the most recent 5 years and have a population of at least 50,000. EMAs and TGAs range in size from one city or county to entities spanning more than one State; the boundaries are based on U.S. Census designation of Metropolitan Statistical Areas.

EMA and TGA funding helps bring necessary support to locales that are most severely affected by the HIV/AIDS epidemic. Some of these are the original HIV epicenters while others represent areas more newly-affected. All, however, have large numbers of AIDS cases. EMA and TGA funds are given directly to the chief elected official of the city or county that provides health-care services to the greatest number of people living with AIDS within that service area.

In the section that follows is a case study of the Indianapolis TGA and, specifically, how this grantee is extending HRSA's work in health information technology (HIT). The Indianapolis grantee also exemplified what's possible with the influx of Ryan White HIV/AIDS Program funding, support, and capacity building. (To learn more about the Part A program, visit: [www.hab.hrsa.gov/about/hab/parta.html](http://www.hab.hrsa.gov/about/hab/parta.html).)

## CASE STUDY: THE CITY OF INDIANAPOLIS

More than 2,000 providers across the United States and its Territories are funded through the Ryan White HIV/AIDS Program, yet the Program's transformative power is felt in a unique way here in Indianapolis. For it is in this city that Ryan White himself received care.

Ryan came to Indianapolis from Kokomo, Indiana in a very different world, fighting a tide of discrimination, stigma, and ignorance about the disease that eventually claimed his life. Today, Indianapolis offers care that a boy like Ryan could only have dreamed about.

Central to the delivery of HIV medical care in Indianapolis is the Infectious Disease Clinic (IDC) at Wishard Health Services, which offers state-of-the-art, wraparound services complete with an in-house pharmacy stocked with lifesaving HIV medications. "People

### PART A: GRANTS TO ELIGIBLE METROPOLITAN AREAS AND TRANSITIONAL GRANT AREAS

Part A of the Ryan White HIV/AIDS Treatment Extension Act funds emergency assistance to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs).

In 2012, Part A received \$637.5 million in funding.



**EMAs:** Grants are awarded to eligible areas with populations of more than 50,000 that report at least 2,000 AIDS cases in the most recent 5 years and have a cumulative total of more than 3,000 living cases of AIDS. There are 24 EMA programs.

**TGAs:** Grants are awarded to eligible areas with populations of at least 50,000 that report 1,000 to 1,999 AIDS cases in the most recent 5 years and have a cumulative total of more than 1,500 living AIDS cases. There are 28 TGA programs.



come here because we have some of the best infectious disease experts in the State,” says Danielle Osterholzer, physician at Indiana University (IU) School of Medicine and medical director of the IDC.

To ensure that patients are aware of their HIV status and are accessing the plethora of available services, Wishard offers HIV testing in its hospital emergency room and, in conjunction with IU, is conducting HIV clinical trials. In addition, the Marion County Health Department has partnered with IU on a quality improvement project focused on increasing HIV awareness and testing among pregnant women in their third trimester so that they enter—and stay—in care, until their baby’s birth and well into the future.

### THE QUEST FOR RYAN WHITE FUNDING

Ryan, and disenfranchised people like him, have always had allies. Virginia Caine, Marion County health director, for example, has been working to fight HIV from early on. “I met Ryan White and his mother,” she recalls. “I was appointed as the chairperson of the HIV School Guidelines Committee by Dr. Woodrow Meyers. [He] was the State Health Commissioner and one of the first national leaders in HIV and a champion for Ryan’s fight to attend school.”

Caine spent her days providing sexually transmitted disease (STD) screenings for men who have sex with men (MSM) at a health clinic in Indianapolis. At night,

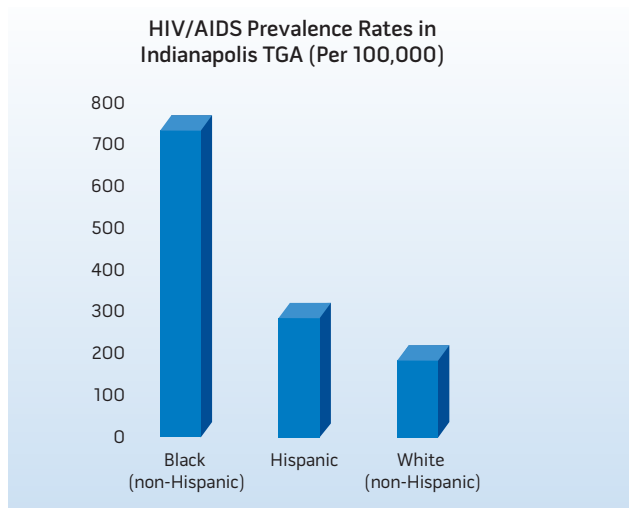


Virginia Caine, Marion County health director, has been a long-time champion for comprehensive HIV services in Indianapolis.

she administered HIV tests and provided education to substance users. It was a different time, with hope often in short supply. Yet nothing seemed to stop her.

Like Caine, Michael Wallace, Marion County director of Ryan White HIV Services, felt a personal call and connection to the disease. Through the years, Caine and Wallace were tireless in their work and in their advocacy for better care for PLWHA. “Too many people were dying, and I wanted to get involved in the community in which I was living. I think most of us who do this work, work from a place of passion,” Wallace says.

Still, the community suffered. HIV infections were on the rise; oral health service offerings were scarce; need for case management, particularly the kind of intensive case management required by many high-risk populations, outweighed availability; and while HIV testing was done, the city could not routinize it to the extent they wished. But this was all about to change.



Health and Hospital Corporation of Marion County. Health and Hospital Corporation of Marion County Indianapolis TGA Ryan White Part A Program FY 2012. [Program narrative.] 2012.

In 2007, Caine and Wallace embarked on an endeavor that would change their community—and the lives of PLWHA in Indianapolis—forever: They wrote the Ryan White Part A Transitional Grant Area (TGA) grant application. Later that same year, they received Part A funding. The news brought great excitement to the area’s

public health field, and PLWHA and their allies. It also brought badly-needed new resources to a community determined to take care of its own.

The funding freed up State monies to be used in rural areas with notorious unmet need while addressing the kinds of issues that plagued the city of Indianapolis. As Brad Gumbert, co-executive director of the community-based organization Step-Up, Inc., explains, “The TGA funding allowed us to offer more support services. Before, if a client needed groceries, housing assistance, or utilities, we didn’t have the resources. Now we do. That’s not little. That’s what keeps people in care.”



Michael Wallace, Marion County director of Ryan White HIV Services, (featured here) stands in the heart of downtown Indianapolis.

### THE POWER CONTINUES

Milestones in AIDS care continue to occur in part thanks to people like Caine and Wallace and, of course, the support of the Ryan White HIV/AIDS Program.

### Digital Age

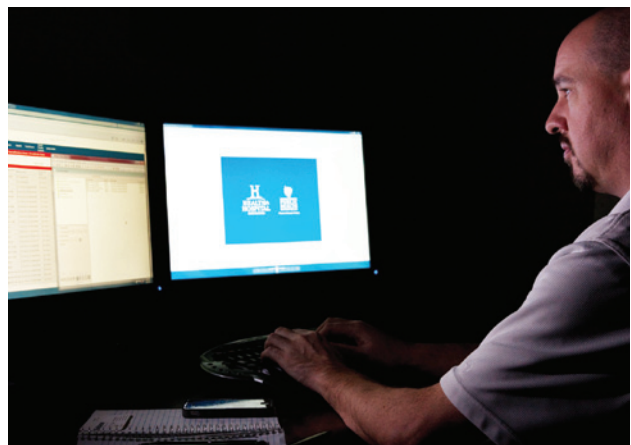
With \$3.04 million in TGA funding, however, came new demands for Step-Up, Inc. The new TGA designation meant that Caine, as the Marion County health director, and Wallace, as the Marion County director of Ryan White HIV Services, needed a comprehensive tracking mechanism for these new dollars. Enter Scott Gardner and Belinda Le Blanc, information technology specialists at the Marion County Health Department.



Belinda Le Blanc, (featured here) has been integral in the Marion County Health Department’s use of health information technology.

Together, Gardner and Le Blanc developed the Ryan White Information Services Enterprise (RISE) data system—testament of what’s possible when grantees dream big and have the resources to follow through. HRSA has long supported customized approaches to addressing local challenges, and the RISE system is no exception.

RISE is a secure network that allows the Marion County Health Department to easily track health-care delivery and compliance with HRSA reporting requirements. At the end of the day, however, data systems are all about answering the question of how grantees can do better—and go further—for PLWHA. For this reason, RISE incorporated money management into the system. This



Scott Gardner (featured here) accesses the RISE data system which tracks and coordinates the Marion County Health Department’s compliance with HRSA standards.

feature allows the Marion County Health Department to readily identify duplication of services and ensure appropriate allotment of funds to those areas where the community has the most need. It's creating a more robust health-care system and achieving the goal of the Ryan White HIV/AIDS Program itself: healthier people and fuller lives.

Take support services, which address patients' basic needs. Immediate access to these services can mean the difference between staying in care and dropping out, between having a hot meal and going hungry. Le Blanc tells the story of a Marion County Health Department case manager who was on a trip in Washington, DC, when a patient desperately needed a referral. "The system is built so you can work outside the building so long as you log into our network. Our case manager was able to process all of the patient referral paperwork immediately online—something she never would have been able to do before."

With the increase in Federal dollars comes increased responsibility. RISE revealed that many patients were accessing the same services at multiple sites, resulting in duplications in lab work and, consequently, incurring unnecessary costs to the TGA. Armed with data, the Marion County Health Department worked to improve coordination, reduce duplication, and free up funds for patient care.

### Oral Health Care

The influx of Part A funds has allowed the Marion County Health Department not only to identify new areas of unmet need, but to offer increased services for issues like oral health care that have long plagued PLWHA. Although the Marion County Health Department had established its first specialized HIV dental clinic in the early 1990s, demand had outweighed resources.

Nationally, between 32 and 46 percent of people with HIV disease will have at least one major HIV-related oral health problem.<sup>2</sup>

HRSA has created models for effective dental care and these values can be found at the IU School of Dentistry, a leader in increasing access to oral health care for PLWHA in Indianapolis, thanks to a program established by Stuart Schrader, professor at the IU School of Dentistry. The IU program receives Part A funding, which aims to increase the cultural competency and treatment acumen of dentists treating HIV-positive people.

What prompted Schrader to initiate this work dates back to his early years. He says, "I remember seeing health care and medical students find out someone had HIV, and they acted awkwardly and uncomfortable around them. I wanted to positively transform that clinical and social interaction." The support of Part A funding has allowed him to do just that. Today, the IU School of Dentistry is a recipient of the Orna Shanley Prize, an award given by the American Dental Education Association and the International Federation of Dental



**Ryan McConnel, care coordination program manager at the Damien Center, talks with a client. The Damien Center is the largest care coordination site in the State of Indiana.**

<sup>2</sup> Health Resources and Services Administration, HIV/AIDS Bureau. *Oral health and HIV [fact sheet]*. 2011. Available at: [www.hab.hrsa.gov/about/hab/files/oral\\_health\\_fact\\_sheet.pdf](http://www.hab.hrsa.gov/about/hab/files/oral_health_fact_sheet.pdf). Accessed March 23, 2012.



Stuart Schrader, PhD, (featured here) stands in the dental clinic at Indiana University School of Medicine. Schrader has been integral in bringing dental services to HIV-positive people in Indianapolis.

Educators and Associations in recognition of an academic dental institution that has demonstrated innovative solutions addressing local access-to-care issues.

Before the TGA funding, Willis, who has HIV, had nowhere to go to get affordable dental care. He had difficulty chewing and was underweight at 140 pounds. His lack of food was affecting his antiretroviral therapy absorption. Since the IU program's expansion, Willis weighs in at a healthy 180 pounds, and has a new pair of perfectly fitted dentures and a healthy appetite.

"I looked in the mirror," Willis says, "and I was like, 'Thank you Jesus.' Finally! Now, I walk around and I can't stop smiling." In addition to his confidence, Willis' health has improved, too. His favorite part of having new teeth? "Ribs!" he says with a laugh, and another big smile. "And Thanksgiving!"

### Women's Care

Consumer surveys revealed a need for greater access to gynecological services, particularly cervical cancer

screenings. According to patients, however, increased availability might not equal increased use: gynecological care and screenings needed to be colocated with other services.

The Marion County Health Department, thanks to the RISE system, saw this unmet need and was able to direct the newly freed-up funds to support these necessary—and lifesaving—screenings. Life Care at Methodist Hospital, a local community partner that readily treats HIV-infected women, has now brought gynecological services onsite. No matter how automated systems become, patients still need clinicians who can help them.

Technology facilitates the process of connecting—and caring—for patients and illustrates how Ryan White grantees are dedicated to finding the best way to serve PLWHA. In this manner, the homegrown information technology system built in Indianapolis serves the needs of patients as well as administrators.



Willis (featured here) examines his new dentures. "Now I can't stop smiling, smiling, smiling," he says. "This has really improved my quality of life." Willis receives oral health care at the IU School of Dentistry, a Ryan White HIV/AIDS Program Part A subgrantee.

### AHEAD OF THE CURVE

Despite the Nation's extraordinary progress in addressing the epidemic, the NHAS highlights the number of HIV-infected people still out of care, and the CDC estimates that 21 percent of people who are HIV positive aren't aware of their serostatus.<sup>3</sup> In Indianapolis, the power and promise of the Ryan White HIV/AIDS Program are being brought to bear against this problem.

### Reaching People Not In Care: Step-Up, Inc.

Step-Up, Inc., is a Part A subgrantee that focuses on the highest-risk populations in Indianapolis. The organization focuses heavily on outreach, sending employees like Ryan Nix into bars to educate people about the risks of HIV and resources available. In 2011, Step-Up provided nearly 900 HIV tests.

Step-Up goes wherever people at risk for HIV congregate. Today, the program's attention is focused

on Indianapolis' MSM and incarcerated populations, which data show are at increased risk for HIV infection. Recently, Step-Up arranged an HIV testing station in the parking lot of a methadone clinic.

Step-Up goes online, too. The organization has established a Facebook page that describes the organization and provides information on testing events and



Ryan Nix, prevention director & testing coordinator at Step-Up, Inc., (- here) discusses paperwork with a client.

<sup>3</sup> U.S. Centers for Disease Control and Prevention. *HIV in the United States*. July 2010. Available at [www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf](http://www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf).



Staff from the Wishard Infectious Disease Clinic in Indianapolis, Indiana.

prevention. In addition, it's using gay social networking services to perform virtual outreach, going into chat rooms and offering health information.

This cutting-edge approach to reaching people not in care reflects the Marion County Health Department's focus on—and encouragement of—innovation. The Indianapolis TGA pushes boundaries and is rethinking business as usual in order to achieve extraordinary results. Nix says that he's been in the community doing outreach with MSM and he's taken those opportunities to do targeted prevention messaging so that men at risk or unaware of their status are tested and those in need of care are referred to services. This is just one more way the Ryan White HIV/AIDS Program is, and has always been, ahead of the curve.

## LEARNING FROM THE PAST, LOOKING TO THE FUTURE

Indianapolis illustrates what happens when a community is given the resources with which to act and what's possible when people reach outside themselves for the good of their community. But the story of Indianapolis' response to the HIV/AIDS epidemic is also about how the Ryan White HIV/AIDS Program continues to evolve—funding areas with emerging epidemics, encouraging grantees to customize their local response to HIV, and arming grantees with the tools and support they need to achieve results. “We followed every piece of advice HAB gave us,” says Caine. “The Federal government really was AMAZING!”

Wallace says,

With Ryan White it forces agencies not to be competitive against one another but to come together as partners... We regularly meet with Indiana State Department of Health to coordinate Parts A, B, and C funding to set priorities and maximize the allocation of funds. We've truly become a model of a successful Federal, State, and local partnership. This is all done with the goal, of course, of improving peoples' health and the health of our community—and that's exactly what we're doing.

Indianapolis, and HIV care in general, have come a long way since Ryan White was treated here. With TGA funding and HRSA support, Indianapolis has been able to transform itself into a city with the kind of high-quality, lifesaving care that Ryan's mother had always hoped would be possible for her son. It's the kind of care the program that bears his name is dedicated to creating.

3. PART B PROGRAM: STATES AND TERRITORIES



WHEN I STARTED GETTING INVOLVED IN HIV I REALIZED  
IT WASN'T THE END OF THE WORLD, BUT THE  
BEGINNING OF ANOTHER LIFE.

DELPHINE, PATIENT AT BOSTON MEDICAL CENTER

Part B of the Ryan White HIV/AIDS Program provides grants to States and U.S. Territories and consists of a base grant, the AIDS Drug Assistance Program (ADAP), ADAP supplemental funds, ADAP Emergency Relief grants, and funding for Emerging Communities (those areas reporting between 500 and 999 cumulative AIDS cases over the most recent 5 years). All 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and the 6 U.S. Pacific Territories/Associated Jurisdictions receive funding.

Grantees are State health departments or other State entities that implement and manage State public health programs. The Part B program enables all areas of the Nation to address HIV/AIDS within their State regardless of HIV epidemic size. The ADAP program brings life-saving—and live extending—HIV antiretroviral medications to some of the most disenfranchised populations. Many of these individuals, without the Ryan White HIV/AIDS Program, would have no other means for purchasing these necessary drugs.

The Ryan White HIV/AIDS Program has always served as a safety net for people living with HIV disease. In the section that follows is a case study of the Massachusetts Part B grantee outlining the work they're doing to further strengthen this safety net and ensure the highest quality care for those in need. (To learn more about the Part B program, visit: [www.hab.hrsa.gov/about/hab/partbstates.html](http://www.hab.hrsa.gov/about/hab/partbstates.html).)

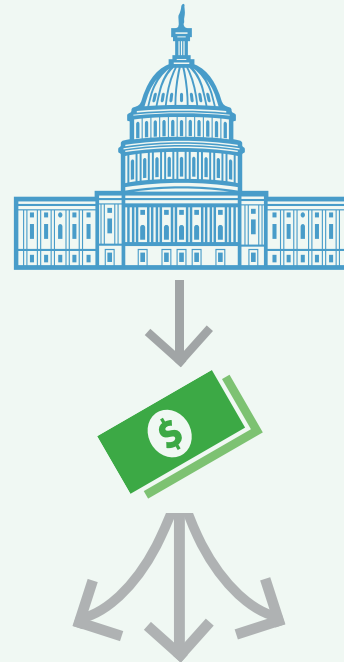
### CASE STUDY: STATE OF MASSACHUSETTS

Listening to the myriad voices of Massachusetts' various advocacy groups plays an essential role in helping state, county, and local health agencies and the HIV/AIDS care provider community achieve the "ultimate vision" that they share: that consumers can go to any health-services or case-management provider and receive the same high-quality care no matter who they are or where they reside in the State.

### PART B: GRANTS TO STATES AND TERRITORIES

Provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 6 U.S. Pacific Territories or Associated Jurisdictions.

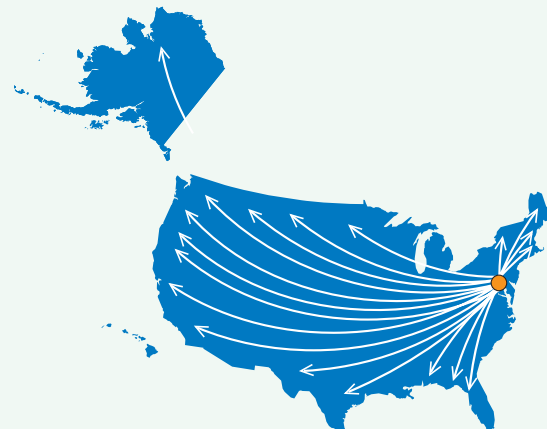
In 2012, Part B received \$1.2 billion in funding.



**Base Grants:**  
Awarded to States and Territories using a formula based on reported living cases of HIV/AIDS.

**AIDS Drug Assistance Program (ADAP):**  
Funds are determined using a formula and earmarked for State ADAPs, for the primary purpose of paying for medications.

**Grants to States with Emerging Communities:**  
Cities with at least 500 but less than 1,000 reported HIV/AIDS cases in most recent 5-year period and have a cumulative total of 750 or more living AIDS cases.



Funds are awarded to States and Territories, which allocate them to public and nonprofit providers of HIV/AIDS services. States with more than 1 percent of total HIV/AIDS cases reported in the United States in the past 2 years must match funds provided by Ryan White.



### ***IF YOU BUILD IT TOGETHER, THEY WILL COME***

According to Dawn Fukuda, director of the Office of HIV/AIDS at the Massachusetts Department of Public Health (DPH), “We have different consumer and provider advisory boards for different services. This helps ensure that the models we are proposing are consistent with the expectations of the people we serve. We know that if we build it, they won’t come if it doesn’t make sense in their universe.”

The history and, indeed, the foundation of the Ryan White HIV/AIDS Program were developed on and around consumer involvement—an innovation that began more than 20 years ago and continues to this day. The Massachusetts DPH, a Ryan White Part B grantee, has gone above and beyond this call of duty and incorporated consumers in virtually every aspect of care delivery. (See box on page 24.)

To ensure consumers are receiving the best possible care, the Massachusetts DPH has embarked on a multi-year, quality-of-care analysis across its service area. The goal is to create a stronger, more responsive service system for HIV-positive residents and build healthier communities. The State has made significant investments in data gathering and analysis. The data are used for planning and also for moving funds to where they are most necessary. One result is that the



**Barry Callis, director of the HIV/AIDS Prevention and Screening Unit at the Massachusetts DPH (featured here) supports direct services to substance users heavily impacted by HIV and Hepatitis C. Callis says, “This work has brought my experience in sexual health, addiction, and trauma together to support individuals on their path to recovery.”**

incidence of HIV in Massachusetts is declining, unlike in other States. This is due in part to Medicaid expansion (HIV waiver), State health reform, substantial State investment, funding of safety net hospitals, and an extensive community health center system.

The Massachusetts DPH analysis yielded some surprising results. As Kevin Cranston, director of the Bureau of Infectious Disease at the Massachusetts DPH explains,

I think we would have expected to see racial and ethnic disparity among people utilizing the care system



**Clients and supporters of the New Bedford Community Health Center (featured here) help foster Massachusetts’ consumer-focused health care system.**

## MASSACHUSETTS DPH: ADVISORY BOARDS AT A GLANCE

These advisory boards help the Massachusetts DPH in meeting the goals and requirements associated with the Ryan White HIV/AIDS Program and ensure that community and consumer voices are heard. Involvement of advisory boards is a hallmark of the Ryan White HIV/AIDS Program.

- > **Consumer Office:** The office resides in the Office of HIV/AIDS and is staffed by PLWHA. The Consumer Office coordinates the Statewide Consumer Advisory Board (SWCAB) and provides technical assistance to agency consumer advisory boards (CABs).
- > **Statewide Consumer Advisory Board (SWCAB):** The SWCAB ensures routine input from consumers into HIV-related policies, strategies, programmatic issues, and services affecting the lives of PLWHA.
- > **Scientific Advisory Board:** The board includes consumers, epidemiologists, medical providers, and educators. They guide the development of policies for the State HIV Drug Assistance Program (HDAP).
- > **PrEP (Pre-Exposure Prophylaxis) Clinical Advisory Group:** This group consists of clinical providers that offer guidance on implementation of PrEP interventions as a component of HIV prevention services.
- > **The Massachusetts Integrated Prevention and Care Committee (MIPCC):** MIPCC members represent cities, communities, and populations with the greatest incidence and prevalence of HIV disease in the State. Their primary responsibility is to provide input on processes and products mandated by HRSA and the CDC.
- > **One Love:** This is an advisory body of HIV-positive youth ages 18 to 25 who provide guidance on program development for youth and on issues such as transitioning perinatally-infected youth to adult care. One official youth member also participates on the MIPCC and the SWCAB (see above).
- > **HIV Surveillance Implementation Team:** The team provides critical assessment of proposed policies related to the management of HIV surveillance data, and guidance about how such data are used to inform program priorities.

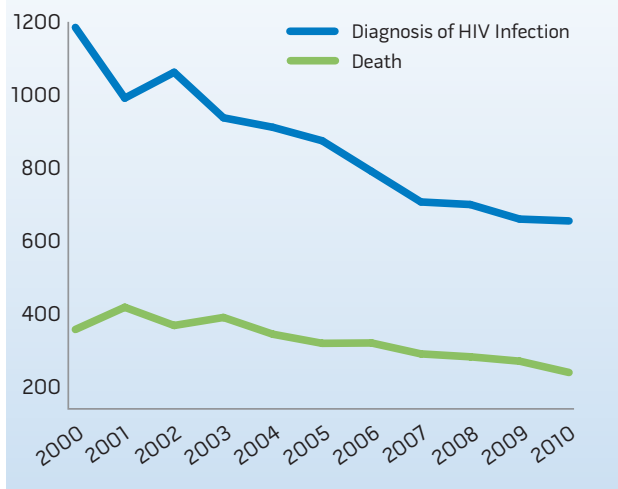
and being virally suppressed, and we just didn't see that in the data we collected. When people get into our system, regardless of economics, race, ethnicity, or immigration history, they're doing very well across the board.

To ensure PLWHA take that critical first step of engaging the system, Massachusetts is participating in the SPNS Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative (the Systems Linkages Initiative). This initiative marks the first set of SPNS grants specific to Part B State grantees.



Kevin Cranston (left) and Dawn Fukuda (right) pose in front of the Massachusetts DPH building.

Trends in HIV Infection\* and Death Among People Reported with HIV/AIDS by Year: Massachusetts, 2000-2010



\*Reflects year of diagnosis for HIV infection among all individuals reported with HIV infection, with or without AIDS diagnosis. Data Source: MDPH HIV/AIDS Surveillance Program. Data as of 1/1/12

It is just one more way HRSA—and the Massachusetts DPH—are achieving the goals of the NHAS, which are:

1. To reduce the number of persons infected with HIV.
2. To increase access to care and optimize health outcomes for people with HIV.
3. To reduce health disparities.<sup>4</sup>

The SPNS project involves collaboration and data sharing between the Massachusetts Part B grantee with Boston's Part A EMA. Cranston, Fukuda, and their staff are optimistic that this project will assist in reaching late presenters in their State, and maximize engagement and retention in care for the most vulnerable residents living with HIV/AIDS.

The Massachusetts grantee and the Ryan White HIV/AIDS Program at large illustrate what can happen when people are committed to taking care of the under-served. In this way, the entire program has always been, and remains, ahead of the curve.

<sup>4</sup>White House Office of National AIDS Policy. Community ideas for improving the response to the domestic HIV epidemic: a report on a national dialogue on HIV/AIDS. April 2010. Available at: [www.aids.gov/federal-resources/policies/national-hiv-aids-strategy/onap\\_rpt.pdf](http://www.aids.gov/federal-resources/policies/national-hiv-aids-strategy/onap_rpt.pdf). Accessed March 30, 2012.

### COLLABORATION = BETTER CARE FOR EVERYONE

Over the years, the Massachusetts Part B grantee has been committed to working closely with the Boston Part A EMA. Their joint efforts improve State and EMA planning, reduce duplication of services, improve communication, and ultimately enhance the process of identifying unmet need and then responding to it.

The first health reform State, Massachusetts has a strong service delivery system and one which Part A and B grantees helped build. Together, they commissioned a State- and EMA-wide consumer needs assessment of over 1,000 HIV-positive respondents, compiling the results into a report entitled *Massachusetts and Southern New Hampshire HIV/AIDS Consumer Study*. As Cranston explains, "This is something we're very proud of. It is no small thing for city and State health departments to coordinate their work in any area. We rely on one another... [and] we have committed ourselves from the very beginning of the epidemic to coordinate our funding, our procurement of services, our data systems, and our policy approaches."

He adds, "We have found ways to build efficiencies and coordination, so that consumers and providers have an integrated system they can really rely on and that no matter where the money comes from, to people living with HIV/AIDS it looks seamless."

### GREATER NEW BEDFORD COMMUNITY HEALTH CENTER: THE ONLY HIV CARE PROVIDER IN TOWN

It's impossible to talk about the Greater New Bedford Community Health Center (GNBCHC), a Part B sub-grantee and safety net provider, without talking about Paul Cassidy, program coordinator. He's fought for HIV care in southeastern Massachusetts—an area of the State where his agency is the sole clinical provider for persons living with HIV/AIDS. Without GNBCHC, patients unable to travel 60 miles into Boston would be, as he describes, "isolated in their diagnosis."

Cassidy has been working in HIV care since the early years of the epidemic. "A close friend of mine was



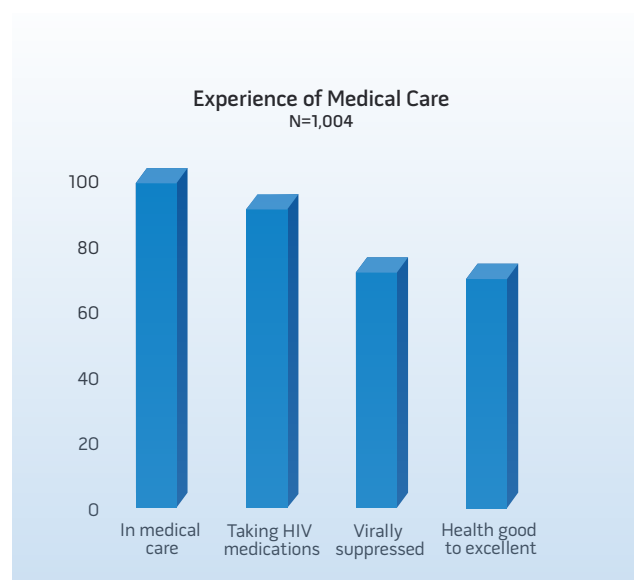
"There's been a lot of consistency in our staff," says Paul Cassidy (left) of the Greater New Bedford Community Health Center with Linda Spinner (right). "It's been clear why we do this work and we take a lot of pride in it."

diagnosed with HIV and passed away in 1989," says Cassidy. "I had just finished my social work degree and being a gay man, it seemed like a natural fit for me. I wasn't afraid to do this work."

Cassidy boils his success down to one thing: relationships. Linda Spinner was one of Cassidy's first patients at New Bedford. "I think the HIV community here would be lost without Paul. It doesn't matter what you are... or which side of the table you sit on, we're all equals here. Paul listens. He has compassion."

Spinner remembers being diagnosed with HIV in 1991. When most people learn she contracted HIV through heterosexual contact, "They'll say I'm a 'victim,' but we're all victims here. No one deserves HIV," she says. To try to counter stigma, discrimination, and misinformation, Spinner has initiated a women's support group and a women's conference entitled, "It Could Never Happen to Me."

The title of the conference reflects the importance of outreach and education among populations that still in 2012 may not understand risks for HIV. Always determined to combat health challenges as they arise, the



Source: JSI Research and Training, Inc. Massachusetts and southern New Hampshire HIV/AIDS consumer study final report. December 2011.



Paul Glass (featured here) works to educate the Massachusetts community about HIV disease and counter the stigma he felt in the early years of his diagnosis.

Massachusetts DPH funded a report examining this issue, which revealed that up to 70 percent of women recently diagnosed with HIV were exposed heterosexually.<sup>5</sup>

The first conference was the occasion on which Spinner first publicly disclosed her status. She credits this to the support lent by GNBCHC and Cassidy in particular. “For a long time I hid behind other peoples’ shadows, but now it’s my time to give back.”

### SERVING OTHERS

Determined to give back, Paul Glass has participated in clinical trials as part of the AIDS Clinical Trials Group

for Harvard and Boston Medical Center teaching hospitals, and in Fenway’s Black Gay and Bisexual Men and HIV Conference. He is also a community educator for the Fenway Community Health Center (a Part A and B subgrantee and a Part C grantee), and their HIV Prevention Trials Network—the first community-based HIV research program in the Nation. In his role as educator, Glass is on the frontlines working to make the Massachusetts service area even stronger. He encourages dialogue between community members and researchers, increases HIV awareness, and is involved in groundbreaking HIV trials.

Glass says he absolutely perceived himself at risk for HIV. Still, the diagnosis was a terrifying one—which he kept hidden from his family and friends for years. “I stuck my head in the sand and immersed myself in work; I denied

<sup>5</sup>Massachusetts Department of Public Health Bureau of Infectious Disease Office of HIV/AIDS. *Intersecting risks: HIV infection among heterosexual women and men in Massachusetts*. December 1, 2010. Available at: [www.mass.gov/eohhs/docs/dph/aids/intersecting-risks.pdf](http://www.mass.gov/eohhs/docs/dph/aids/intersecting-risks.pdf).



HIV and STD testing as well as infectious disease and primary care are among the comprehensive suite of services offered at Boston Medical Center, a Ryan White Part B subgrantee.

both being HIV positive, and being a gay man. I was scared.” Then September 11, 2001 happened.

At the time, Glass was living near the World Trade Center towers and describes the cleanup as a toxic and noisy environment. “Trucks would pull up day after day with debris from ground zero and drop it onto a barge in the Hudson. It shook my building. It sounded like the Trade buildings collapsing over and over again, every 15 minutes of every day.”

Glass felt unstable and unsafe. His sleeping waned as his anxiety rose, making him lethargic all the time. He sought medical attention, never expecting to hear just how far his T-cell count had plummeted: from 550 to 150. “This was the second time I was looking death in the face and, somehow, I felt it was physically more real this time.” Glass needed a change; he needed to go home to Massachusetts.

Glass’ journey hasn’t simply been a physical one, but a spiritual one as well. “I declared my status to my family. To my surprise, and comfort, they were very accepting.” Coming back to Massachusetts offered Glass not only the high-quality HIV care he needed, but new opportunities as well. “I reconnected with some friends, many who were involved in HIV/AIDS and with MOCAA—Men of Color Against AIDS,” he says.

What began as a few support group meetings soon propelled Glass to a spot he never thought he’d hold: a position out front in the community and now, after all these years, open about himself, his experience, and his status.



Delphine (left) and Kelley (right), both patients at BMC, have supported one another through their journeys with HIV and their dreams ahead. As Delphine says, "I'm hoping to have another baby—maybe a baby girl. Many women don't realize you can have an HIV-negative child but it's true!"

Glass says he's proud of his HIV work but that there's another role he's prepping to play: that of newlywed. "I'm a happy, proud, HIV-positive, gay, Black man and I'm engaged to marry another HIV-positive, gay, Black man. And you know what? We're healthy and we couldn't be happier."

### ***BOSTON MEDICAL CENTER: A MODEL FOR CARE DELIVERY***

Boston Medical Center (BMC) is a Part B subgrantee safety net hospital committed to serving the poor and underserved. BMC is housed in a fantastic new facility, although if you ask patients why they choose BMC it's about more than the cutting-edge setting.

To be sure, high-quality care services offered through a multidisciplinary, one-stop shop model in a state-of-the-art setting are enormously compelling to patients. Yet, HIV care has always been about connecting with people and addressing not only HIV but all of their primary care and psychosocial needs. This has been a hallmark of the Ryan White HIV/AIDS Program, and it's one that Meg Sullivan, clinical director of infectious diseases, has taken to heart. She explains, "At the start of every visit, I take a breath and give the patient my full attention. I want them to feel like they're the most important person in my day at that moment."

This individualized attention is paying off. "I adore my doctors," says Kelley, a long-time patient here. "I trust them to take care of me, and they do. When I come here, I'm at home." Kelley, however, had a long journey to get to where she is today. She learned her diagnosis in March of 1992, never having perceived herself to be at risk for HIV. Heartbroken, she tried to make sense of the situation. "I was told to get my affairs in order. I

was told I was going to die," she says. Kelley was just 27 years old.

She still vividly recalls sitting down with her parents and drafting plans for her funeral. "Finding out I was HIV-positive was an awakening." Kelley underscores that in order to fight to live, it means believing you're worth fighting for. Thanks to the Ryan White HIV/AIDS Program and the quality health care of BMC, Kelley's continued this fight for 20 years.

Kelley's story is one of perseverance, and it's a story that's been told and retold in so many different ways by so many different people. It's the story of overcoming HIV despite the odds and against all adversities, the story of survival and what's possible when patients and providers work together, and it's the story—and promise—of the Ryan White HIV/AIDS Program. "It's been a journey of self acceptance and forgiveness," Kelley says. "But every day I wake up, no matter how I feel, I know it's a good day: I'm still alive."



"I'm here as one of the faces of people living with HIV," said Dorene Russo (featured here). "But I'm also a small business owner, a mother, and a grandmother." Like many women with HIV, Russo was infected through heterosexual contact. She is trying to raise awareness. Women, like Dorene, are served through all Ryan White HIV/AIDS Program Parts.



4. PART C, D, AND F PROGRAMS: EARLY INTERVENTION SERVICES; WOMEN, INFANTS, CHILDREN, YOUTH,  
AND THEIR FAMILIES; DENTAL CARE



I CONTINUE TO FEEL WE ARE IN CRISIS MODE EVEN YEARS AFTER  
KATRINA... MANY PEOPLE CAME BACK FROM THE HURRICANE HAVING  
TO RESTART MEDICATIONS IN UNSTABLE LIVING SITUATIONS.  
IT WAS LIKE STARTING OVER FOR ALL OF US. THEY WERE  
IN SURVIVAL MODE AND, PERHAPS, NOT ACCESSING ALL OF  
THE CARE THEY NEEDED FOR THEIR HIV AND OTHER COINFECTIONS.

RHONDA EUBANKS, RN AT THE HIV OUTPATIENT PROGRAM (HOP) CLINIC

The Part C Early Intervention Services (EIS) component of the Ryan White HIV/AIDS Program funds comprehensive primary health care in outpatient settings for people living with HIV/AIDS. These grants are given to clinics, hospitals, community based and faith based organizations, Federally Qualified Health Centers, Family planning grantees, and comprehensive hemophilia diagnostic and treatment centers. EIS costs are associated with the direct provision of medical care. (To learn more about the Part C program, visit: [www.hab.hrsa.gov/abouthab/partc.html](http://www.hab.hrsa.gov/abouthab/partc.html).)

Part D of the Ryan White HIV/AIDS Program similarly provides outpatient or ambulatory primary medical care. Part D, however, is focused on family-centered care and was created specifically to treat the unique needs of women, infants, children, youth and their families. (To learn more about the Part B program, visit: [www.hab.hrsa.gov/abouthab/partd.html](http://www.hab.hrsa.gov/abouthab/partd.html).)

Part F Dental Programs include the Dental Reimbursement Program (DRP) and the Community-Based Dental Partnership Program (CBDPP). These programs support the provision of oral health services and funding of oral health care for people with HIV. In addition, funding of education and training for oral health providers is a key program component. Dental care is often an unmet but important need among people living with HIV/AIDS, as poor oral health can complicate HIV disease and medication absorption while HIV disease can lead to oral infections of the mouth. (To learn more about the Part F program, visit: [www.hab.hrsa.gov/abouthab/partfdental.html](http://www.hab.hrsa.gov/abouthab/partfdental.html).)

In the case study that follows is the Louisiana State University (LSU) Public Hospital HIV Outpatient Program (HOP) Clinic, a Ryan White HIV/AIDS Program Part C, D, and F grantee. The Clinic's work underscores the importance of a medical home with direct medical care services that are co-located under one roof. Comprehensive care is characteristic of the Ryan White HIV/AIDS Program and the HOP Clinic exemplifies how this approach helps care for the truly underserved.

## CASE STUDY: LSU HOP CLINIC IN NEW ORLEANS

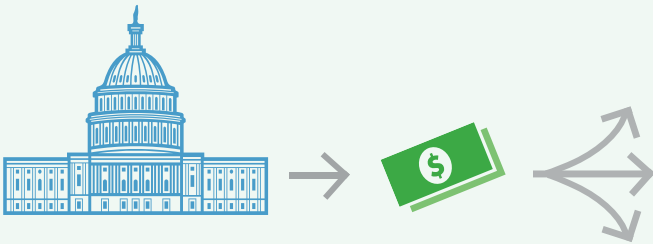
Talk to just about anyone in New Orleans and everything is prefaced with "before" and "after." The event, of course, is Hurricane Katrina, which devastated communities along the Gulf Coast in 2005. Prior to the storm and the levee failures, the New Orleans Metropolitan Area had 1.3 million residents; immediately afterward, the population decreased by 33 percent. AIDS case rates and prevalence have skyrocketed post-storm and thereafter, creating an ever-increased burden to a city—and clinic—trying desperately to rebuild.<sup>6</sup>

<sup>6</sup> Interim LSU Public Hospital/a.k.a. Medical Center of Louisiana at New Orleans, *HIV Outpatient Program. Part C EIS competing continuation*. 2011.

**PARTS C + D**

Both Part C and Part D are unique from other Parts of the Ryan White HIV/AIDS Program in that their funds go directly to clinics to provide critical primary care services.

In 2012, \$192.2 million was spent on Part C EIS, \$1.2 million on capacity building, and \$68.3 million on Part D.



**Part C Early Intervention Services:** Funds comprehensive health care in outpatient settings for PLWHA.

**Part C Capacity Development Grant:** Assists public health centers and non-profits with organizational infrastructure, as well as improves capacity to develop, enhance, or expand access to superior HIV health care services for PLWHA in minority and rural communities.

**PART D Services For Women, Infants, Children, Youth, and their Families:** Provides outpatient or ambulatory family-centered primary medical care for women, infants, children, and youth with HIV/AIDS. Funds are divided between primary and specialty medical care and support services.

Note: To see a diagram of Ryan White Part F programs, see page 42.

Rebecca Clark is an LSU professor of medicine and lead physician at the Interim LSU Public Hospital HOP clinic in New Orleans, a Ryan White Part C, D, and F provider. When Katrina struck, Clark fled New Orleans with her two five-year-old children, but was determined to get back and make sure that her patients were okay.

Clark recalls, "It was a ghost town. There were no functioning ATMs. If you needed money or gas you had to get yourself to Baton Rouge because nothing in New Orleans seemed to be working. There was no electricity, no water. If there was a grocery store open, you had to bring your ice chest and pack it full."

Clark was among a group of HOP staff determined to ensure continuity of care, and to set up a clinic in Baton Rouge within a month of the storm. Unlike New Orleans, nearby Baton Rouge had not suffered the same level of devastation and flooding. Clark set forth writing

prescriptions for patients who had evacuated the city without their lifesaving antiretrovirals or who had simply run out.

When the clinic first began seeing patients again in New Orleans, it was at partner agencies and makeshift clinic space across various locations.

In the interim, the original flooded HOP Clinic location was receiving extensive renovations. Eight months after the hurricane, the HOP Clinic could officially reopen its doors in its pre-Katrina location.

Nurse practitioner Julie Dargis was on hand to help in the reestablishment period of the clinic. When Dargis had finished nursing school, she joined the Army. Shortly thereafter came the September 11, 2001 terrorist attacks. Dargis found herself in Iraq treating 50–100 soldiers a day, sometimes well into the night. When her



Rebecca Clark, MD, (featured here) has been a mainstay in HIV care delivery in New Orleans. She's published more than 50 papers since 2000 as well as written two books on women's health, including one specific to women and HIV based on her clinical work, including her time as a clinician for the LSU HOP clinic, a Ryan White HIV/AIDS Program Part C, D, and F grantee.



Nurse Practitioner Julie Dargis (left) examines a patient at the HOP Clinic in New Orleans.

tour in Iraq ended, Dargis swapped one emergency zone for another—this time in Louisiana.

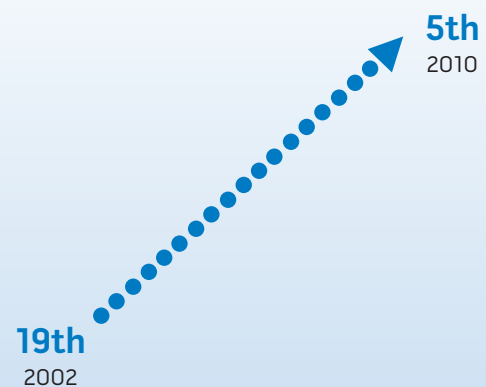
Many HOP Clinic patients were, and continue to be, living well below the Federal Poverty Level.<sup>7</sup> It was not uncommon for multiple families to be living under the same roof, happy at least to have found shelter from the storm. For those who lost their homes and were hoping to start afresh, they faced yet another challenge to surmount: inflated housing prices.

Some support service organizations either no longer have the budgets or staff they once did, or are struggling to meet increased patient needs caused by the storm; some have simply been forced to close their doors. The HOP Clinic, however, has not only risen from the wreckage, but has built the kind of comprehensive services

<sup>7</sup>Federal Poverty Level (FPL) is based on family size and monthly or yearly income and, often, is used to determine eligibility for assistance programs. For example, yearly gross income for a family of one is \$11,170 and \$23,050 for a family of four. To learn more about HHS poverty guidelines visit: [aspe.hhs.gov/poverty/12poverty.shtml](http://aspe.hhs.gov/poverty/12poverty.shtml).

PLWHA so desperately need. “I still firmly believe in what I’m doing here,” says Ronald Wilcox, director of the Ryan White HIV/AIDS Program Delta Region AIDS Education and Training Center (AETC), responsible for training Ryan White clinical staff and keeping them up to date on new—and changing—clinical care issues. “Ryan White

AIDS rates among largest cities in U.S.:  
New Orleans’ position

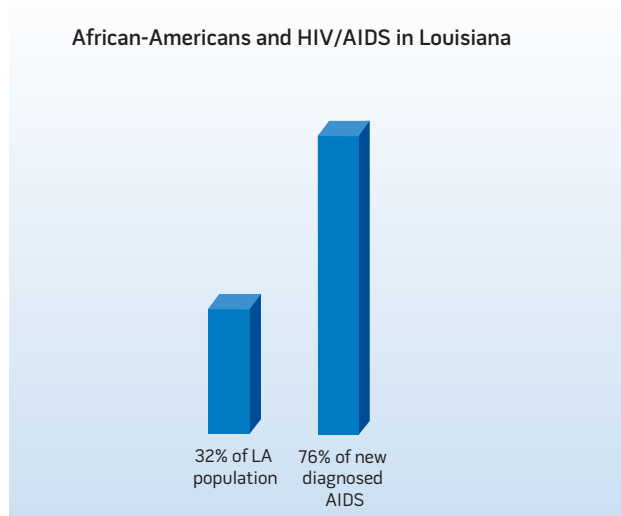


Source: Interim LSU Public Hospital/a.k.a. Medical Center of Louisiana at New Orleans, *HIV Outpatient Program. Part C EIS competing continuation*. 2011.

really does treat marginalized populations that the greater health care system doesn't."

Indeed, with the help of the Ryan White HIV/AIDS Program and a fiercely dedicated staff, the HOP Clinic beat the odds and reinvented itself, never once turning away from its horribly battered city or from PLWHA.

It certainly would have been easier for staff not to return after Hurricane Katrina. Why rebuild your home, and office, when you could start over some place new with fewer demands and greater resources? Why return to a



Source: Interim LSU Public Hospital/a.k.a. Medical Center of Louisiana at New Orleans, *HIV Outpatient Program. Part C EIS competing continuation*. 2011.

place of constant reminders of trauma and loss?

The answer is passion, and the result has been a miraculous one. "What keeps us here is that we really do make a difference," says Patrick Byers, medication assisted program coordinator. "You go home and know you've done something truly important. It's an activism kind of mentality... and no matter the challenges, there's nothing better than helping improve a life."

According to Delta Region AETC director Wilcox, younger patients have generally stayed away and rebuilt elsewhere; patients who have returned in the storm's aftermath have been poorer, older, long-term survivors, reflecting a shift in the overall patient demographics from what they once were. Many of these patients lack

access to care and require HIV primary care, age-related subspecialty care, and social support services.

The HOP Clinic staff and patients have persevered. They had a dream of what the clinic could be one day: That it would become bigger, better, more coordinated than ever, and it would include colocated services for the patients who, like them, braved their way back to New Orleans and refuse to call it anything but home.

### COMPREHENSIVE CARE ONSITE

The HOP Clinic offers truly wraparound one-stop shop services, particularly to vulnerable and aging populations. From mental health care to geriatric care, from eye care to women's health issues, the HOP Clinic works to address all of their patient needs. This kind of medical home model is not only characteristic of the Ryan White HIV/AIDS Program but assists in retaining patients in care.

Mental illness, for example, is widespread among PLWHA. In fact, the HIV Costs and Services Utilization Study (HCSUS) found that nearly 50 percent of adults being treated for HIV have symptoms of a psychiatric disorder—prevalence that is 4 to 8 times higher than in the general population.<sup>8</sup> The incidence of mental illness among PLWHA, however, far surpasses available mental health services. For residents in New Orleans, addressing mental health also means addressing post-traumatic stress disorder (PTSD), something else the hurricane and subsequent flooding brought in its wake.

PTSD has struck patients like JoAnn, a long-time patient and New Orleans resident. She says there are times when she goes completely numb. "It took me two full years to get my house back together," she says. "I'm not leaving New Orleans but I have my moments where it becomes so hard," she admits. "I'll see abandoned buildings and it affects me." But JoAnn has fought for her life, for her city, and for her health. A long-term survivor, she says, "I haven't missed one appointment in 18 years. I've done everything the Clinic has told me to do."

<sup>8</sup> Bing EG, Burnam A, Longshore D, et al. Psychiatric disorders and drug use among HIV-infected adults in the US. *Arch Gen Psychiatry*. 2001;58:721–8.



Thanks to participation in a National Institutes of Health (NIH) study, the HOP Clinic is able to bring eye care onsite for HIV patients as well as advance research on the role of AIDS and ocular health.

Many HIV patients, like JoAnn, are living longer, in part, because of the scientific and clinical service advances. To help address the needs of an aging patient population, the HOP Clinic added geriatric care, including colonoscopy and bone density scans to address the increasing need of the aging patient population. Perhaps the most impressive feature of the clinic is the multitude of services offered at one location. The HOP Clinic partners with the National Institutes of Health (NIH) Study of Ocular Complications of AIDS to provide important eye care services and partners with the LSU School of Dentistry to provide a comprehensive oral health clinic.



Daniele Farrisi, health education specialist, (featured here) goes over HIV materials to increase patient health literacy.

Many of the patients' needs can be met at the HOP Clinic. For health literacy, there is a dedicated health educator. For women and girls, there is gynecology. To access necessary support services, there are medical social workers and case managers. The HOP Clinic has added pain management services for patients with ongoing high levels of chronic pain.

Since the State of Louisiana's ADAP has a waiting list, the HOP Clinic's medication-assistance program coordinator position is even more important than ever. In this role, Byers enrolls patients in pharmaceutical assistance programs and completes patient paperwork for medication vouchers so that no patient at the HOP Clinic goes without lifesaving HIV medications.

For those patients who are no longer accessing HIV primary care, there is the Louisiana Public Health Information Exchange (LaPHIE) which, like the HOP Clinic, is under the umbrella of the LSU system. The program, supported by the SPNS Enhancement and Evaluation of Existing Health Information Electronic Network Systems for PLWHA in Underserved Communities Initiative (to learn more, visit: [www.hab.hrsa.gov/about/hab/special/underservedcommunities.html](http://www.hab.hrsa.gov/about/hab/special/underservedcommunities.html)), scans Louisiana Health Department CD4 and



A patient receives dental care onsite at the HOP Clinic, a Part F Ryan White HIV/AIDS Program grantee. According to coordinator Rodrigo Gamarra, "HRSA makes this all possible!"

viral load records whenever a patient enters care within the LSU system. If a patient is HIV positive and has failed to have lab work completed in the last 12 months, a message pops up alerting the doctor or nurse. This is just one example of the activities—in this case driven by health information technology (HIT)—geared to retaining and returning lost-to-care patients to the clinic. As one HOP Clinic employee explains, "We've turned missed opportunities into seized opportunities."

Providers, too, are equipped with access to many education resources provided onsite. The HOP Clinic is home to the Ryan White HIV/AIDS Program Delta Region AETC, where staff access trainings, stay current on HIV

medications, and share best practices. (See Chapter 6 to learn more about AETCs and see the chart about this and other Part F programs on page 42.) Another HIT innovation, electronic medical records (EMRs), in which patient information is stored in an electronic database, have also been incorporated to ease coordination and improve care delivery.

### **REBUILDING TEETH, REBUILDING HEALTH**

In addition to receiving Ryan White HIV/AIDS Program Parts C and D funding, the HOP Clinic is also a Part F Dental Reimbursement Program grantee. "Often there's a gap between medicine and dentistry, but this clinic bridges that gap," says Jeevan Yenuganti, assistant

professor and dental services provider at the HOP Dental Clinic, who oversees the dental services and staff, which includes another dentist, a hygienist, three dental assistants, a dental nurse, a dental coordinator, and an administrative coordinator—another testament to the HOP Clinic’s devotion to meeting patient needs. Yenuganti says they conduct between 200 and 280 patient visits a month. Oral health services funded by the Ryan White HIV/AIDS Program are often the only access point to dental services for this vulnerable population. Where would these patients go without the HOP Clinic? How else could they afford these vital health care services?

The clinic, a part of the LSU system, takes advantage of fourth-year dental students to help meet their demand. In this way, they’re not only rebuilding a clinic, but also building up a workforce for the future.

“Many of these patients have lost teeth and, in some cases, bone because of their age or prolonged lack of access to dental care. We work with a wide range of restorative options so they can chew and function as normal,” says Yenuganti. He coordinates services with Leigh Anne Kammerman-Burns, a full-time clinical nutritionist who is also onsite. Proper nutrition is key to dental health and overall health.

It’s a critical role. Some patients at the HOP Clinic have such severe dental needs they can only consume soft foods and liquid supplements. Others, because of severe poverty, suffer from malnutrition. Kammerman-Burns recalls an adult patient who came in at 80 pounds. Nutrition was introduced slowly to ensure the patient’s electrolytes did not dip dangerously low, and to monitor for cardiac arrhythmia related to refeeding syndrome.

“The beauty of the HOP Clinic,” says Kammerman-Burns, “is that we’re a close knit group. When patient dental needs are addressed, their nutrition improves too... When their nutrition improves, they can take [antiretroviral medication] and that affects their HIV and primary health.” Together, all of these components have created a safety net for PLWHA, for people like Felipe.



The HOP Clinic uses electronic medical records and data systems to best coordinate and streamline care.

### STAYING ALIVE AND STAYING IN CARE

August 31, 1989, 7:30 pm: It’s a time stamp for when Felipe’s life changed forever—he received his positive HIV diagnosis. Born and raised in New Orleans, Felipe is a self-described “river rat,” the nickname given to those who live along the waters of the French Quarter.

Latino MSM like Felipe represent a growing proportion of the epidemic; in 2010, Latino men who have sex with men (MSM) accounted for 23 percent of estimated new AIDS diagnoses in the United States.<sup>9</sup> Felipe says, however, his father had none of the machismo he felt was common in his culture. As he recalls, “My father said, ‘You have my blood running through you. You’re family,’ and that meant a lot.”

Much like his father’s love, Felipe’s obstacles have seemed nearly endless. By 1994, Felipe had AIDS; that same year he came down with meningitis and was told he had 6 months to live. “I was sent to a nursing facility,” he recalls. “I had so many pills; it was horrible. But then 6 months passed and then a year, and I was still alive.”

<sup>9</sup> CDC. *Diagnoses of HIV infection and AIDS in the United States and Dependent Areas, 2010*. Available at: [www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm](http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm). Accessed March 16, 2012.





Long-time HOP Clinic patient Felipe (pictured here on Calle de San Felipe in New Orleans) exemplifies what's possible with access to comprehensive services, an HIV primary care team, and antiretroviral medications. The HOP Clinic receives Ryan White Part C, D, and F funding.

Felipe moved home but became addicted to pain medications. "My friends used to say, 'You're going to die one day so why not pop a few?'" Finding a friend dead from an overdose shook Felipe awake. "To get healthy I had to distance myself from that crowd. Now, I've outlived them all."

But just when things looked up, Felipe was diagnosed with anal cancer. Despite worries about what chemotherapy and radiation might do to his compromised immune system, Felipe chose treatment. Many months later, he learned he was in remission.

*"I feel like I cheated death on more than one occasion. Spiritually, physically, and financially I've been transformed for the good. It sounds crazy, but if you look closely, you'll see."*

FELIPE, HOP CLINIC PATIENT

Shortly after Felipe left the hospital, he was hit by a car, breaking four bones, including his hip, bruising his spleen, and puncturing a lung. This time, when Felipe was released, he thought it couldn't get worse—until the terrible pains began. A broken rib had punctured his heart.

Many people would have had a crisis of faith after just one, let alone all, of these obstacles, but Felipe says, by the grace of God and the health care from LSU Hospital and HOP Clinic, he overcame. He found renewal through the support he received at the clinic. Even when Hurricane Katrina washed away his house, he returned to the city and continued fighting. "I really believed in my heart that it wasn't my time. I kept trying to stay positive."

The HOP Clinic and the LSU Hospital have given Felipe something more than health: confidence. Kammerman-Burns worked with Felipe to get his 235 pounds to a



**David Little, HIV outpatient program manager, has been integral in securing new space for the HOP Clinic and in encouraging increasing standards of care.**

muscular 168, and reduce his high cholesterol. Today, he works and is going back to school to study theology. He shares his story readily, takes care of his mother with Alzheimer's, and prays over the sick and suffering.

"I feel like I cheated death on more than one occasion. Spiritually, physically, and financially I've been transformed for the good. It sounds crazy, but if you look closely, you'll see." Felipe, much like the HOP Clinic and, indeed, the city of New Orleans itself, have come a long, long way and show no signs of stopping.

Hospital

**BY THE STRENGTH OF GOD, I HAVE OVERCOME.  
HE MUST STILL HAVE WORK FOR ME TO DO!**

TAMMY, PATIENT AT GUIDE TO HEALING PROGRAM:  
ENHANCING ACCESS FOR HIV+ WOMEN IN THE RURAL SOUTH AT  
THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

The Part F Special Projects of National Significance (SPNS) Program supports innovative research models to respond to emerging needs of clients served by the Ryan White HIV/AIDS Program. SPNS evaluates the effectiveness of the models' design, implementation, utilization, cost, and health-related outcomes, while promoting the dissemination and replication of successful models. The mission of the SPNS program is to provide HIV service delivery through demonstration projects and evaluation focused on primarily underserved, underinsured, and uninsured populations. Grantees include public and private nonprofit organizations that serve people living with HIV/AIDS (PLWHA). (To learn more about the Part F program, visit: [www.hab.hrsa.gov/about/partfspns.html](http://www.hab.hrsa.gov/about/partfspns.html).)

The grantee case study that follows examines the work being done by the Guide to Healing program. This SPNS grantee is addressing the needs of women of color in the deep South—a growing population of PLWHA. HRSA has consistently evolved to address emerging needs and this SPNS initiative is just one more way they're doing so. This work also helps achieve the NHAS goals of reducing health disparities and increasing care access and utilization.

## CASE STUDY: GUIDE TO HEALING PROGRAM

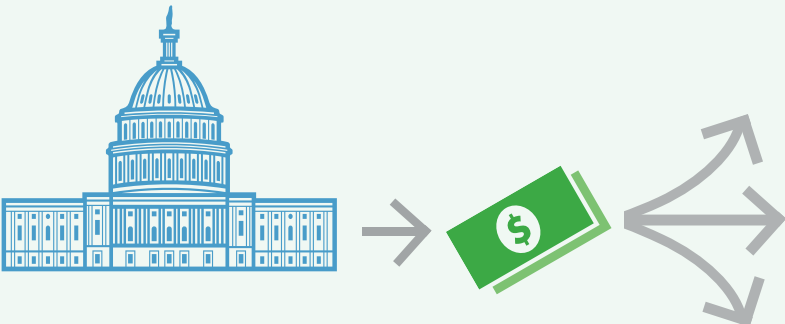
When nurse practitioner Lynda Bell, assistant clinic director and instructor at the University of North Carolina at Chapel Hill (UNC-Chapel Hill) Infectious Diseases Clinic, transitioned to the clinic, she saw a lot of HIV-positive women there. Bell says, "They were just regular women like me. Many thought they were in monogamous relationships with their husbands or boy-friends. That's when I realized just how widespread this epidemic really was. I knew it clinically before, but now I knew it personally."

Among HIV-infected women, minorities have always been disproportionately represented—particularly African-Americans. But over the years, Bell was seeing other trends, too: These women were coming in for care later, were sicker, and lacked the support systems that other subgroups seemed to have.

The Ryan White HIV/AIDS Program has always worked to target the most marginalized communities; in fact, 83 percent of Ryan White female patients are women

**PART F**

In 2012, \$25 million was spent on SPNS, \$12.8 million on dental programs, and \$31.96 million on AETCs.



**AIDS Education and Training Centers (AETC) Program:** Network of 11 regional centers and 5 national resource centers that provide education and training programs for providers.

**Special Projects of National Significance (SPNS) Program:** Advances knowledge and skills in delivery of health and support services to underserved populations living with HIV/AIDS.

**Dental Programs (56 DRP and 12 CBDPP grantees):** Supports oral health care for people with HIV. Comprises two main programs, the Dental Reimbursement Program (DRP) and the Community Based Dental Partnership Program (CBDPP).

**The Minority AIDS Initiative (MAI):** Provides funding to evaluate and address the disproportionate impact of HIV/AIDS on African-Americans and other minorities.

of color. Still, barriers to care exist, and there is much work to do.

When Bell met with Byrd Quinlivan, associate professor of medicine and director of the UNC-Chapel Hill Infectious Diseases Clinic, they brainstormed how exactly they—and UNC-Chapel Hill—could address these issues. “Over 60 percent of the women of color I’ve been seeing have had some experience with verbal, sexual, or physical abuse and because of these experiences,” says Bell, “they got messages early on that they weren’t worth it.”

The clinic’s nurses and nurse practitioners embarked on a small project focusing on patients with low CD4 counts. Patients received calls between appointments, and education about lab work, medication side effects, and other issues. They experienced initial success with improving retention; however, Bell and Quinlivan knew much more was needed if they were to achieve the kind of ambitious goals they had set for themselves—and their patients.

Enter the SPNS Enhancing Access for Women of Color (WOC) Initiative. (To learn more, visit: [www.hab.hrsa.gov/about/hab/special/womencolor.html](http://www.hab.hrsa.gov/about/hab/special/womencolor.html)). “When the opportunity came up to apply for the SPNS grant, it was a no brainer,” says Quinlivan. “The influx of resources really allowed me to say what was missing from our program and that we wanted to focus a lot on new patients,” she says.



Lynda Bell (left) examines Guide to Healing program patient Tammy (right), ensuring she remains in good health.



Most women in the Guide to Healing program travel from rural parts of North Carolina to Chapel Hill to access care services.

Like many Ryan White HIV/AIDS Program researchers and providers, Quinlivan knew that patients new to care are at increased risk of dropping out, and that those who do not stay in care their first year have higher rates of morbidity and mortality.<sup>10</sup> Thus, her focused effort on this population wasn’t just necessary; it was life-changing.

*“You want women to feel that they can build a life that HIV fits into. That they don’t need to build their life around their disease. HIV doesn’t go away but they can have whatever it is they want, and that’s the piece I was thinking of when I put ‘healing’ into the title of our program.”*

BYRD QUINLIVAN, ASSOCIATE PROFESSOR OF MEDICINE AND DIRECTOR OF UNC-CHAPEL HILL INFECTIOUS DISEASE CLINIC

UNC-Chapel Hill is one of the foremost public health research centers in the country. It is equipped with a team of investigators, AIDS clinical trials, a Center for AIDS Research, and comprehensive, multidisciplinary clinical care. These reasons, along with the personalized and friendly staff with the Guide to Healing program, motivate women to participate in the SPNS study. Many patients drive up to 4 hours or board Medicaid buses at 5:00 am to get from rural communities across the State to come to Chapel Hill.

<sup>10</sup> National Quality Center. in+care Campaign. *Reasons behind indicator development*. 2011.

Nearly one-half (approximately 44 percent) of the patients at Guide to Healing program have accessed a gas card—an incentive particularly helpful for women traveling from far distances in the rural South to reach the clinic.\*

\*Current through February 28, 2012.

UNC-Chapel Hill has participated in HIV research development as well as a number of SPNS projects over the years. SPNS is the research arm of the Ryan White HIV/AIDS Program and has always been well ahead of the curve. Long before the NHAS called for providers to focus on populations most at risk for HIV, SPNS and the Ryan White HIV/AIDS Program were funding and evaluating programs doing just that.

Quinlivan has worked on the following groundbreaking Ryan White HIV/AIDS Program Part F SPNS studies that created best practices and lessons learned to be shared with the greater Ryan White community:

- > Prevention With HIV Infected Persons Seen in Primary Care Settings Initiative ([www.hab.hrsa.gov/abouthab/special/primarycaresettings.html](http://www.hab.hrsa.gov/abouthab/special/primarycaresettings.html)),
- > Innovations in Oral Health Care Initiative ([www.hab.hrsa.gov/abouthab/special/oralhealth.html](http://www.hab.hrsa.gov/abouthab/special/oralhealth.html)),
- > Outreach, Care, and Prevention to Engage HIV Seropositive Young MSM of Color Initiative ([www.hab.hrsa.gov/abouthab/special/youngmsmcolor.html](http://www.hab.hrsa.gov/abouthab/special/youngmsmcolor.html)), and



Byrd Quinlivan, MD, (featured here) has spearheaded many innovative SPNS initiatives during her tenure at UNC-Chapel Hill.

- > Statewide Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative. ([www.hab.hrsa.gov/abouthab/special/systemslinkages.html](http://www.hab.hrsa.gov/abouthab/special/systemslinkages.html))

Patients find it rewarding to participate in research projects and, according to Quinlivan, patients “feel committed to the idea that HIV shouldn’t happen to anyone else.”

Guide to Healing program is grounded in self-determination theory, which offers a framework to study human motivation and personality, as well as cognitive and social development. So many of the patients at Guide to Healing program are bombarded with financial, psychosocial, and structural barriers as well as enormous stigma in their small, rural towns. The program, however, gives these women a voice—involving them in their own care and moving them along toward

#### WHAT WORK IS BEING DONE?

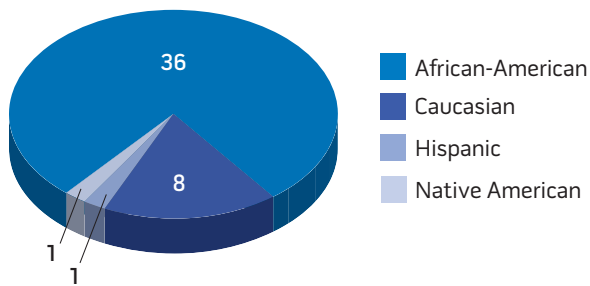
SPNS works with over 100 grantees to:

- > Advance the health care knowledge and skills needed to improve quality of life for people living with HIV,
- > Support and assess effectiveness of innovative models of care,
- > Build and improve information technology capacities, and
- > Promote dissemination and replication of effective models of care, locally and nationally.

full autonomy. Thus far, Guide to Healing program has seen some women achieve phenomenal results.

While evaluative in nature, the SPNS program allows grantees to investigate new and innovative strategies for addressing the latest HIV challenges. This approach is entrenched in the Ryan White HIV/AIDS Program's long history and its belief that the best solutions to problems in local communities lie within those

Breakdown of Guide to Healing Program Patients by Race/Ethnicity N=46\*



\*Source: Number of patients current through February 2012. Data provided by Guide to Living program.

CURRENT SPNS INITIATIVES:

- > Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color Initiative
- > Hepatitis C Treatment Expansion Initiative
- > Capacity Building to Develop Standard Electronic Client Information Systems
- > Innovations in Oral Health Care Initiative
- > Enhancement and Evaluation of Existing Health Information Electronic Network Systems for PLWHA in Underserved Communities
- > Enhancing Linkages to HIV Primary Care and Services in Jail Settings.

To learn more about each initiative, as well as past ones, visit: <http://hab.hrsa.gov/abouthab/partfspns.html>.



"I've always enjoyed working with people in vulnerable populations," says Nurse Guide Andrea Blickman (featured here).

communities themselves. Together, SPNS responses build a collective knowledge that informs the Nation and transforms the lives of PLWHA.

### **NURSE-LED INTERVENTION**

Guide to Healing program used some of its SPNS funding to hire Andrea Blickman to serve as a nurse guide to provide patients with systems navigation support. While other WOC Initiative sites have outreach components, Guide to Healing program is the only model to staff this position with an RN, which they believe will help with care team communication. Since UNC-Chapel Hill is an academic and clinical setting, rather than a community-based one, they felt it made sense to hire someone with a clinical background similar to rest of the team. It also allows Blickman to serve as the key point of contact for both clinic and clinical questions.

Blickman applies her experience in mental health and risk reduction to her role in the study, ensuring culturally competent care and addressing issues related to retention.

Without Blickman, most patients would be overwhelmed or simply unable to get enrolled in programs, navigate the complicated system of a large university setting or, in the case of new patient Janet, even know that they could survive—and thrive—with this disease.



**Guide to Healing program employees participate in case conferencing.**

For many women, Guide to Healing program is one of the few places where they can truly be themselves, where they can disclose their HIV and other issues. “For a lot of women, there’s a certain sadness about being HIV positive. For many, it’s a constant reminder of some relationship betrayal,” explains Blickman. “We acknowledge how they feel is real and don’t sweep it under the rug.”

In this way, Guide to Healing program is treating the whole person and meeting them “where they are at,” both defining characteristics of the Ryan White HIV/AIDS Program and key ingredients to its success.

#### **DID YOU KNOW?**

- > SPNS is the foremost research arm of the Ryan White HIV/AIDS Program.
- > The SPNS program focuses on populations disproportionately affected by the HIV epidemic and seeks to find innovative, replicable models of care.
- > SPNS bulletins on best practices and grantee success stories can be accessed here: [www.hab.hrsa.gov/abouthab/special/spnsproducts.html](http://www.hab.hrsa.gov/abouthab/special/spnsproducts.html).
- > SPNS is continuing its dedication to developing—and sharing—research advancements through its SPNS Integrating HIV Innovative Practices (IHIP) work. The project facilitates the creation of training manuals, curriculum, Webinars, and an interactive Web site. Together, these establish an online community allowing grantees to readily benefit from SPNS research and to share lessons learned with one another. To access these training materials, visit: [www.careacttarget.org/library/integrating-hiv-innovative-practices-ihip](http://www.careacttarget.org/library/integrating-hiv-innovative-practices-ihip).





Guide to Healing program staff member Ethel (left) shares a laugh with Guide to Healing program patient Tammy (right).

All of these efforts are paying off. At the clinic, patients address Blickman familiarly and with admiration. They regard the team at Guide to Healing program as “family” and are quick to admit that they couldn’t have done this alone—that the members of Guide to Healing program are quite literally lifesavers.

### IDENTIFYING CHALLENGES, SEARCHING FOR SOLUTIONS

“I was at the health department when I found out,” says Janet, a Guide to Healing program patient. That was just 3 months ago.\* “I was in shock. I still am.” Janet describes this as devastating news but is quick to point out that promptly on its heels, she learned something else that shocked her, too—that she could live a good and productive life if she got into care and stayed on antiretroviral therapy.

Before Guide to Healing program, Janet didn’t even have a doctor. Health care and the health-care system

were entirely new to her. That’s why people like Blickman are so integral in helping patients find their way until they’re able to do it on their own.

Already, Janet has made miraculous strides. For starters, she followed up on her referral immediately and was enrolled in the Ryan White ADAP for HIV medication support. Guide to Healing program has also helped Janet get her diabetes in check. She’s been referred to a doctor in radiology for a mammogram, and to the dental clinic to address oral health needs.

And this, Janet says, is the blessing of Ryan White. “This funding is needed for people like me without insurance, without transportation. Without [Ryan White], there’s no other way I could get this care or afford my meds. I know this, so I put forth the effort and my doctors do, too. We’re a partnership! They seem to be doing everything humanly possible to help me, so now I’m trying to help myself.”

\*Includes 3 months at time of interview, not time of publication.



"They don't judge you here," says Guide to Healing program patient, Janet (featured here). "They're here to help."

Janet says she'd like to one day find a companion and get married again. It's something she was ready to give up on, that is until Blickman, Bell, and others at Guide to Healing program told her that dreams like this one don't have to die, that Janet can be both healthy and happy.

Now, Janet's dreaming big. "I want to see my babies grow and get married, and I want to continue to stay healthy. I come from a line of long 'live-ers.' My grandma is about to turn 99, so I aim for that," she says.

#### **THE PICTURE OF HEALTH, THE PROMISE OF SPNS**

"When Tammy came here, she had a T-cell count of 10, along with cervical cancer. She couldn't get through everyday activities, and she thought she was dying," explains Bell. The Tammy that walked through the clinic doors on day one could not sound further from the Tammy of today. "Look at me, I look good!" Tammy exclaims, and she does. Today, Tammy is the picture of health. "I'm a fighter!" she explains. "I had cervical cancer but that cancer didn't know who it was messing with! I kicked cancer's butt!"

Five months after getting into care at Guide to Healing program, Tammy was cancer-free and had an undetectable viral load—both testaments to the outstanding clinical care and coordination made possible thanks to Guide to Healing program and the UNC-Chapel Hill Oncology Department.

Tammy finds support in her family, her church, and her strong sense of self. "I always believe in my Lord," she says. "He's stuck by me and seen me through." There have been times, however, when Tammy felt like hiding away, when she started feeling sorry herself, but her family wouldn't have it. The strength they gave her and the confidence and health provided by Guide to Healing program emboldened Tammy, so much so that she disclosed her HIV status at a recent family reunion. In this way, Tammy is helping others, through the SPNS research work and through her own personal story.

"I'm just glad God gave me a second chance so I can get it right," she says. "When you have HIV you have one foot in the grave, and it's up to you to take it out." Tammy fights to live for her nephews, her mother, and—now—her husband. It's a fight she credits Guide to Healing program with helping her to win.

According to Blickman, "The opportunity to be invited into someone else's life on such an intimate level is really a privilege, and I never lose sight of that or take it for granted. And that's a powerful space to work with someone to get them healthy." It shows.

Today, Tammy has brought in her wedding album to share with Blickman. As the two sit down, you'd swear they were old friends who had come together to catch up, their comfort and encouragement undeniable. As Tammy, the blushing bride, cracks open the album, she leans over and confesses to Blickman, "If it wasn't for you. I couldn't have done this."

6. PART F PROGRAM: AIDS EDUCATION AND TRAINING CENTERS

**IT'S A VIRTUAL ONE-STOP SHOP.**

DEBRA STIMPSON, PHYSICIAN'S ASSISTANT AT THE HIV CLINIC AT  
INTERNAL MEDICINE RESIDENCY SPOKANE

The Ryan White HIV/AIDS Program Part F AIDS Education and Training Centers (AETCs) support a network that conducts targeted, multidisciplinary education and training programs for health-care providers treating people living with HIV/AIDS. AETCs serve all 50 States, the District of Columbia, the Virgin Islands, Puerto Rico, and the six U.S. Pacific jurisdictions. The AETC Program increases the number of health-care providers who are educated and motivated to counsel, diagnose, treat, and medically manage people with HIV disease and to help prevent high-risk behaviors that lead to HIV transmission. (To learn more about the Part F program, visit: [www.hab.hrsa.gov/abouthab/partfededucation.html](http://www.hab.hrsa.gov/abouthab/partfededucation.html).)

Featured below is a case study on the Northwest (NW) AETC and the work they're doing to train medical providers and how they've tapped into the telehealth technology to do so. This work ties in with HRSA efforts to increase provider capacity and share clinical best practices to the greater health care community.

### CASE STUDY: NORTHWEST AIDS EDUCATION AND TRAINING CENTER

Twenty-seven percent of the total U.S. land mass—that's the daunting size of the Northwest AIDS Education and Training Center service area (NW AETC). The grantee is the University of Washington in Seattle. The NW AETC is responsible for increasing provider capacity in HIV care by training providers across Washington, Oregon, Montana, Idaho, and Alaska. The NW AETC is 1 of 11 regional AETCs across the country. These centers are part of the backbone of the Ryan White HIV/AIDS Program and exemplify HRSA's commitment to keeping providers at the forefront of HIV research and care developments.

In carrying out its mission, the NW AETC faces many challenges. Population density—and HIV/AIDS prevalence—is lower in the NW AETC service area than in other parts of the country, and the geographic

service area encompasses medically underserved areas as well as diverse populations and cultures. In Alaska, approximately 20 Native languages are spoken across the State. Only 2 percent of the land is served by roads,



The NW AETC Web site provides a plethora of helpful resources on HIV care.



David Spach, MD, (featured here) has been working in HIV care since the early days of the epidemic. In 2010, his work as NW AETC clinical director was recognized by HRSA with an award for dedicated leadership and development of innovative training and capacity building.

leaving many towns and villages isolated. As Elizabeth Saltonstall, medical director of the Alaska Native Tribal Health Consortium explains, “It’s not how long you have to drive to see your provider, it’s how long you have to fly.”

Long travel times are familiar to residents living farther south in the greater NW AETC region. In Washington’s Olympic Peninsula, for example, many drive 2 to 3 hours to reach the nearest primary care doctor; the same is true in many areas of Montana.

These vast areas have significant unmet needs for HIV care. The demand for skilled—and willing—providers to treat PLWHA has never been greater. The NW AETC is intent on meeting these challenges and HRSA is at the ready, offering training and technical assistance. (To learn more about AETCs, visit: <http://hab.hrsa.gov/living-history/programs/Part-F.htm>.)

The NW AETC is using technology to bridge barriers, address workforce shortages, and ensure that primary-care doctors are delivering the high-quality HIV care characteristic of the Ryan White HIV/AIDS Program. In this way, the NW AETC is a model program with much to teach the Nation.

### **BUILDING BLOCKS FOR CARE**

David Spach takes the adage “Practice what you preach” quite literally. He is the clinical director of the NW AETC as well as a practicing clinician. “I learn so much from my patients and my clinical experiences that it makes me a better educator,” he explains. In fact, many of Spach’s difficult clinical cases are used as NW AETC case studies.

Spach works closely with Laurie Conratt, director of the NW AETC. Together, they are using innovative HIT technology—specifically, telehealth tools—to bridge the

communication and training gap created by the sheer size of their region. "We felt like we needed a tool that could be accessible everywhere. There was tremendous interest in distance and Internet learning, and it really just blossomed from there," explains Spach.

The NW AETC telehealth activities include Web-based training; video conferencing; and HIV Web Study, a case-based clinical curriculum (see [www.hivwebstudy.org](http://www.hivwebstudy.org) for more information).

The NW AETC and the HIV Clinic at Internal Medicine Residency Spokane have helped people like John Frlan, internist and faculty at the Internal Medicine Residency Spokane, Washington clinic, add HIV care services to their résumé. "I've always had an interest," says Frlan. "Now I have an opportunity."

Frlan believes that many providers are hesitant and overwhelmed at the prospect of learning about HIV. He advises, "The AETC is here to offer support and help overcome those barriers." When complex cases arise,



"This really is the most satisfying work," says NW AETC Director Laurie Conratt (featured here). "We're all here for the same reason: to make a difference."

## HEALTH INFORMATION TECHNOLOGY (HIT)

HRSA has produced multiple publications and resources focused on health IT including those discussing the movement towards electronic medical records and shared data systems. These include:

- > **The Power of Technology**  
<http://hab.hrsa.gov/newspublications/careactionnewsletter/march2008.pdf>
- > **Scaling the Mountain: Managing Data in the Age of Accountability**  
[www.hab.hrsa.gov/newspublications/careactionnewsletter/may2007.pdf.pdf](http://www.hab.hrsa.gov/newspublications/careactionnewsletter/may2007.pdf.pdf)
- > **Building IT Capacity: Using Client-Level Data to Meet Consumer Needs**  
[www.hab.hrsa.gov/abouthab/files/cyberspns\\_itcapacity.pdf](http://www.hab.hrsa.gov/abouthab/files/cyberspns_itcapacity.pdf)
- > **Information Technology: Improving HIV/AIDS Care**  
[www.hab.hrsa.gov/abouthab/files/cyberspns\\_it.pdf](http://www.hab.hrsa.gov/abouthab/files/cyberspns_it.pdf)
- > **How Can I Use Health IT for Reporting to HRSA/HAB?**  
[www.hrsa.gov/healthit/toolbox/HIVAIDSCaretoolbox/ImprovingQuality/howcaniusehit4dr.html](http://www.hrsa.gov/healthit/toolbox/HIVAIDSCaretoolbox/ImprovingQuality/howcaniusehit4dr.html)

like an HIV/hepatitis C-coinfected patient preparing for cancer chemotherapy, they pick up a phone and call the NW AETC.

"Having the ability to contact experts at a moment's notice is invaluable. It's like a virtual one-stop shop," says Debra Stimpson, physician's assistant at the HIV Clinic at Internal Medicine Residency Spokane. "At another clinic you can go down the hall and grab a social worker, pharmacist, or specialist, but with us, we grab a phone. We're still able to 'bring' experts in for a consult to ensure our patients receive the best possible care and advice out there."

## BRINGING THE CARE TO YOU

The building and, in fact, the very floor that houses the NW AETC is also home to the International Training and Education Center for Health (I-TECH), and to Project ECHO (Extension for Community Healthcare Outcomes), a new distance learning project targeting

providers in low-prevalence areas. The colocation of these teaching entities allows them to share best practices and lessons learned and, ultimately, to create more informed educators, a richer provider community, and ever-improving care for PLWHA, and the NHAS.

Christian Ramers splits his time between I-TECH, NW AETC, and the Madison Clinic (a large, Ryan White-funded HIV clinic with sites in Seattle and satellite clinic sites in surrounding counties). He sees patients in clinics, and serves as a trainer throughout the Pacific Northwest with the NW AETC as well as in Sub-Saharan Africa with I-TECH. According to Ramers, all of these training components “work together beautifully,” he says. “My clinical work, NW AETC trainings, and activities with I-TECH are predominantly in rural areas,” explains Ramers.

Although he visits a satellite clinic in Snohomish County, 30 miles north of Seattle, along with another in Kitsap County across the Puget Sound, Ramers says that HIT “has been the latest and greatest way to overcome some of these distances.”

His onsite care and training is notable, as is his willingness to commute hours by car or ferry boat to get there from downtown Seattle.

### Because Every Patient With HIV Deserves Innovative and Effective Care

Providers in low-incidence areas are often generalists with low HIV/AIDS caseloads. Learning the intricacies, medications, and complications of HIV can seem daunting.

“There’s a real delicate balance with getting providers on the frontlines who have maybe 10 HIV patients to get excited about taking an active role,” says Ramers. “In terms of the workforce, however, there just are not enough HIV specialists to take care of everyone with HIV, especially in the rural areas, so we need these other providers now more than ever.”

Enter Project ECHO, an innovative clinical consultation model first created and pioneered by Sanjeev Arora in New Mexico. The NW AETC ECHO program specifically targets clinicians with fewer than 25 HIV patients—all providers need is a computer, an Internet connection,

#### NW AETC FULL OFFERINGS

NW AETC also participates in the following projects and programs:

- > Center for Palliative Care. This jointly funded HRSA and Robert Wood Johnson Foundation project works to improve the quality of end-of-life care and increase provider competency around palliative care.
- > CDC Routine Testing Initiative. This HRSA–CDC cooperative agreement provides funding to train health-care providers on up-to-the-minute testing policies and procedures.
- > AIDS Clinical Conference. One of the longest-running clinical HIV conferences in the United States, the AIDS Clinical Conference takes place at the Harborview Medical Center, next door to the NW AETC office. Attendees include regional providers, University of Washington faculty, students, public health officials, and other stakeholders. They meet approximately once a month to discuss myriad issues surrounding HIV care.



Christian Ramers, MD (left) of the NW AETC, communicates with health care providers at the Alaska Native Tribal Health Consortium in Anchorage, Alaska using videoconferencing.

and a willingness to learn. The online conference call includes a video chat component. A provider presents a case to participating experts—a multidisciplinary team of physicians, case managers, psychiatrists, social workers, and others pertinent to the particular case under discussion.

Before each Project ECHO meeting, providers identify a patient case to present. A case form is filled out and submitted 2 days prior to the session so experts have time to review and pull any literature as needed. For confidentiality purposes, patient names and other identifying information are not included. (To learn

more about Project ECHO, visit: [depts.washington.edu/nwaetc/echo/index.html](http://depts.washington.edu/nwaetc/echo/index.html).)

In this way, the NW AETC has harnessed technology to make a vast service area feel small and intimate. It affords rural providers invaluable access not only to HIV specialists, but also mental health specialists—access that is hard to come by in rural America, but desperately needed by so many PLWHA.

This approach builds confidence among providers by reassuring them that they can do this work but needn't go it alone. In short, this is the one-stop shop model, 2.0 style.



### LOCAL PERFORMANCE SITES

While the NW AETC is housed in Seattle, Washington, it also has five regional offices (one in each State within the AETC) and five population-based organizations. These population-specific organizations ensure the AETC is offering culturally competent care to African-Americans, Native Americans, Latino farm workers, and Alaska Natives—all disproportionately affected minority groups within the NW AETC jurisdiction.

The Alaska Native Tribal Health Consortium, for example, is one such minority-serving organization. Based in Anchorage, the consortium offers training to the entire State of Alaska. The consortium has also created an innovative solution for villages that are isolated and lack traditional clinical care access: community health aides.

Each aide undergoes 4 months of intensive training. “The aides follow what we call ‘cookbook medicine,’” says Terri Bramel, physician’s assistant at the Consortium. “If this, then that. If this, then call a medical specialist,” she explains. Health aides fax their patient information to the Anchorage clinic each day for expert review. It may not sound incredibly advanced, but for villages so isolated that they don’t have road access, such technology has been a lifeline. Twice a year, a mid-level provider goes out to monitor the aides’ work.

The aides are recruited directly from the villages in which they serve, making them intimately aware of community and cultural cues. Still, there are barriers. Although most residents of Alaska speak English, some elders prefer information in their Native Alaskan language. With 20 Native languages spoken in Alaska,

#### SHARING LESSONS LEARNED

The Ryan White HIV/AIDS Program has much to teach the Nation and, indeed, the world about delivering HIV care to those most in need. This is achieved through HRSA’s Global HIV/AIDS Program, funded by U.S. President’s Emergency Plan for AIDS Relief, and I–TECH.

Many of the technological advancements made at the NW AETC are being examined and repurposed for an international audience. Currently, I–TECH is interested in replicating the case study work of Project ECHO and using it to link experts to others in the field.

As Ramers, clinical advisor to I–TECH, explains, “There’s a 10-week course we offer on how to manage HIV with a real sensitivity toward developing countries. It’s beamed out via Adobe Connect to a lot of international sites.”

Ramers recalls bringing HIV information to the ground level in Mozambique. “There are packed rooms of people watching the courses and staying an hour afterward to have vigorous conversation,” he explains. Today, the Ministry of Health in Mozambique is taking this information and doing their own kind of telemedicine. “It’s so exciting to be involved in this innovation that just catches on like wildfire, and people are thirsty to do more of it.”



Featured here is a clinical case conference conducted through the AETC-funded Project ECHO. Attendees include clinicians and pharmacists across the NW AETC service area.

it can prove difficult to translate some of the HIV/AIDS-related scientific and medical terminology for prevention education and care delivery. For this reason, Bramel and Saltonstall train health aides to navigate communication as well as clinical challenges.

For lab work, blood is drawn in the villages and taken to the nearest hospital. When complicated cases arise, Bramel and Saltonstall know they can call on the NW AETC staff, who offer assistance, customizing their approaches to each patient case. As Saltonstall explains, "I swear David Spach and Laurie Conratt walk on water!"

### **PRECEPTORSHIPS: TRAINING THE NEXT GENERATION**

#### **Clinical Pharmacy: Much More Than Medications**

In Idaho, David Hachey, a clinical pharmacist, is the key point of contact for many HIV patients in his community and, increasingly, those with HIV/hepatitis C coinfection. Without him, many patients would have

nowhere to go. While he's a pharmacist by trade, he assists in everything from case management to processing patient insurance paperwork.

Hachey recalls a sentiment that gained currency about 6 years ago that rural providers shouldn't be caring for HIV and that rural patients should be referred out to specialty care. But Hachey saw that these patients weren't following up on such referrals and, in many cases, simply couldn't because of their HIV disease. Hachey was put in touch with Spach at the NW AETC along with Judy Thorne, an AIDS educator at a NW AETC local performance site on the other side of Idaho. Thorne served as a resource and ally in the State of Idaho, and Spach immediately became a clinical consult.

"It began with me emailing about more difficult cases and patients," explains Hachey of his communication with the NW AETC. Today, Hachey, a pharmacy nurse practitioner, and nursing staff have all completed



HIV Web Study is an online educational case-based clinical curriculum to help educate Ryan White HIV/AIDS Program providers.

various preceptorships: free-of-charge teaching opportunities funded by HRSA and offered by the NW AETC for providers to directly observe and assist experts.

“The work of the AETC is crucial,” says Hachey. Capitalizing on the AETC trainings, Hachey attends

Project ECHO. “These trainings allow us to learn, develop networks, and bring down the walls of isolation.”

#### Where Family Medicine Meets HIV Care

According to John Nusser, family physician at Family Medicine of Southwest Washington in Vancouver,

Washington, "Continuing medical education doesn't necessarily change provider behavior. In contrast, having specific feedback from AETC expert preceptors significantly improved my patient care."

As a family doctor, Nusser may not be the most obvious candidate to come to deliver HIV care. He's the first to admit that there may be crying babies in the waiting room, but the fact is, there are few HIV clinicians nearby. Family physicians are trained to manage chronic disease, screen for mental health issues, and take a patient-centered approach, all of which are key components to HIV care.

This training and NW AETC educational support have helped Nusser to fashion his clinic into a patient-centered medical home for his HIV patients. "HIV is a chronic disease that primary care clinicians with HIV training can manage well, and the NW AETC is key to empowering clinicians to provide that care."

Nusser is the kind of physician the NW AETC is so proud to have reached. "I'm so impressed by the clinicians, especially in many of the rural areas, who are willing to provide HIV clinical care, many of them without formal training," says Spach. "Working with them is incredibly rewarding and humbling, too."

Nusser is now teaching resident physicians to provide HIV care. "We call this the 'multiplier effect,'" says Conratt. "We're doing trainings to build capacity among clinicians, and then they themselves become trainers, consultants, and mentors to other providers in their region, and the cycle continues."

#### REGIONAL AND NATIONAL AETCs: PROVIDING TARGETED, MULTIDISCIPLINARY EDUCATION AND TRAINING FOR PROVIDERS

##### REGIONAL AETCs: 11 CENTERS

- > Delta Region AETC  
[www.deltaaetc.org](http://www.deltaaetc.org)
- > Florida/Caribbean AETC  
[www.faetc.org](http://www.faetc.org)
- > Midwest AETC  
[www.matec.info](http://www.matec.info)
- > Mountain Plains AETC  
[www.mpaetc.org/default.asp](http://www.mpaetc.org/default.asp)
- > New England AETC  
[www.neaetc.org](http://www.neaetc.org)
- > New York/New Jersey AETC  
[www.nynjaetc.org](http://www.nynjaetc.org)
- > Northwest AETC  
<http://depts.washington.edu/nwaetc>
- > Pacific AETC  
[www.paetc.org](http://www.paetc.org)
- > Pennsylvania/MidAtlantic AETC  
[www.pamaaetc.org](http://www.pamaaetc.org)
- > Southeast AETC  
[www.seatec.emory.edu](http://www.seatec.emory.edu)
- > Texas/Oklahoma AETC  
[www.aidseducation.org](http://www.aidseducation.org)

##### NATIONAL AETCs: 5 CENTERS

- > AETC National Resource Center  
[www.aidsetc.org](http://www.aidsetc.org)
- > AETC National Evaluation Center  
[aetcnec.ucsf.edu](http://aetcnec.ucsf.edu)
- > AETC National HIV/AIDS Clinicians' Consultation Center  
[www.nccc.ucsf.edu](http://www.nccc.ucsf.edu)
- > AETC National Multicultural Center  
[www.aetcnmc.org](http://www.aetcnmc.org)
- > AETC National Center for HIV Care in Minority Communities  
[www.healthhiv.org/NCHCMC](http://www.healthhiv.org/NCHCMC)

## PHOTO CREDITS

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Page 43 (bottom): Nurse Practitioner Lynda Bell (left) examines patient Tammy (right) at the Guide to Healing program, HRSA HIV/AIDS Bureau  
Page 44: Byrd Quinlivan, MD, Guide to Healing program, HRSA HIV/AIDS Bureau  
Page 45: Nurse Guide Andrea Blickman, Guide to Healing program, HRSA HIV/AIDS Bureau  
Page 46: Guide to Healing program employees, HRSA HIV/AIDS Bureau  
Page 47: Ethel (left), Guide to Healing program staff member; Tammy (right), Guide to Healing program patient, HRSA HIV/AIDS Bureau  
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