

# Improving Health Outcomes Through Data Utilization

## 2016 Ryan White HIV/AIDS Program Highlights



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



## CONTENTS

Foreword.....	ii
How RWHAP Uses Data to Improve HIV Care .....	v
<b>Chapter 1. Improving HIV Care in States With Large Rural Populations .....</b>	<b>1</b>
<b>CASE STUDY: Iowa Department of Public Health.....</b>	<b>3</b>
<b>Chapter 2. Reducing Disparities in Metropolitan Areas .....</b>	<b>9</b>
<b>CASE STUDY: Hennepin County Human Services and Public Health Department.....</b>	<b>11</b>
<b>Chapter 3. Reducing Disparities Through the Integration of Early Intervention and Core Medical and Support Services .....</b>	<b>19</b>
<b>CASE STUDY: Franklin Primary Health Center .....</b>	<b>21</b>
<b>Chapter 4. Supporting Providers Across Large Geographic Areas.....</b>	<b>27</b>
<b>CASE STUDY: Midwest AIDS Training + Education Center.....</b>	<b>29</b>
<b>Chapter 5. Innovating to Reach Underserved Populations: Special Projects of National Significance.....</b>	<b>35</b>
<b>CASE STUDY: Friends Community Center.....</b>	<b>37</b>
<b>CASE STUDY: Coastal Bend Wellness Foundation .....</b>	<b>43</b>
References.....	47

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# FOREWORD

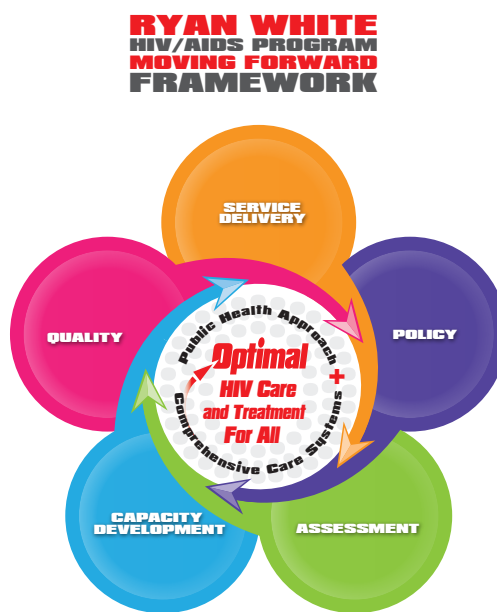
The Ryan White HIV/AIDS Program (RWHAP) provides a comprehensive system of care and treatment, including primary medical care and essential support services, for low-income people living with HIV (PLWH) who are uninsured or underinsured. RWHAP funds states, counties/cities, and local community-based organizations, which provide HIV care and treatment services to more than one-half million people each year, reaching approximately 50 percent of all individuals diagnosed with HIV in the United States. The Program also funds clinician training, technical assistance, and the development of innovative models of care to improve health outcomes and reduce HIV transmission. RWHAP-funded recipients collect data on key components of their programs and use those data to plan, evaluate, and improve services.

August 18, 2015, marked the 25th anniversary of the Ryan White Comprehensive AIDS Resources Emergency Act (commonly known as the CARE Act), the legislation that created RWHAP. First authorized in 1990, RWHAP has continually evolved in response to advances in HIV medicine, shifts in the health care landscape, and the changing needs of PLWH.

RWHAP is the largest federal program focused specifically on HIV care and treatment. The Program, funded at \$2.32 billion in fiscal year 2016, is administered by the U.S. Department of Health and Human Services (HHS) through the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB).

HAB's vision is "optimal HIV/AIDS care and treatment for all." The RWHAP Moving Forward Framework illustrates the elements critical to realizing this vision:

- **Service delivery.** Ensure a seamless, comprehensive system of care with a public health approach.
- **Policy.** Establish federal HIV care and treatment guidelines; review and advise on policy initiatives from HHS and other federal agencies.
- **Assessment.** At the federal level, monitor for capacity and training needs, emerging models of care, state and local system improvements, and public health impact of the program. At the jurisdictional and service area levels, conduct needs assessments to guide planning and resource allocation.
- **Capacity development.** Provide technical assistance and training in such areas as interdisciplinary care, clinical practices, and adoption of health information systems, in cooperation with other government agencies and national organizations.
- **Quality.** Fund improvement programs and help lead the development and broad use of reliable quality measures.



Effective use of data is essential to each of these elements. HAB is committed to gathering, sharing, and making the best use of all available data to provide HIV health care and support services for those with the greatest need, reduce HIV-related disparities, improve the quality of care, and improve outcomes along the HIV care continuum. In 2015, HAB published its inaugural RWHAP *Annual Client-Level Data Report*. The *Report* presents the demographic and socioeconomic characteristics of clients served between 2010 and 2014 and provides an analysis of progress toward achieving both retention in HIV medical care and increased viral suppression. In 2016, HAB reviewed and updated its six strategic priorities, one of which specifically focuses on data utilization:

*Use data from HIV program reporting systems, surveillance, modeling, and other programs, as well as results from evaluation and special projects efforts, to target, prioritize, and improve policies, programs, and service delivery.*

To highlight the innovative models of care that RWHAP recipients implement in communities across the country, HAB publishes a report every two years. These reports provide an update of RWHAP efforts to improve health outcomes for PLWH, showcase data on client demographics and services received, and document the successes and challenges of recipients.

This report highlights the activities of six RWHAP recipients and illustrates how they are harnessing data to reduce disparities in HIV care and improve health outcomes for PLWH.

## **HRSA Recognizes 25th Anniversary of the Ryan White CARE Act**

August 18, 2015, marked the 25th anniversary of the Ryan White CARE Act, which created RWHAP. Senator Edward Kennedy introduced the legislation in March 1990, and President George H.W. Bush signed it into law that summer. Although HRSA was already awarding grants through the AIDS Service Demonstration Grants program, the Ryan White CARE Act created a number of programs to fund treatment for PLWH when no other resources were available.

The CARE Act commemorates a 13-year-old boy named Ryan White who received an AIDS diagnosis in 1984. Ryan was born with hemophilia—his blood would not clot easily—and he contracted AIDS through a blood transfusion. At the time, very little was known about HIV/AIDS. After his diagnosis, Ryan was expelled from school due to fear of and ignorance about AIDS among teachers and parents. Ryan and his mother, Jeanne White Ginder, fought for his right to attend school. In doing so, they attracted international attention for their efforts and raised awareness of the disease. Ryan died in April 1990, one month before his high school graduation and only months before Congress passed the legislation named in his honor.

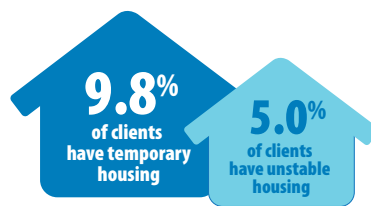
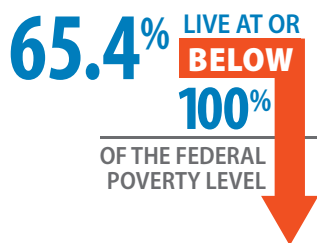
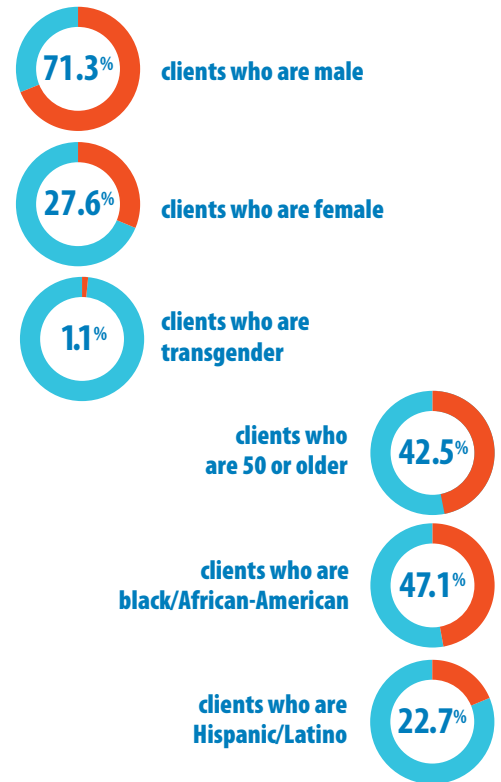
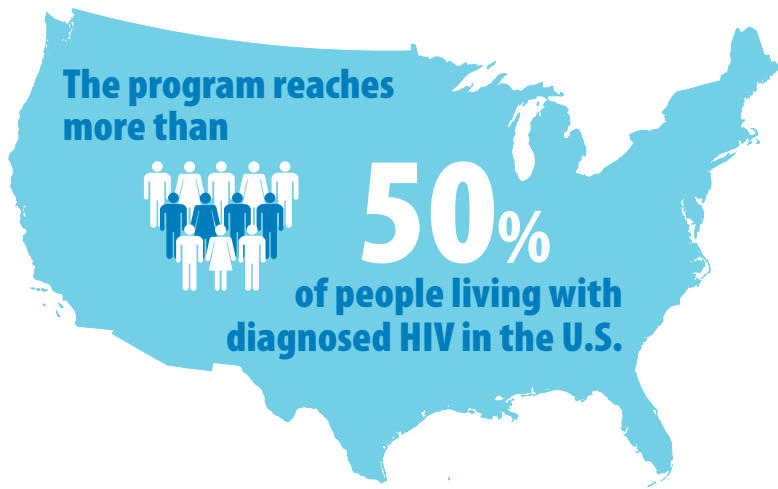
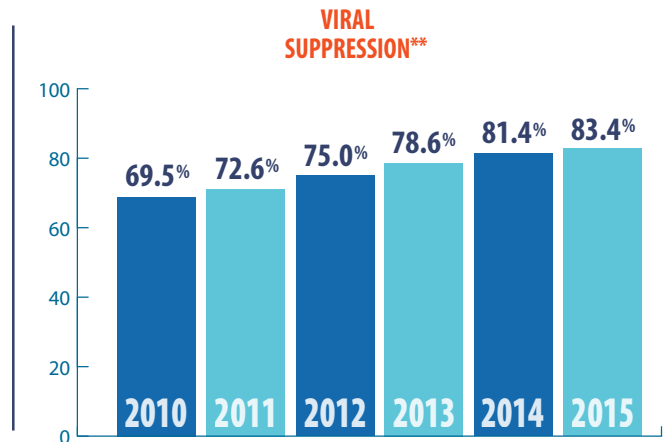
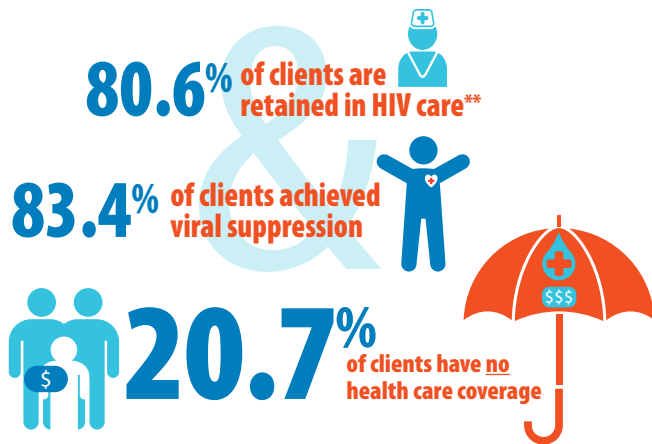
Today, RWHAP works with states, cities, and local community-based organizations to provide HIV care and treatment services to more than one-half million people each year who are uninsured or underinsured. RWHAP serves a diverse population, and the majority of clients are low-income and male. The program delivers a broad range of services to ensure PLWH are able to access and remain in care.



# Ryan White HIV/AIDS Program\*

## BY THE NUMBERS

\*2015 numbers as reported in the Ryan White HIV/AIDS Program Annual Client-Level Data Report; 2015 is the most recent year for which data are available.



\*\*Retention in care is based on data for people living with HIV (PLWH) who had at least one outpatient ambulatory medical care (OAMC) visit by September 1 of the measurement year, with a second visit at least 90 days later. Viral suppression is based on data for PLWH who had at least one OAMC visit and at least one viral load test during the measurement year and whose most recent viral load test result was less than 200 copies/mL.

Data source: Ryan White HIV/AIDS Program Annual Client-Level Data Report, 2015.



# HOW RWHAP USES DATA TO IMPROVE HIV CARE

RWHAP recipients at the national, state, and local levels use data to—

- Identify and engage or re-engage people living with diagnosed HIV infection who are not in care.
- Inform the monitoring of the HIV care continuum, including identification of gaps in care.
- Identify trends in HIV-related health outcomes over time and within and across jurisdictions, clinics, and programs.
- Identify disparities in access to care to help improve HIV-related health outcomes.
- Determine programmatic needs by measuring and analyzing gaps in care, barriers to care, and health disparities.
- Identify characteristics and needs of vulnerable populations to guide the tailoring of interventions.

## Data Sources Used by RWHAP-Funded Recipients

Depending on program objectives, client needs, and partners, RWHAP recipients collect, access, analyze, and interpret many different types of data. Examples of data sources used by recipients include—

- RWHAP client-level data systems (e.g., CAREWare, a free, scalable software platform for managing and monitoring HIV clinical and supportive care that quickly produces a complete RWHAP Services Report)
- AIDS Drug Assistance Program data systems
- HIVQual databases
- HAB core performance measure reports
- National HIV Prevention Program Monitoring and Evaluation data systems
- U.S. Census Bureau data sets
- Social Security Death Master File
- National surveys, such as the Behavioral Risk Factor Surveillance System and Youth Risk Behavior Surveillance System
- Medical Monitoring Project
- National Death Index
- Vital statistics
- STD surveillance systems
- Viral hepatitis and tuberculosis surveillance systems
- Ancillary HIV Surveillance Laboratory databases maintained by state health departments
- Enhanced HIV/AIDS Reporting System (commonly known as eHARS)
- State health information exchanges
- State Medicaid data sets
- Department of Corrections databases
- Department of Motor Vehicles databases
- Housing databases
- Surveys conducted by state and local health departments
- Electronic health records
- Data obtained through medical chart reviews
- Health center-controlled networks
- Payer data sets
- Documents, videos, internal databases, and other sources of qualitative and quantitative data collected as part of program activities, evaluation efforts, and dissemination projects, such as Special Projects of National Significance

In recent years, several national initiatives have expanded the types of data available, collected, and used by RWHAP recipients to monitor and improve HIV services and health outcomes. In order to monitor client characteristics and health outcomes, HAB began collecting client-level data by unique identifier to better quantify and describe RWHAP clients and the services provided through RWHAP. Beginning in 2010, RWHAP client-level data were collected from grant recipients and subrecipients through the Ryan White HIV/AIDS Services Report (RSR). These data are used to assess the number and types of clients receiving services through RWHAP and their HIV-related health outcomes. HAB shares these data with recipients to support their efforts to improve care and treatment for PLWH. Client-level data are reported in RWHAP's *Annual Client-Level Data Report*.<sup>1</sup> RWHAP client-level data also are used to measure progress toward achieving selected indicators described in the *National HIV/AIDS Strategy for the United States: Updated to 2020 (NHAS 2020)*.

### ***National HIV/AIDS Strategy for the United States: Updated to 2020***

Released on July 13, 2010, the National HIV/AIDS Strategy (NHAS) was initially a 5-year plan that identified priorities and strategic action steps tied to measurable outcomes for moving the nation forward in responding to the domestic HIV epidemic. In July 2015, the plan was updated and released as *NHAS 2020*. The *NHAS 2020* plan reflects the work accomplished and new scientific developments since 2010 and charts a course for collective action across the federal government and all sectors of society to achieve the Strategy's vision. *NHAS 2020* outlines four goals for a coordinated national response to HIV: (1) reduce the number of people who become infected with HIV, (2) increase access to care and improve health outcomes for PLWH, (3) reduce HIV-related health disparities, and (4) achieve a more coordinated national response to the HIV epidemic.<sup>2</sup> *NHAS 2020* highlights several focus populations for enhancing efforts toward improved health outcomes. These populations include women; transgender individuals; gay, bisexual, and other men who have sex with men (MSM); blacks/African Americans; Hispanics/Latinos; youth; young black/African-American MSM; young black/African-American women; and people who inject drugs.<sup>3</sup>

HRSA is committed to advancing *NHAS 2020* and the associated Federal Action Plan for 2016–2020 to improve outcomes along the HIV care continuum and reduce new HIV infections. HRSA initiatives that respond to each of the four *NHAS 2020* goals are highlighted at [hab.hrsa.gov/nationalstrategy/index.html](http://hab.hrsa.gov/nationalstrategy/index.html).

Data to Care is a public health strategy that aims to use HIV case surveillance data collected by health departments to improve outcomes across the HIV care continuum. The Centers for Disease Control and Prevention (CDC) initiated the Data to Care approach because of its potential to identify PLWH who are not in care and link them to—or re-engage them with—HIV care and treatment services. Under Data to Care, surveillance data also are being used by health departments and their partners to inform strategies for improving outreach and access to care for PLWH. Some RWHAP recipients now are collaborating with their state's HIV surveillance program to determine whether clients who have not received care at local RWHAP clinics for more than six months are being seen by another provider. The AIDS Drug Assistance Program and other RWHAP client-level databases (e.g., CAREWare) also can be used to determine whether a client truly has fallen out of care.<sup>4</sup>

## Summary of Approaches Employed by Featured Recipients for Using Data to Improve Care

Six RWHAP recipients are featured in the case studies presented in this report's five chapters. Each case study highlights the accomplishments of these programs selected by HRSA for their innovative work with underserved populations. The case studies also describe how the programs use data to engage and reengage people in care, identify health disparities and gaps in HIV care, and generally improve health outcomes for PLWH.

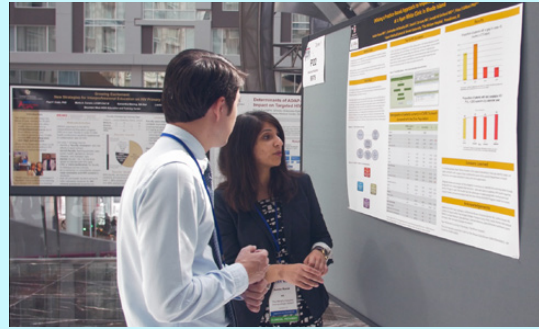
The six featured recipients employ a wide range of strategies for using data to improve HIV care. Most recipients use qualitative and quantitative data from multiple sources to evaluate their services and inform the modification of existing services or development of new strategies and interventions. Recipients emphasize the importance of using and, when possible, integrating multiple data sources to identify patterns in services, outcomes, and demographics that might necessitate a change in program activities. Recipients work with community partners that often provide access to supplemental data (outside of the data collected by the program itself) and assist with outreach, data collection, and client followup. Surveillance and community survey data are frequently used to identify HIV health disparities in service areas that suggest the need for targeted outreach efforts.

Many of the featured recipients report using a Data to Care approach to identify, confirm, locate, and follow up with clients who have fallen out of care. CAREWare, HIV surveillance data, and electronic health records (EHRs) are used to obtain information on these clients to determine whether they are still receiving care from any source. Recipients also use these data to monitor the progress of individual clients and identify challenges and support needs. Most recipients rely on case managers or peer navigators to follow up with clients who have fallen out of care or who are struggling to meet their HIV care goals to offer support services and, when necessary, re-connect them with an HIV care provider.



## The 2016 National Ryan White Conference on HIV Care and Treatment Highlights Data to Care

The 2016 National Ryan White Conference on HIV Care and Treatment was held August 23–26, 2016, in Washington, D.C., focusing on the theme of “Forward Momentum: Accelerating Access. Optimizing Care. Transforming Public Health.” More than 2,400 HIV health care providers, RWHAP recipients, consumers, and national stakeholders from across the United States convened to learn about the latest advances in HIV care and treatment from leaders in the field, identify strategies to enhance recipients’ programmatic and fiscal knowledge, offer opportunities for collaboration, and share best practices.



Data to Care was one of six conference session tracks that served as the foundation for presentations and poster sessions. Other session tracks were Emerging Issues, Healthcare Landscape, Quality Management, Innovative Practices, and Clinical Pathways. Many of these session tracks also had a strong data focus. For example, the Innovative Practices track covered innovative programmatic approaches for using data to improve health outcomes for PLWH. The Quality Management track examined mechanisms and best clinical quality management practices to measure and improve patient care, health outcomes, and patient satisfaction.<sup>5</sup>

# 1

## Improving HIV Care in States With Large Rural Populations



# 1

## Improving HIV Care in States With Large Rural Populations

Part B of the Ryan White HIV/AIDS Treatment Extension Act of 2009 provides grants to all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and six Associated Pacific Jurisdictions to improve the quality, availability, and organization of HIV health care and support services. The specific allowable services funded by each state/territory are determined at the state/territory level based on needs assessments and available funding. Part B has grown into the single largest component of the Ryan White HIV/AIDS Program (RWHAP), primarily as a result of increases in funds to support access to HIV drug therapies.<sup>6</sup> More information about RWHAP Part B grants is available at [hab.hrsa.gov/about-ryan-white-hivaids-program/part-b-grants-states-territories](http://hab.hrsa.gov/about-ryan-white-hivaids-program/part-b-grants-states-territories).

Data collection, management, and analysis are critical components of Part B recipient activities. Part B recipients must provide data demonstrating that support services are linked to medical outcomes. In addition, Part B recipients are required to spend at least 75 percent of their Part B grant funds on core medical services and no more than 25 percent on support services, which makes ongoing collection of high-quality data on program services necessary to the operation of these programs.<sup>7</sup>

The following case study highlights how one Part B recipient, the Iowa Department of Public Health (IDPH), has effectively used Part B funds to bring HIV care and support services to both urban and rural populations across the largely rural state of Iowa. The case study demonstrates the critical role of data to IDPH RWHAP activities and the innovative ways that the program uses data to improve care.



Ryan White HIV/AIDS Program Team from left to right: Holly Hanson, Program Manager; Elizabeth “Biz” McChesney, Client Services Coordinator; Katie Herting, Ryan White Program Evaluation and Quality Management Coordinator; Meredith Heckmann, Benefits Specialist/Interim ADAP Coordinator; and Elsa Goldman, Special Project Coordinator.

## CASE STUDY

### *Iowa Department of Public Health*

IDPH receives RWHAP Part B/AIDS Drug Assistance Program (ADAP) funds for health care and support services, including health insurance premium and cost-sharing assistance and access to medications. Ten provider organizations throughout Iowa are funded through RWHAP Part B to offer case management, transportation to and from doctor’s appointments, assistance with medical and dental bills, and assistance with substance abuse and mental health treatment. The 10 organizations are Siouxland Community Health Center, Nebraska AIDS Project, Mid-Iowa Community Action Agency, The Project of Primary Health Care, Cedar AIDS Support System, Dubuque Visiting Nurses Association, University of Iowa Health Care, Linn County Community Services, The Project Quad Cities, and North Iowa Community Action Organization.<sup>8</sup>

Iowa is somewhat unique in how the population of people living with HIV (PLWH) is distributed throughout the state. According to Ms. Holly Hanson, RWHAP Part B Program Manager at IDPH, approximately 30 percent of PLWH are residing in rural areas. “Des Moines has just 30 percent of the HIV epidemic, and that’s our largest city, and that’s our largest epicenter. If you take the top 10 most populous large towns or small cities, you’re still only accounting for 70 percent of PLWH,” she said. This distribution of PLWH presents unique challenges. For example, Ms. Hanson noted that PLWH in less-populated areas can feel stigma more intensely because they are isolated from other PLWH. Stigma is compounded by other challenges in rural areas, such as the long distances that many people must travel to obtain HIV testing and care. The RWHAP-funded programs are working in tandem with CDC HIV prevention-funded efforts

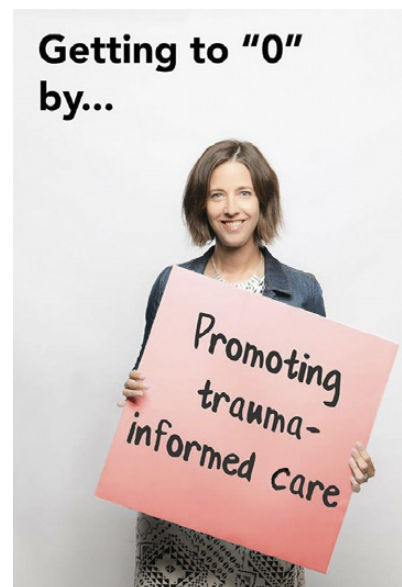
to reduce barriers to HIV testing and increase diagnosis rates in Iowa. For example, opt-out HIV testing is being implemented in community health centers.

## ■ 2012–2015 COMPREHENSIVE HIV PLAN

Recent IDPH RWHAP activities have been guided by Iowa’s 2012–2015 Comprehensive HIV Plan, which was developed to align with the National HIV/AIDS Strategy and the HIV care continuum framework. “What we do is take the jurisdictional strategic plan that we’re operating under and then the RWHAP plan, and we look at those and see as a program what we need to do to further those goals,” explained Ms. Hanson. These planning activities have resulted in an expansion of HIV services in Iowa. “We started a push in 2012, expanding our focus from providing core and support services to integrating services along the HIV care continuum,” she said.

## ■ TRAUMA-INFORMED CARE

IDPH RWHAP is implementing a unique approach to the provision of services along the HIV care continuum. This approach, trauma-informed care (TIC), is premised on the idea that clients are not simply ill, but experiencing trauma. This paradigm came out of the Adverse Childhood Experiences Study, which found that adverse childhood experiences were linked to health and health behavior problems, such as HIV, substance abuse, and suicide.<sup>9</sup> IDPH RWHAP is emphasizing TIC through training for case managers. “Internally at the health department, we have done a significant amount of work on reducing the silos within IDPH, on the work that we’re doing within trauma, so that we can learn from each other and collaborate with each other,” explained Ms. Elizabeth McChesney, Client Services Coordinator for IDPH RWHAP. IDPH added questions from the Adverse Childhood Experience module in the Behavioral Risk Factor Surveillance System to this year’s online consumer needs assessment, which is done regularly in anticipation of the Department’s integrated planning process. Resulting data will ultimately help inform how IDPH provides HIV care and support.



## ■ USING DATA TO IMPROVE CARE

In the last five years, data have driven a transformational change in how IDPH manages and directs HIV care and support services provided by RWHAP to Iowans living with HIV. “Not only do we spend a lot of time using data to communicate with our contractors and other stakeholders on the care continuum and what their role is in raising the bar, we spend a lot of time asking of ourselves, ‘What are the things we can do to help them raise the bar?’” said Ms. Hanson.

### *Tiered Case Management Approach*

IDPH used data to develop, test, and implement a four-tiered system designed to improve the coordination of case management services. This system allows different levels of engagement based on the current needs

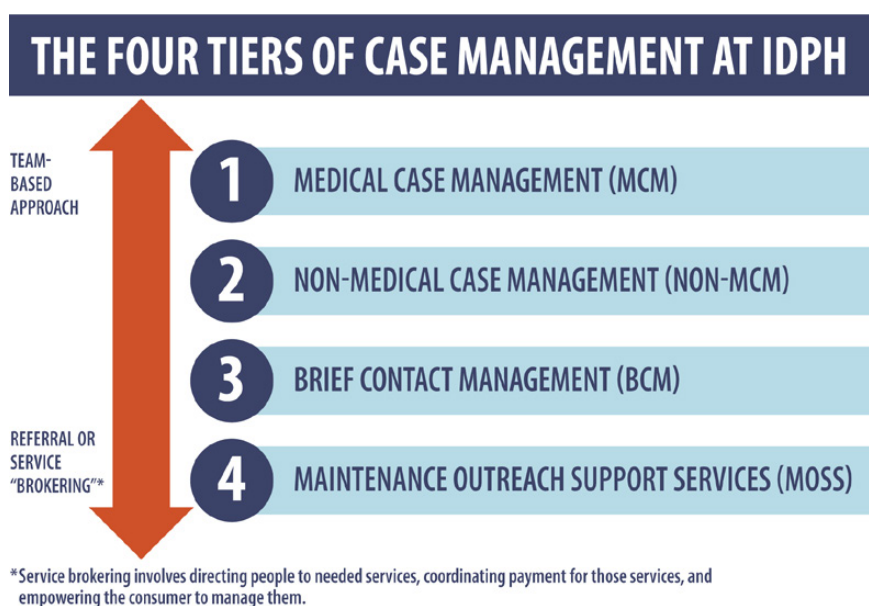
of the client. Case managers rely on client-level data to determine the level of case management required by the client. The first, most intensive level of engagement (Tier 1), involves proactive medical case management (MCM). Tier 1 is intended for PLWH who may require assistance with access, utilization, retention, and adherence to medications or health care services. The next level of engagement (Tier 2), involves non-medical case management (non-MCM). This proactive case management model is intended for PLWH who manage

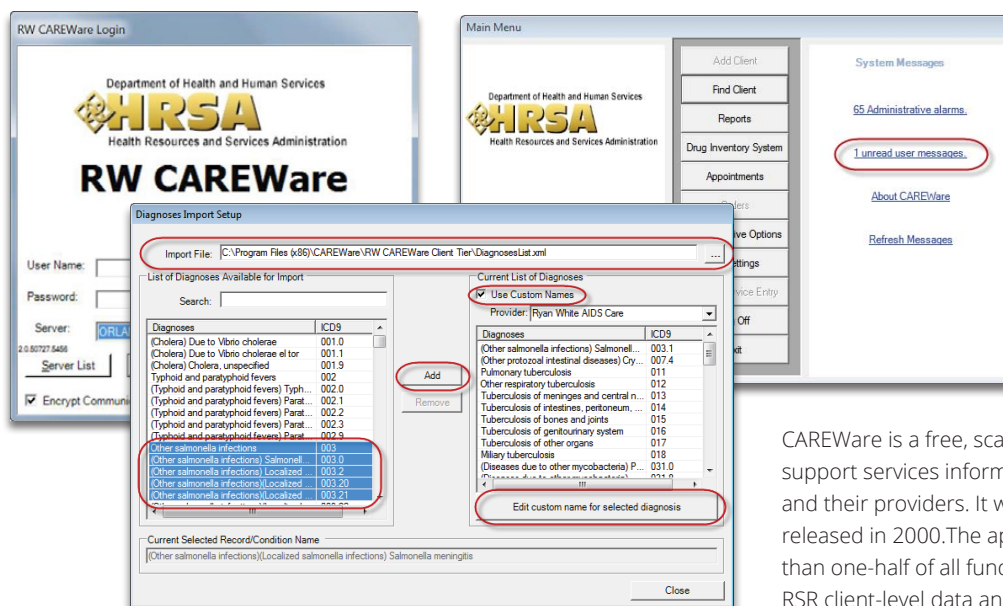
their care well enough to avoid chronic disruption, but still require psychosocial support to maintain a stable lifestyle. Non-MCM is also appropriate for clients who have completed MCM, but still require periodic support. The third tier of engagement involves brief contact management (BCM). The BCM case management model is intended to support PLWH independence in decision-making and in accessing health-related and psychosocial services. BCM clients have the life skills and personal resources needed to self-manage their care with only occasional assistance. The least intensive level of engagement (Tier 4), is maintenance outreach support services (MOSS), which is designed for PLWH formerly engaged in more intensive case management who have progressed to self-management. MOSS assesses self-management and provides services needed to prevent lapses in care.<sup>10</sup>

The tiered case management system was pilot-tested at diverse provider organizations. “The innovative or above-and-beyond piece is that we’ve spent the time to think through what is going to work for our folks and then spent quite a bit of time with them on implementation,” said Ms. Hanson. The pilot tests found that the tiered system “really helps case managers handle and prioritize their caseloads in such a way as to reduce burnout and provide better care.”

### *Monitoring Case Management Efforts*

According to Ms. McChesney, data help tell the story of the work Iowa case managers are doing. “One of the things we noticed looking at the Ryan White HIV/AIDS Services Report (RSR) data was that our case managers were really underreporting their time spent doing case management. We know our case managers are busy, and a lot of them spend more than 40 hours a week working with their clients, but that wasn’t being reflected in our RSR and ultimately what HRSA sees.” Ms. Hanson emphasized the importance of accurate reporting of case manager activities to continuous quality improvement, as well as to the development of new projects, adding, “We also can’t design programs around what’s going to work best for them [case managers] if we don’t know what they’re really doing.” To improve the accuracy of case management activity reporting, IDPH RWHAP pilot-tested a project to train case managers on what information to enter into CAREWare. According to Ms. McChesney, this project “was extremely successful, and we then





CAREWare is a free, scalable electronic health and social support services information system for RWHPAP recipients and their providers. It was developed by HRSA and first released in 2000. The application is currently used by more than one-half of all funded recipients to report year-end RSR client-level data and to monitor quality of care.

rolled it out with all of our contractors.” Each month, contractors get a report of how much time they entered into CAREWare compared to how much time they submitted for reimbursement. Ms. McChesney explained that the program performs “targeted technical assistance with each agency to help them identify the challenges and barriers they’re having to get their time entered in CAREWare to show an accurate picture of the work they’re doing.... It’s an exciting thing to see.”

### Strengthening Re-Engagement

Ms. Becky Johnson, Coordinator for Data to Care at IDPH, was initially charged with developing an HIV care re-engagement program. One of her first steps was to implement an active surveillance program, because, as she stated, “You have to have good data to work with before you can design a program to re-engage people.” Her current surveillance program collects information from all departments and contractors and includes information from external data sources, including social media, when needed.

Developing an effective surveillance program involved improving communication with contractors about client status, particularly when their clients move or leave care. “The first phase of re-engagement is focusing on ‘the internal investigation’—before we ever call a client, you really need to have your ducks in a row.

These are the toughest of the tough cases, people who may be out of care for a reason, and you need a good picture of that client and what their barriers may be,” said Ms. Johnson. “Or maybe they are in care and you just have a problem with the lab reporting.” Ms. Johnson uses Epi Info™, an epidemiological software program designed by CDC, to prioritize the cases of those individuals who are found to be truly out of care. Ms. Johnson is currently developing strategies to reach the PLWH who are out of care.

“You have to have good data to work with before you can design a program to re-engage people.”

— Becky Johnson, Coordinator for Data to Care, IDPH

### *Improving Access to ADAP*

IDPH uses data to improve timely completion and submission of ADAP applications. Late, often incomplete ADAP applications have presented a significant problem in the past. IDPH collected baseline data on the on-time submission rate of completed applications for each agency. IDPH provided the agencies with their rates and communicated the need to increase those rates. Ms. Hanson found that simply having data on timely submission rates helped the agencies increase their rates. “We saw rates go up significantly, but then we followed that up with technical assistance and capacity building.” IDPH also offered an incentive within the contract if agencies achieved specific submission rates. “We actually customized their targets based on internal factors, and that was extremely successful and helped them put in place regular strategies to get a better rate,” said Ms. Hanson.

### *Assuring Quality Across Programs*

Two years ago, IDPH strengthened its quality management program by hiring Quality Management Coordinator Katie Herting. According to Ms. Hanson, “The hire allowed IDPH to get off the ground all the quality initiatives that needed to be there. Now we’ve been really able to use data to drive quality improvement.” Ms. Herting oversees three quality managers at the agencies that have both RWHAP Part B and Part C funding. IDPH also plans to provide at least one informatics specialist to the Des Moines contractor to assist with complex data issues and the use of CAREWare.

## ■ LESSONS LEARNED AT IDPH

IDPH has used data to innovate while expanding the care and support it provides to PLWH. “One of things that Iowa has done that maybe our rural and frontier state counterparts haven’t been able to do is hire the staff necessary to do the work,” noted Ms. Hanson. “It didn’t just happen that we were able to expand our staff—we’ve been able to use data to make the case for the need for staff to support our work to improve the care continuum.” She also emphasized the importance of using the HIV care continuum as a framework for IDPH HIV efforts and the planning that is necessary to implement those efforts. Referring to this framework, Ms. Hanson added that, “We have never had better results.... It’s never been easier to explain to our contractors what they’re doing, why they’re doing it, where it fits, and why it’s so important.”



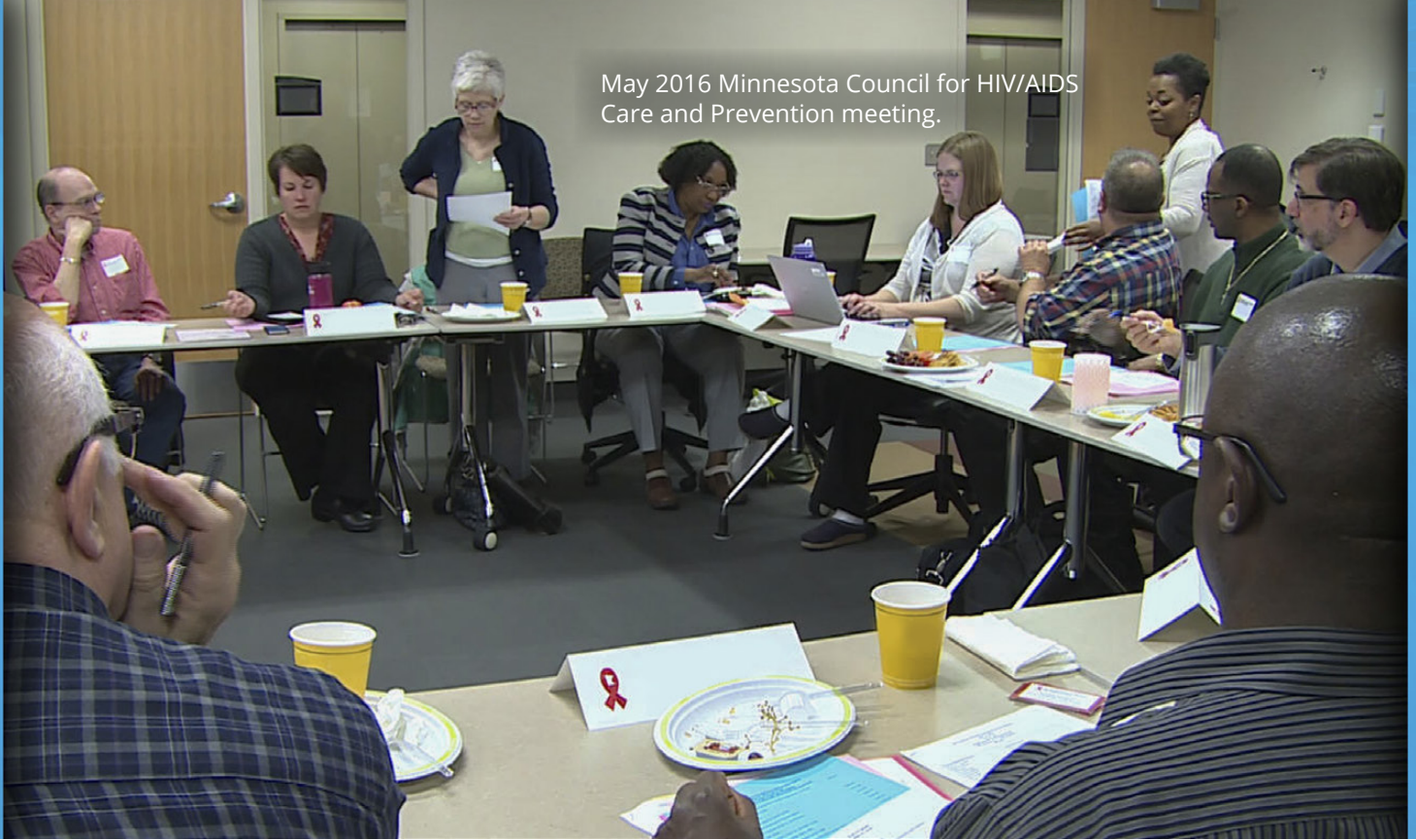
# 2

## Reducing Disparities in Metropolitan Areas





May 2016 Minnesota Council for HIV/AIDS Care and Prevention meeting.



## CASE STUDY

### *Hennepin County Human Services and Public Health Department*

Hennepin County HSPHD administers the RWHAP Part A grant and uses these funds to provide support to clinics and community-based organizations providing core medical and support services to low-income PLWH in the Minneapolis–St. Paul metropolitan area in Minnesota. Hennepin County HSPHD plans RWHAP activities in collaboration with the state-level RWHAP Part B to provide 21 of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau-fundable services in the state. Part B funds many services critical to client retention in HIV care and viral suppression, such as AIDS pharmaceutical assistance and the majority of medical transportation services in the Hennepin County RWHAP Part A service area. Hennepin County RWHAP administers a portion of Part B base funds because many providers are located in the Part A grant area and receive some Part A funding. According to Dr. Jonathan Hanft, RWHAP Coordinator in the Hennepin County HSPHD, “We really can manage and prevent duplication of services that way.”

Hennepin County RWHAP also provides staffing for the new Minnesota Council for HIV/AIDS Care and Prevention. This Council plans all HIV services for Minnesota and meets all funding agency requirements, including RWHAP Parts A and B planning requirements, as well as Centers for Disease Control and Prevention (CDC) HIV Prevention Community Planning Group requirements.

## ■ HENNEPIN COUNTY RWHAP SERVICES

Hennepin County’s RWHAP Part A works with multiple partners to provide a wide range of services, as outlined in Table 1. Medical case management (MCM) is the largest RWHAP-funded service category in Minnesota. Dr. Hanft attributed the program’s success with HIV retention in care (now 88 percent of clients) and viral suppression to the extensive MCM services provided. Outpatient ambulatory medical care is another important RWHAP-funded service provided by Hennepin County HSPHD. A large component of this service focuses on Latinos and is supported by both RWHAP Part A and Part F MAI funds. The outpatient HIV services for Latinos are provided primarily through West Side Community Health Services (West Side), which reaches nearly one-quarter of all Latinos living in Minnesota. Many other services provided through RWHAP Part A funding are critical to retaining PLWH in care. These services, many of which are culturally specific, include food banks and home-delivered meals, psychosocial support, and health and risk-reduction education. Mr. Thuan Tran, Hennepin County RWHAP Senior Planning Analyst, illustrated the importance of the psychosocial support services through a story about a client who, “through working with his peers in the Men’s Psychosocial Support Group has become more motivated to...develop his interpersonal skills and become a better advocate for himself.” Since attending the psychosocial support group, this client has become interested in helping his community and has started working toward a degree in human services.

Table 1. Services Provided Through RWHAP Part A in the Hennepin County Service Area

PARTNERS DELIVERING THE SERVICES	SERVICES	
African-American AIDS Task Force, Allina, Children’s Hospital and Clinics of Minnesota, HealthPartners, Minneapolis Medical Research Foundation, West Side, Sub-Saharan African Youth and Family Services of Minnesota, Hennepin County Medical Center (HCMC)	Medical case management	
Hennepin County Public Health Clinic	HIV outreach, education, prevention, early intervention	
Aliveness, Minnesota AIDS Project, Open Arms	Food bank and home-delivered meal programs for people living with HIV	
West Side and Minnesota AIDS Project	Health and risk reduction education	
Minnesota AIDS Project	Health insurance, housing, legal, and emergency financial assistance	
Pinnacle Services	Home and community-based HIV services	
Sub-Saharan African Youth and Family Services of Minnesota	Medical transportation	
Aliveness and HCMC	Medical nutrition therapy	
HCMC, Sub-Saharan African Youth and Family Services of Minnesota, West Side	Mental health	
Minnesota Department of Human Services	Oral health	
HealthPartners, HCMC, West Side	Outpatient ambulatory HIV medical care	
Aliveness	Peer outreach	
Pinnacle Services, Minnesota AIDS Project, Sub-Saharan African Youth and Family Services of Minnesota, West Side	Psychosocial support	
Minneapolis Medical Research Foundation, Minnesota AIDS Project	Outpatient substance abuse treatment	

Based on information from the June 2016 *Hennepin Ryan White Provider News*  
 Source: [content.govdelivery.com/accounts/MNHENNE/bulletins/14aeba0](http://content.govdelivery.com/accounts/MNHENNE/bulletins/14aeba0).

In 2015, the Minnesota Council for HIV/AIDS Care and Prevention allocated a significant amount of the Minnesota Department of Human Services (MDHS) HIV/AIDS Unmet Need and Rebate Fund for core HIV medical and support services. This fund is the result of a legislative mandate directing the MDHS HIV/AIDS Unit to work with stakeholders to identify unmet needs of PLWH in Minnesota and the appropriate use of AIDS Drug Assistance Program (ADAP) pharmaceutical rebate revenue to meet the identified needs.<sup>11</sup> Hennepin County RWHAP administers the majority of these funds, which has allowed the program to expand early intervention and other services, as well as to expand interventions for communities disproportionately affected by HIV.<sup>12</sup> Most early intervention funding goes to the Hennepin County Public Health Clinic, which is the largest public health clinic in Minnesota. Dr. Hanft explained that this clinic is “the ‘go-to’ place as a public health clinic for HIV and STI [sexually transmitted infection] testing.” This clinic has worked with gay, bisexual, and other men who have sex with men (MSM) for several decades. The clinic has a program that was modeled after the rapid HIV testing program originally implemented in Washington, D.C.

When people come to the clinic for rapid HIV testing, those who test positive also see a nurse practitioner, have bloodwork done to confirm their CD4 count and viral load, and obtain complete STI screening at the same location. A health navigator who is living with HIV is present at the Hennepin County Public Health Clinic to help newly diagnosed patients set up their followup medical appointments at a clinic that will prescribe antiretroviral therapy. The navigator can often arrange followup appointments within 48 hours of diagnosis. The navigator also helps patients obtain coverage for HIV care and medications through the Minnesota ADAP, Medicaid, and/or qualifying health plans in the state insurance exchange. While waiting to obtain health insurance, patients can continue to receive HIV care at the Public Health Clinic or the Positive Care Center at Hennepin County Medical Center (HCMC), which is the largest HIV specialty clinic in Minnesota. The Hennepin County Public Health Clinic works closely with the Positive Care Center and shares a clinical director.

## ■ REDUCING DISPARITIES THROUGH COMMUNITY WORK GROUPS

A goal of Minnesota’s new integrated HIV Prevention and Care Plan is the reduction of HIV-related disparities, and the Minnesota Council for HIV/AIDS Care and Prevention Disparities Elimination Committee has developed objectives and activities for this goal. Hennepin County RWHAP has supported the goal of reducing HIV-related disparities by increasing efforts to improve engagement of communities disproportionately affected by HIV in recent years. A community-based participatory approach is used to plan, implement, and evaluate



Co-Chairs of the Minnesota Council for HIV/AIDS Care and Prevention at the May 2016 meeting, from left to right: Larry McPherson, Rob Yaeger, and Roger Ernst. Mr. Yaeger left the Minnesota Department of Health later in 2016. Mr. McPherson and Mr. Ernst continue to serve as Council Co-Chairs.

The Hennepin County Department of Public Health RWHAP relies on three community-based work groups to guide its efforts to serve special populations. These work groups include the African-Born Leaders Work Group, which focuses on African immigrants, the African-American Gay/Bi/MSM Work Group, and the Latino Gay/Bi/MSM and Latina Transgender Work Group.

“The data that we have don’t show us the whole picture. With regard to gaps in services and HIV disparities, we rely on these groups to provide key informant interview responses.”

— *Thuan Tran, Hennepin County RWHAP Senior Planning Analyst*

services, particularly for priority populations in Minnesota. As part of this approach, three work groups composed of representatives from priority communities have been meeting for the past three years to address disparities in access to HIV care and prevention services and HIV outcomes in Minnesota. These work groups include the African-Born Leaders Work Group, which focuses on African immigrants, the African-American Gay/Bi/MSM Work Group, and the Latino Gay/Bi/MSM and Latina Transgender Work Group.

According to Mr. Tran, “The data that we have don’t show us the whole picture. With regard to gaps in services and HIV disparities, we rely on these groups to provide key informant interview responses.” The qualitative data provided by these interviews provide greater insight into the needs of the priority communities. For example, community input helped to identify and overcome challenges encountered in implementing a sexual health assessment tool with the African-born immigrant population. The program worked with the Office of Minority Health Resource Center (OMHRC) to develop a culturally specific sexual health assessment tool using feedback from key informant interviews with members of the African immigrant community in Minnesota. “We really rely heavily on consumer input, community input, so that we can improve services and have the same level of customer service across the Ryan White HIV/AIDS Program system for all populations,” said Mr. Tran.

The African-Born Leaders Work Group was formed to represent African immigrants, who form a significant proportion of PLWH in Minnesota. African immigrants represent an unusually high proportion of PLWH in the state because Minnesota was one of six states that resettled PLWH from refugee camps in East Africa in the 1990s. The African-Born Leaders Work Group has been actively engaged in improving HIV services for this relatively new population in recent years. For example, the Work Group convened an African Health Summit in 2015 that was supported by OMHRC. The Work Group also conducted a strategic planning session in the summer of 2016. In addition, a Hennepin County RWHAP intern worked with Kenyan immigrant faith leaders to develop a health education curriculum to promote HIV prevention and testing in their community. Dr. Hanft plans to engage a provider to develop that curriculum into a training module for African immigrant faith leaders to use with their communities.

The African-American Gay/Bi/MSM and Latino Gay/Bi/MSM and Latina Transgender Work Groups are also engaging in critical strategic planning activities in 2016. Funded pilot projects have been executed in response to data collected by these work groups, and the results of the projects will inform future

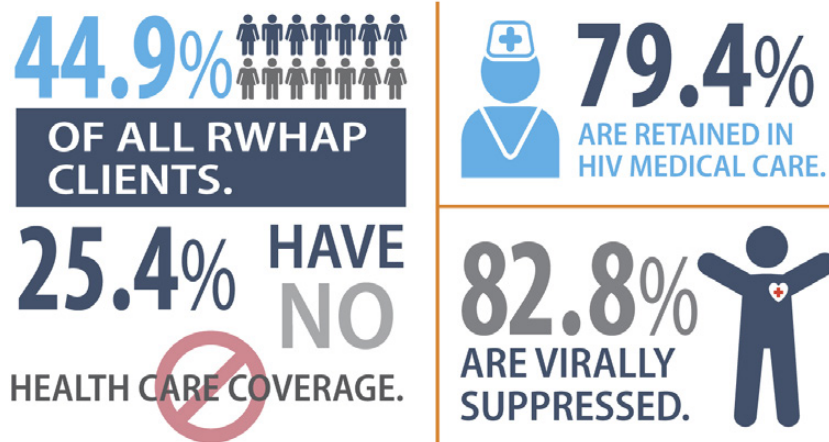
RWHAP-supported services for these populations. The African-American Gay/Bi/MSM Work Group also implemented several activities in 2015. For example, the African-American Gay/Bi/MSM Work Group Summit was convened in April 2015 with the support of Hennepin County RWHAP, OMHRC, the Minnesota HIV Services Planning Council, Minnesota Department of Human Services, and Minnesota Department of Health. The Work Group also worked with OMHRC to conduct a community assessment,

including key informant interviews and focus group discussions in early 2015. The results of these data collection efforts are being used by Hennepin County RWHAP to guide improvements in HIV prevention, treatment, and supportive services for African-American MSM.<sup>13</sup> For example, qualitative data collected by the Work Group led to an expansion of early intervention services for the African-American community. According to Mr. Tran, key informant interviews revealed that “with the African-American Gay/Bi/MSM, there’s a need for spiritual affirmation.” This finding led to a collaboration with a faith-based organization and a community health center to increase HIV testing among African Americans, with a focus on gay/bisexual/MSM. The Latino Gay/Bi/MSM and Latina Transgender Work Groups have also conducted a needs assessment that involved key informant and client interviews. This assessment identified a need for culturally specific psychosocial support. In response to this finding, Hennepin County RWHAP provided additional resources for services focused on Latino populations, using RWHAP Part A and MAI funds.

## ■ USING DATA TO IMPROVE CARE

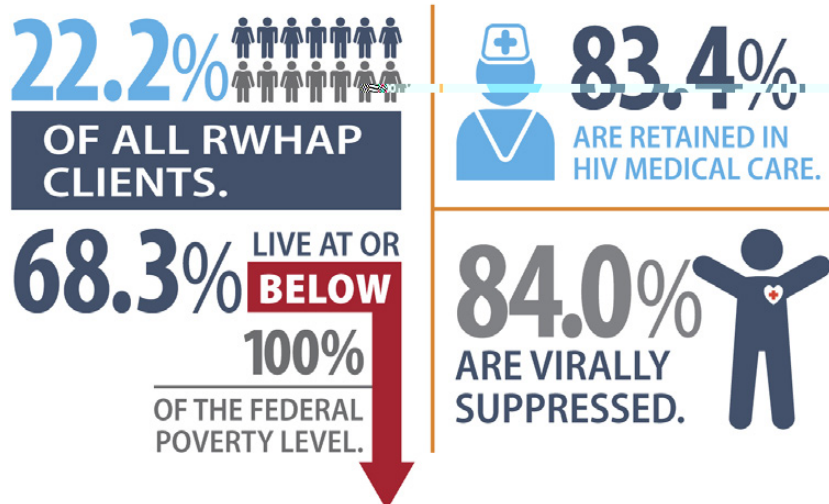
Minnesota RWHAP uses a centralized CAREWare system that is customized to the meet state HIV program data management and analysis needs. CAREWare allows the program to “drill down with all our demographic data on who’s receiving services and the outcomes,” explained Dr. Hanft. This information helps Hennepin County RWHAP focus its resources where they are most needed. For example, CAREWare data showing that Latinos in Minnesota have higher rates of HIV infection and lower rates of

### RWHAP Gay, Bisexual, and Other MSM Clients, 2014



Data source: 2014 Annual Client-Level Data Report.

### RWHAP Hispanic/Latino Clients, 2014



Data source: 2014 Annual Client-Level Data Report.

retention in care and viral suppression than non-Hispanic whites led to an expansion of primary care and MCM services for Latinos.

CAREWare also is used to track and re-engage clients who might have been lost to care. The customization of the CAREWare system included the addition of a question that requires medical providers to assess whether their clients living with HIV have had a medical appointment in the past six months. If clients have not had a medical appointment in the past six months, providers are required to refer those clients to an appropriate provider and follow up on that referral. CAREWare tracks each step in this process and feeds information to the quality management program. All providers are also required to submit an annual quality improvement plan with baseline measures, specific goals for improving data quality and client-level outcomes, and client engagement strategies, as well as to report semiannually on their progress toward achieving goals. According to Dr. Hanft, “If one of our providers shows that 30 percent of clients have not had an appointment in the last six months, we would work with them to incorporate a quality improvement goal to improve retention.”

In March 2016, the Minnesota Council for HIV/AIDS Care and Prevention launched “eHARS to CAREWare” to coordinate Minnesota’s HIV surveillance system with Minnesota CAREWare. This initiative will help community-based providers improve tracking of clients’ retention in HIV care and their viral suppression. Dr. Hanft noted, “We are hoping, in the next year, that we’ll have CD4 and viral load [data] on almost all of our Part A-funded clients.” The initiative will also improve the evaluation of HIV care and treatment efforts, which will ultimately lead to the reduction of new infections.

Hennepin County HSPHD also has implemented a Data to Care Project, which will use HIV surveillance data for every person living with HIV in Hennepin County to develop a quarterly out-of-care list. Other data sources will be used to improve the accuracy of the out-of-care list, including electronic medical records from HCMC and the Hennepin County Public Health Clinic and CAREWare data. Dr. Hanft explained, “We know from other jurisdictions that are doing this that usually at least 50 percent of those [people] that seem to be out of care based on whether or not they have a CD4 or viral load are actually either in care or they’ve left the state, and usually a handful have died.” A disease intervention navigator model will be used to reach out to people who have been determined to be out of care and living in the state. An accurate out-of-care list will help ensure that health navigators use their valuable time to reach out to people who truly are out of care.

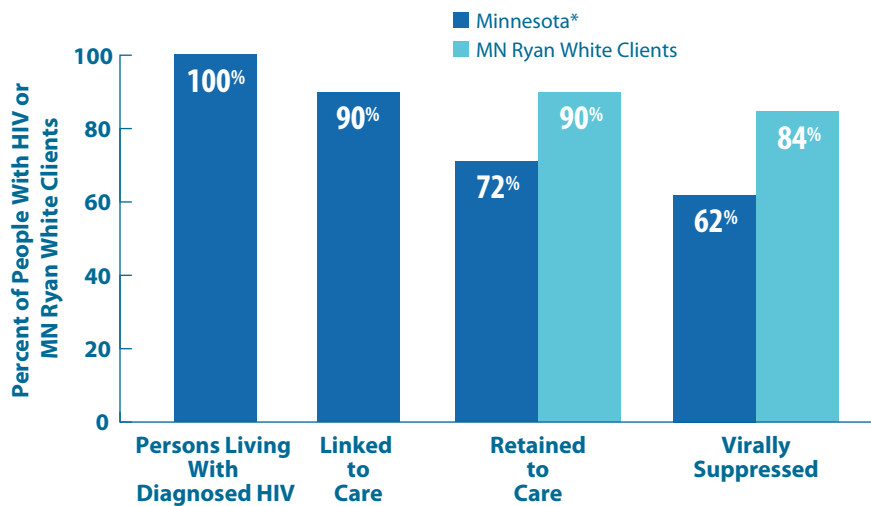
In addition to HIV surveillance data, Hennepin County RWHAP uses data from the Survey of the Health of All the Populations and the Environment (SHAPE), which is conducted every four years in Minnesota. SHAPE includes questions about sexual orientation and gender identity. Dr. Hanft noted that, “We’ve learned from past SHAPE studies that young gay and bisexual men are much less likely to have a regular medical care provider than their non-gay/bisexual counterparts. So we’re able to use that data to inform some of the programs, particularly early intervention for gays and bisexuals.” This survey also provides local estimates of the size of the gay and bisexual male populations.



## ■ LESSONS LEARNED AT HENNEPIN COUNTY HSPHD

Dr. Hanft emphasizes the importance of integrating data systems to improve HIV care and treatment. “The more we can integrate our data systems, I think we’ll be able to have much stronger tools to improve the care continuum.” Hennepin County RWHAP has a strong relationship with the Minnesota Department of Health, which allows the program to combine HIV surveillance data with client-level data. According to Dr. Hanft, the challenge will be to discover how best to use “CAREWare and surveillance data to work with our providers to help them improve their tracking of clients who are out of care and re-engaging them.”

RWHAP Part A clients have higher rates of retention in care and viral suppression than other PLWH in Minnesota



\* Percent of Minnesotans known to be living with HIV in 2014.

\*\* Percent of Ryan White Part A clients in 2014.

\*\*\* Percent of Ryan White Part A outpatient/ambulatory medical care patients in 2014.

Data source: [content.govdelivery.com/accounts/MNHENNE/bulletins/14aeba0](http://content.govdelivery.com/accounts/MNHENNE/bulletins/14aeba0).

# 3

## Reducing Disparities Through the Integration of Early Intervention and Core Medical and Support Services



# 3

## Reducing Disparities Through the Integration of Early Intervention and Core Medical and Support Services

Part C of the Ryan White HIV/AIDS Program (RWHAP) funds local community-based organizations that provide comprehensive primary health care and support services in an outpatient setting to people living with HIV (PLWH). RWHAP Part C funding supports the Early Intervention Services (EIS) program to provide such services as HIV counseling and testing, monitoring of disease progression, treatment of HIV, diagnosis and treatment of related infections, and case management.<sup>14</sup> In addition, Part C funds capacity development grants to help public and nonprofit organizations strengthen their infrastructure and capacity to develop, enhance, or expand access to high-quality HIV primary health care services for PLWH in underserved communities.<sup>15</sup>

As with RWHAP Parts A and B, data collection, management, and analysis are necessary components of RWHAP Part C recipient activities. Part C recipients must allocate costs in the categories of EIS, core medical services, support services, clinical quality management, and administrative services. This allocation requires ongoing collection and management of accurate data on services and expenditures. More information about RWHAP Part C is available at [hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-c-early-intervention-services-and-capacity-development-program-grants](http://hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-c-early-intervention-services-and-capacity-development-program-grants).

The following case study highlights how RWHAP Part C recipient Franklin Primary Health Center (FPHC) uses funds to bring comprehensive HIV medical care and support services to southwestern Alabama. This recipient also receives RWHAP Part B funding, which allows FPHC to provide a wide range of integrated EIS and core HIV care and support services to medically underserved communities. The case study illustrates the critical role data play in RWHAP activities at FPHC, as well as the innovative ways FPHC uses data to improve care.



Ryan White HIV/AIDS Program Team from left to right: Robert King, Case Manager; Jonnie Parks, Specialty Nurse; William Chastang, Consumer Advocate; Michelle Bernard, Ryan White Program Manager; Kenji Fisher, Case Manager.

## CASE STUDY

### *Franklin Primary Health Center*

FPHC is a nonprofit, federally qualified health center with 21 clinics serving southwestern Alabama, including Baldwin, Choctaw, Conecuh, Escambia, Mobile, and Monroe counties. This RWHAP Part C recipient serves a diverse population, including men who have sex with men (MSM) and individuals who identify as transgender. The majority of clients are black/African American, and a large proportion is youth and young adults aged between 15 and 34. In recent years, the program has also served an increasing number of people aged 55 and older. Through RWHAP Parts B and C funding, FPHC provides primary medical care and specialty care, including obstetrics and gynecological care, laboratory and X-ray services, oral health care, mental health and outpatient substance abuse services, medical nutrition therapy with counseling and consultation, and a complete pharmacy service with patient assistance programs for those who qualify. Supportive services offered to patients include case management, psycho-social support, linguistic services,

#### RWHAP Black/African-American Clients, 2014



Data source: 2014 Annual Client-Level Data Report.

outreach and health education, adherence to treatment counseling, transportation, and referrals for other health care or supportive services.

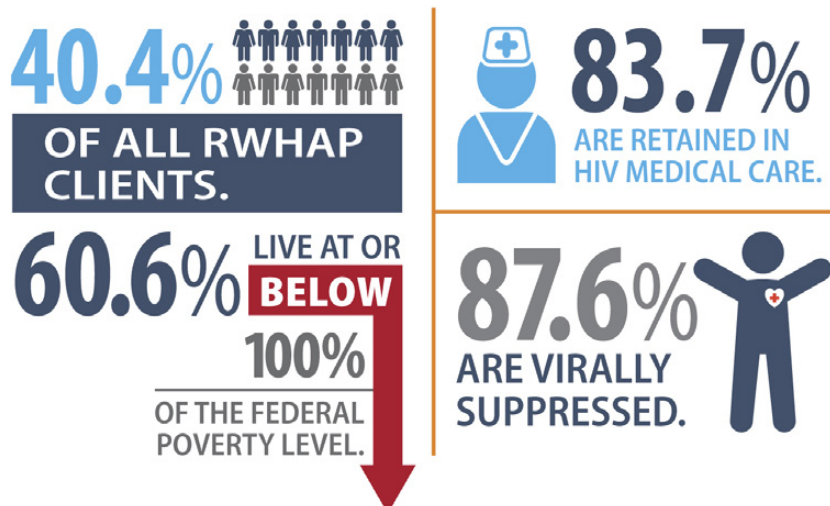
A person entering into HIV care at the FPHC clinic encounters a medical intake experience that goes far beyond the standard process of completing medical histories, background forms, and other paperwork. Individuals diagnosed with HIV meet with a specialty nurse who coordinates needed medical and support care, including lab work, prescriptions, and same-day appointments with either a primary care or infectious disease physician. The nurse works to link clients to a primary care provider at FPHC to manage non-HIV health needs. Appointments with substance abuse counselors, mental health staff, case managers, nutritionists, and consumer advocates also are made as needed. “They will receive all that within the very first time walking into our doors,” said Ms. Michelle Bernard, FPHC’s Ryan White Program Manager. “Our infectious disease clinic pretty much serves as an integrated health care setting under one roof.”

All FPHC RWHAP staff receive HIV training, according to Ms. Bernard. “Any new employee has to go through HIV 101.” Case managers who are not licensed must receive supplemental case management training, which is offered multiple times each year. Program staff also complete annual training on HIV basics, cultural competency, confidentiality, safety, and other topics.

### ■ EARLY INTERVENTION SERVICES

FPHC is focusing early intervention efforts on young MSM and people who are aged 55 and older. Data indicate that MSM in the area are being diagnosed with HIV at younger ages. Data also suggest an increase in HIV rates among senior citizens. Mr. Kenji Fisher, Case Manager, is working on raising awareness of HIV risk in the senior population by conducting “HIV 101 courses [for this population], because you have senior citizens who have been widowed for a while or recently divorced. They’re trying to enter the social scene, so a lot of them are unfamiliar with some of the [sexually transmitted diseases] STDs and some of the practices that are going on now.”

#### RWHAP Clients Aged 50 or Older, 2014



Data source: 2014 Annual Client-Level Data Report.

Outreach to youth, including MSM, is a key element of FPHC RWHAP. FPHC staff conduct HIV education activities at various locations and events that are accessible to youth in the community, such as community colleges and health fairs. Stigma is an important barrier to HIV care, particularly among youth, so HIV education is critical for this population. “Down here in the southeast, we have to deal with a lot of stigma,” explained Mr. Fisher. “So by people being willing to have conversations about it, that’s breaking down those barriers.”



Franklin Primary Health Center in Mobile, Alabama is located in a “medical mall,” where clients can receive a wide range of services at a single location, such as dental and pediatric care. (Courtesy of Google Street View.)

## ■ USING DATA TO IMPROVE CARE

FPHC staff use a wide range of data sources to improve HIV services. “I don’t see how I can do my job without [data],” said Ms. Bernard. “Data analysis is the most vital part of my responsibilities, and I use it for everything.” Ms. Bernard and her team use data to produce several monthly and quarterly reports to ensure that clients are getting the services they need on a continuous basis. These reports include the HIV/AIDS Bureau core performance measures report, a 90-day service delivery report, and an infectious disease clinic preparedness report. The performance measures report includes assessments of patients’ viral suppression, types of prescribed antiretroviral therapy, medical visits attended and missed, and delivery of *Pneumocystis carinii* pneumonia prophylaxis, based on an analysis of medical records. The program also uses data to track client care, including engagement and retention in care for youth aged 15 to 29 years and engagement in substance abuse programs for people who inject drugs (PWID).

FPHC uses multiple data systems for reporting and tracking HIV outcomes. By combining data from different sources, staff can identify patient needs, as well as missed appointments, treatments, and off-site referrals. This information helps identify clients who have been lost to care and ways to re-engage them.

According to Ms. Bernard, strategies for re-engaging clients lost to care are discussed during monthly meetings. “We can identify...who needs what and how we’re going to track those individuals down.” She added that “our [appointment] show rate was not good at one point, but it has increased tremendously,” as

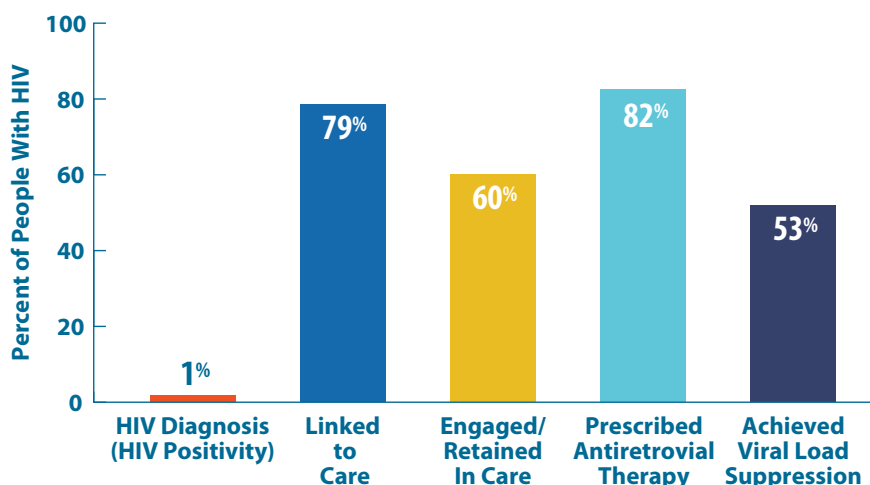
a result of the 90-day service delivery report. The report indicates who is scheduled for clinic visits, and all scheduled clients receive a recorded appointment reminder call. FPHC staff conduct live reminder phone calls in addition to the recorded reminders, so that staff can inform patients of paperwork they need to bring to the appointment and identify needs, such as transportation, that must be met for the client to make the appointment. Letters are sent out immediately to clients who miss appointments to encourage them to reschedule. Mr. Fisher added that data are used to identify clients who have been out of care for an extended period of time (6–12 months). FPHC staff follow up with these individuals to determine whether they have relocated and, if needed, re-engage them in care and connect them with support services. Mr. Fisher explained that, “the benefits that we provide...that makes them more willing to come into the appointments.” Ms. Johnnie Parks, FPHC Specialty Nurse, indicated that she also examines data to identify clients who are missing lab results and said, “I do notify the case managers and the advocate that we need to get in touch with that patient.” In addition, if these clients have seen a primary care physician at FPHC for any reason, staff members notify that physician.

In addition to reviewing the monthly and quarterly reports, Ms. Bernard and her team dedicate one day each month to reviewing the records for every client diagnosed with HIV who received a qualifying service to ensure that their information is captured in CAREWare. As a result of this regular close examination of every client record, FPHC staff have identified services that these clients might need but have not received, such as case management or dental care. Staff follow up with these clients to connect them to additional services.

### *Data’s Role in Addressing Health Disparities*

FPHC staff use State of Alabama epidemiology data reports to identify specific populations in the community who are in need of more targeted outreach efforts. For example, a recent epidemiology report revealed that Mobile, Alabama, has the third-highest HIV prevalence and incidence rate in the state, and young

HIV Care Continuum Data for Franklin’s MSM Population, 2015



As with many RWHAP recipients, MSM is the largest priority population for FPHC. The program was recently awarded capacity-building funding to work specifically with this population in its service areas. On September 1, 2016, FPHC’s RWHAP launched a Chronic Disease Self-Management Program geared toward MSM.

black MSM in this area are particularly affected. In response to this finding, FPHC is increasing monitoring and outreach activities focusing on young black MSM.

The federal poverty level data report, combined with State of Alabama epidemiology data, also provides important information on communities with such HIV risk indicators as poverty and high rates of other infectious diseases. This information can guide decisions about where to locate new centers or implement HIV education and outreach interventions.

Monthly reports from the FPHC substance abuse program revealed disparities in care for PWID, another population at high risk for HIV infection. These reports revealed low participation rates in the substance abuse program among PWID who receive HIV support services. Ms. Bernard highlighted the need to improve strategies for linking PWID clients to substance abuse treatment and for that treatment “to be more accessible for the patients to make that link successfully and in a very dignified manner....‘If this is something you want to work on, we are here for you.’”

## ■ LESSONS LEARNED AT FPHC

A key best practice of FPHC is the wide range of services offered to clients living with HIV. Mr. Fisher shared the example of a client “who had been suffering for a while because they didn’t know that a program like ours existed. They were trying to do it on their own, but the amount and cost of health care that they required was astronomically high, and they couldn’t afford it. So, when they were informed of some of the things that we could provide for them, they were just aghast.” FPHC is able to help many PLWH who have nowhere else to turn for the care and support they need. The quality of the HIV services offered at FPHC was recently recognized by staff at the Alabama Department of Health, who invited Ms. Bernard to deliver a presentation on best practices at FPHC.



# 4

## Supporting Providers Across Large Geographic Areas



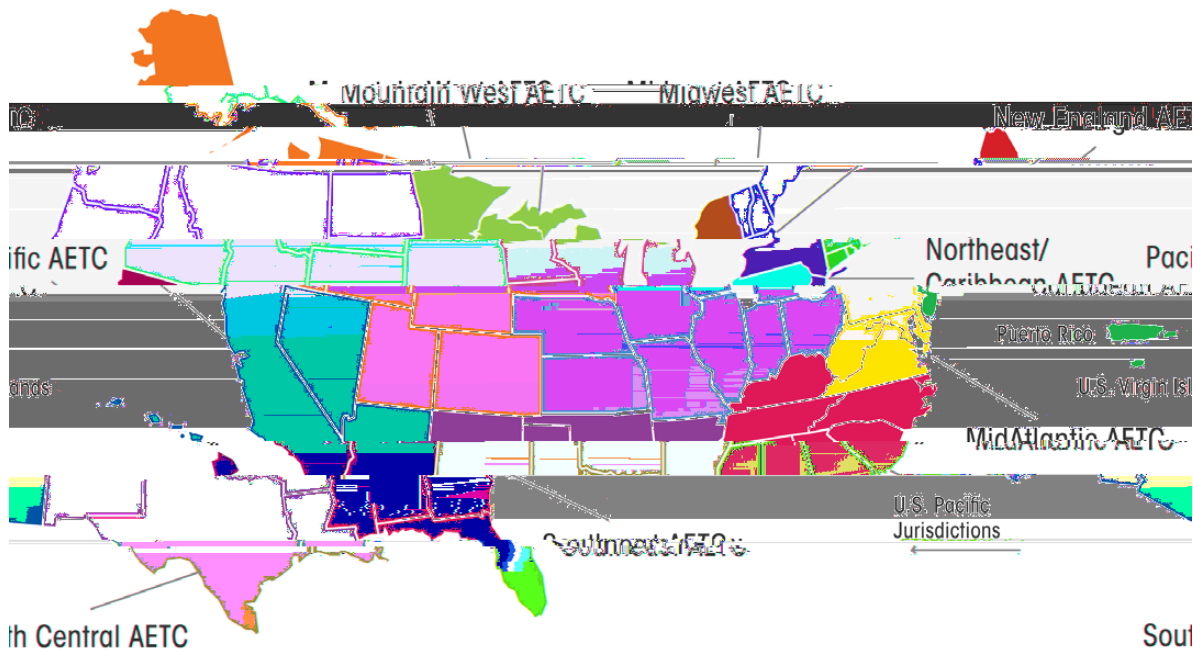
# 4

## Supporting Providers Across Large Geographic Areas


The Ryan White HIV/AIDS Program (RWHAP) Part F AIDS Education and Training Centers (AETC) Program supports a network of eight regional centers (and more than 130 local affiliated sites) and three national centers that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV in the 50 states, the District of Columbia, the U.S. Virgin Islands, Puerto Rico, and six Associated Pacific Jurisdictions. An AETC Education for Nurse Practitioner/Physician Assistant Program also exists to increase the number of culturally competent nurse practitioners and physician assistants who are able to provide primary care to people living with HIV (PLWH).<sup>16</sup>

Each year, the HIV/AIDS Bureau (HAB) collects data from AETC recipients about the training events sponsored and the trainees who participated in those events. HAB also collects information about the trainees, such as their demographic and professional characteristics, the clients they serve, and the HIV services they provide.<sup>17</sup>

The following case study demonstrates how the Midwest AETC program, administered by the Midwest AIDS Training + Education Center (MATEC) at the University of Illinois at Chicago, has been able to train and provide technical support to HIV medical providers in 10 states. The case study highlights the critical role of data to MATEC activities.



Source: [www.aidsctc.org/community/design-files-and-templates](http://www.aidsctc.org/community/design-files-and-templates).

A photograph of Dr. Ricardo Rivero, MATEC Executive Director, presenting at a meeting. He is wearing a light blue button-down shirt, a patterned tie, and glasses. He is holding a small black device in his right hand and has a name tag that reads "Ricardo Rivero, Central Office, MATEC". In the background, other people are seated at a table, and a whiteboard is visible.

MATEC Executive Director, Dr. Ricardo Rivero, presenting at the June 2015 MATEC Executive Committee meeting.

## CASE STUDY

### *Midwest AIDS Training + Education Center (MATEC)*

MATEC is funded by the RWHAP Part F AETC Program and offers specialized clinical education and consultation on HIV transmission, care, treatment, and prevention, as well as technical and capacity-building assistance to physicians, physician assistants, nurses, dentists, pharmacists, and other HIV care providers in the states of Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, Ohio, and Wisconsin. The clinical management of HIV, particularly the use of highly active antiretroviral therapy, is the focus of this training. Every state in the region, with the exception of Iowa, has a formal local performance site (LPS), usually an academic or other large health center, which is responsible for coordinating HIV clinical education and technical assistance in the state. The LPS in each state is well connected with important stakeholders who can identify HIV education and training needs in their state. Although Iowa does not have an LPS, MATEC works with the Iowa Department of Public Health (IDPH) and the University of Iowa to plan and conduct HIV clinical education in Iowa. IDPH staff also co-chair the MATEC Policy Training Advisory Council, and a faculty member from the University of Iowa represents MATEC on the Iowa HIV and Hepatitis Community Planning Group.

### *Clinician Scholars Program*

At MATEC, a large proportion of Minority AIDS Initiative funds supports the Clinician Scholars Program. This program is specifically designed for minority or predominantly minority-serving, front-line clinical care providers (physicians, nurse practitioners, advanced practice nurses, physician assistants, registered nurses, oral health providers, and pharmacists) to increase their capacity to diagnose, treat, manage, and

prevent HIV by providing one year of intensive training in 11 core capabilities identified by MATEC’s regional clinical leadership. Clinicians must apply to this program, and around 20 to 30 are accepted into the program each year.

Evaluation data are analyzed each year to identify areas for Clinician Scholars Program improvements. For example, the evaluation process led to an increase in the number of hours required for clinicians to complete the training. MATEC-Indiana Site Director Malinda Boehler explained that, at the beginning of the program, “we thought ‘most clinicians are really busy, they’re probably only able to do about 20 hours of didactic or skill building plus 12 hours of observation, clinical preceptorship,’ but now we know that that’s closer to 40 hours, and many clinicians do more than that.” The evaluation process also revealed that clinicians needed more time in clinics earlier in the program. This finding led to a requirement that clinicians complete six hours of clinical observation in the first six months of the program. Another evaluation finding was that clinician scholars wanted to be more connected to their regions. In response to this finding, MATEC implemented a webinar series led by regional project staff and faculty for the program participants. MATEC also has organized various events at conferences to allow participants in the Clinician Scholars Program to connect with their regional colleagues.

A recent article, “Developing the HIV Workforce: The MATEC Clinician Scholars Program,” published in the *Journal of the Association of Nurses in AIDS Care*, reviewed the program evaluation data from Years 3 (2012–2013) and 4 (2013–2014) of the Clinician Scholars Program and found that baseline and endpoint self-assessments of clinical knowledge and skills showed significant improvements in all 11 targeted capabilities, in particular, managing antiviral medications, screening and testing methods, incorporating prevention into HIV care, understanding risk reduction methods, and describing current care standards.<sup>18</sup> MATEC is in the process of planning the next Clinician Scholars Program under a new funding cycle and different mandates. Program data from the previous funding cycle will inform these planning efforts. Dr. Ricardo Rivero, MATEC Executive Director, noted that MATEC staff mapped their efforts in the previous cycle to ensure that they were reaching out to HIV care providers in high-prevalence areas. In the process, MATEC staff identified locations where they could improve outreach to these providers.

## ■ RESPONSE TO THE HIV OUTBREAK IN INDIANA

In late 2014, an HIV/Hepatitis C outbreak was identified in Scott County, Indiana, primarily among people who inject drugs. This area previously had fewer than five HIV cases each year, but between December 2014 and May 2016, almost 200 new HIV cases were diagnosed in the area. All cases occurred in non-Hispanic whites with an average age of 33 years old. Approximately equal numbers of



MATEC-Indiana staff worked with multiple partner organizations in Indiana to stop the HIV epidemic in Scott County. From left to right: Rachel Bates, Visual Media Coordinator; Malinda Boehler, Site Director; Dr. Diane Janowicz, Clinical Director; Karen Curd, Site Manager

males and females were infected. More than 90 percent of these HIV cases also were co-infected with hepatitis C.<sup>19</sup> In response to this epidemic, the Indiana AETC staff provided HIV training to law enforcement, department of child services, and community organization personnel at the request of state and local health officials. In addition, the Indiana AETC partnered with the Indiana Primary Health Care Association to deliver routine HIV screening and harm reduction trainings in Scott and surrounding counties.

## ■ PRACTICE TRANSFORMATION NETWORKS

MATEC partners are working with selected clinics in the region as part of the AETC Practice Transformation Project. These clinics provide services for medically underserved communities in high HIV incidence or prevalence areas. MATEC partners will use client-level data to track the number of people tested for HIV, progress toward linking and retaining patients in HIV care, and viral suppression among people in care at each clinic. MATEC partners also will work with the clinics to



MATEC Practice Transformation Project Training, 2015

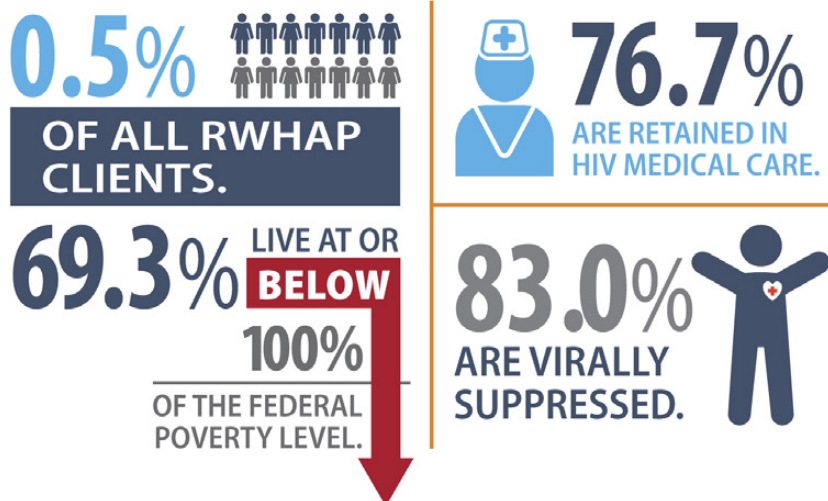
help them improve patient outcomes along the HIV care continuum by applying principles of the patient-centered medical home model and integrating HIV care and behavioral health services.

## ■ USING DATA TO IMPROVE CARE

MATEC uses a wide variety of data to inform its education and other capacity-building efforts. Census data, for example, can indicate areas within each state where education levels are lower than average, poverty rates are higher, and numbers of uninsured people are higher. These areas might require special attention because these indicators of low socioeconomic status (SES) are linked to poorer outcomes at every point on the HIV continuum.<sup>20</sup> Epidemiological data are especially important for identifying HIV “hot spots” in the region covered by MATEC, which includes substantial rural areas. According to Ms. Jenny Richards, Special Projects Manager in Iowa, “We have small populations, little epidemics that are very, very complicated and difficult to treat.” Epidemiological data come from a variety of sources, including stakeholders, state health departments, and the National Clinician Consultation Center. For example, state health departments provide surveillance data on sexually transmitted infections (STIs), which can be used to identify areas that are likely to have high HIV infection rates. Other data on drug overdose cases, sex trafficking, or gang activity also can be used to identify areas at high risk for an HIV outbreak. Ms. Richards gave an example of how data were used to identify two counties in southeastern

Iowa with low average SES and high STI rates, suggesting that residents in these areas were at high risk for HIV infection. This finding led to further qualitative data collection efforts to examine HIV services in these counties. Qualitative data revealed that residents in the counties needed to drive an hour or longer to obtain HIV screening. “An hour to drive for many of these folks who don’t have access to a reliable vehicle or consistent access to hours that they can go to a clinic—it might as well be 1,000 miles away,” explained Ms. Richards. When she called county public health offices to ask

RWHAP American Indian/Alaska Native Clients, 2014



Data source: 2014 Annual Client-Level Data Report.

where they would send people who were HIV positive, “people were very stumped by that.” These combined data collection efforts revealed an area where MATEC capacity-building support was needed.

Because data come from myriad sources that might not be communicating with each other, Ms. Sarah Rybicki, Minnesota AETC Program Director, noted that she reviews everything: “I read everything, I read the newspaper, I read all of those official papers, I read journal articles, I talk to colleagues; but I also make sure that epi [epidemiology] and data are always behind what’s actually happening.” She gave an example of how a review of various data sources allowed program staff to respond to HIV-related health crises that might not have been identified by health departments and health care providers. The Minnesota AETC initiated collaboration with tribal organizations in response to data demonstrating increased rates of syphilis among young American Indian women who live part of the year in the city and the other part on the reservation. According to Ms. Rybicki, many of these women “were injection drug users and also being trafficked. Their home tribal and IHS [Indian Health Service] organizations were not aware of this.” The Minnesota AETC organized meetings with the Red Lake IHS and involved syphilis and tuberculosis (TB) coordinators for the state. During the meetings, staff from MATEC and the state health department educated IHS providers about the relationship between syphilis, HIV, hepatitis C, and TB and discussed strategies for stopping the syphilis epidemic among young American Indian women. According to Ms. Rybicki, “We did some of the best integrative health work, I think, we’ve ever done.”

The MATEC LPSs work with their health departments to determine where HIV testing needs to be implemented or enhanced. For example, in Illinois, “we identified areas of the state where we desperately needed to improve testing,” said Dr. Rivero. “As a result of looking at the prevalence data and looking at what community health centers were in those areas of the state, we made the decision to approach specific community health centers that we worked with for several years.” In Minnesota, MATEC data analyses revealed that linkage to care was substantially slower in rural areas. The Minnesota AETC responded to this finding by conducting regular provider network meetings at five rural locations with high HIV prevalence. Local providers receive consultation and instruction on HIV care at these meetings.

## *Data to Care*

Data to Care is a priority for each health department in the MATEC region. MATEC is well represented in all of the state-level Data to Care planning bodies. Dr. Rivero explained that “through this relationship, our LPSs get to see what it is that the states are doing in terms of Data to Care, and then they look into what we can do from our end to support the efforts of the state around that.” All LPSs have been involved in developing a Data to Care plan.

### ■ LESSONS LEARNED AT MATEC

Ms. Boehler noted that the HIV/Hepatitis C outbreak in Scott County, Indiana, taught MATEC staff the importance of continuous tracking and review of data. “We have to keep our ear to the ground for not only things related to HIV, but things related to [hepatitis] C, things related to drug overdose...all things that could potentially impact HIV,” she explained. “We do that by staying connected to our state health department, by staying connected to our disease intervention specialist.” According to Ms. Boehler, a lesson learned from the outbreak in Indiana was that data cannot be kept in silos. “[HIV] Prevention had a piece of the information, [HIV] Care had a piece of the information, the Pharmacy Board had a piece of the information, but no one had the whole picture until it was too late,” said Ms. Boehler.

MATEC staff repeatedly alluded to the need for ongoing monitoring of data to identify locations where resources can have the greatest effect. The limited resources in rural states make careful, targeted allocation of resources particularly important. According to Dr. Rivero, “Across the region...data in general really help us decide what we do and where we do it.”

# 5

## Innovating to Reach Underserved Populations: Special Projects of National Significance (SPNS)





# 5

## Innovating to Reach Underserved Populations: Special Projects of National Significance

The Ryan White HIV/AIDS Program (RWHAP) Part F Special Projects of National Significance (SPNS) Program supports the development of innovative models of HIV care and treatment to quickly respond to the emerging needs of populations who have been difficult to engage and virally suppress. The SPNS Program evaluates the design, implementation, utilization, cost, and health-related outcomes of innovative treatment models and disseminates successful models for replication and integration by RWHAP-funded recipients.

The case studies in this chapter highlight two organizations that receive RWHAP funding through different SPNS initiatives, Friends Community Center and Coastal Bend Wellness Foundation (CBWF).



Top row standing from left to right: Dr. Kimberly Kisler, Project Director, Miranda Ramirez, Peer Health Navigator, Dr. Cathy Reback, Principal Investigator. Bottom row sitting from left to right: Angelina Alamilla, Peer Health Navigator, Prudence Mendiola, Evaluator.

## CASE STUDY

### *Friends Community Center*

The Friends Community Center receives RWHP Part F funds for two SPNS Program initiatives: *The Alexis Project*, which focuses on identifying, recruiting, linking to care, treating, and retaining in care transgender women of color living with HIV; and *Text Me, Girl!*, a text messaging intervention designed to improve linkage, retention, and health outcomes among HIV-positive young transgender women. The Friends Community Center, which is directed by Dr. Cathy Reback, is the Los Angeles, California, community site for Friends Research Institute. The community center is located on the border of Hollywood and West Hollywood, a location often considered a sex-work district for gay men and transgender women.

### *The Alexis Project*

*The Alexis Project* was named after Alexis Rivera, a proud Latina transgender woman, community activist, and peer advocate who died from complications related to HIV on March 28, 2012. *The Alexis Project* is funded through the SPNS Program initiative “Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color” and is designed specifically for transgender women living with HIV who either are not in HIV care, have not had an HIV medical care visit in more than six months, or are not adherent to HIV treatment or virally suppressed. The objectives of *The Alexis Project* are for participants to reach HIV milestones, including viral suppression, within 9 to 10 months of entering the program.

*The Alexis Project* used a multifaceted approach to meet its recruitment goal of 140 transgender women. Local transgender women recruited other transgender women of color from their social networks into the

project. Participants also were referred by community partner organizations or through street- and venue-based outreach. “Every kind of recruitment strategy you can think of we utilize, because it’s very hard to reach these women and hard to get them into care,” noted Dr. Reback.

The concept for *The Alexis Project* was based on qualitative data collected through focus groups conducted



## the Alexis PROJECT

*The Alexis Project combines Peer Health Navigation and Contingency Management interventions into one program.*

### Eligibility

- Newly diagnosed HIV-infected trans women of color.
- HIV-infected trans women of color who have never received HIV medical care, or have dropped out of HIV medical care.

### Peer Health Navigation

The Peer Health Navigation component of the program works with participants to identify HIV medical care services and other needed services, develop an individual client-centered treatment plan, remove barriers to those services and access those services. A Peer Health Navigator works with each participant to link her into HIV medical care by helping her make medical appointments and, if needed, providing transportation to and from HIV medical appointments. A Peer Health Navigator provides information and emotional support as she works with each participant to address her needs and barriers to accessing HIV medical care.

HIV+ Trans Women of Color Will Be Immediately Linked to a Peer Health Navigator

We provide HIV testing for those who don't know their status or haven't had an HIV test in the last 3 months.

with transgender women of color living with HIV who participated in Friends Community Center programs but were not linked to care. The focus groups revealed a wide range of unmet needs in the local transgender community, which impeded the ability of transgender women in this community to obtain HIV care and adhere to care guidelines. These findings led to the idea to employ peer health navigators, who work with each participant to link and retain her in HIV care services and identify other needed services. The ongoing, personal support provided by

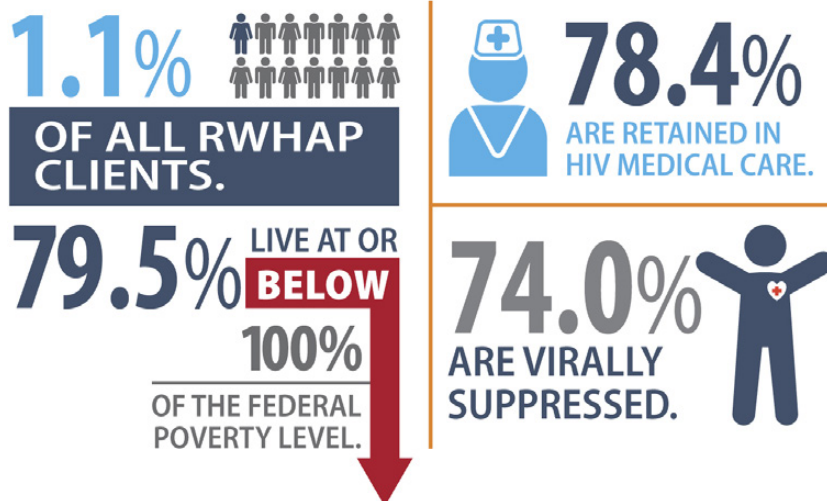
the peer health navigators is particularly important to transgender women of color living with HIV in the community served by the Friends Community Center, many of whom are homeless, have mental health challenges, or misuse substances.

The support provided by peer health navigators is both psychosocial and practical. Ms. Angelina Alamilla, Peer Health Navigator, described how this support might involve something as basic as obtaining an identification card, which is required to obtain health care services. “When we’re sitting at the DMV [Department of Motor Vehicles], people are there sitting around and they’re looking at them, like she’s somebody weird. So we have to convince her, ‘you know what, this is important for you.’ We try to change the whole way she thinks. Like, ‘if somebody is looking at you, maybe she’s admiring your hair.’” With substance abusers, there are additional challenges. “Somebody who might be coming down from drugs or [might be] high on drugs, to convince them to stay until they get their ID is very challenging,” said Ms. Alamilla.

To facilitate access to services for participants, peer health navigators have formed relationships with a variety of community partners, including staff at the local jails where transgender women are sometimes incarcerated. According to Dr. Reback, “We are often the first stop the women make when they get out of jail. They get released, and they come right to our agency to meet with the peer health navigators.” Peer health navigators are transgender women like the people they serve, which is critical to the success of the intervention. According to Ms. Miranda Ramirez, Peer Health Navigator, her experience living

as a transgender women uniquely positions her to help participants “develop the ability to feel human again, the ability to look in the mirror and say, ‘You know what, I may be HIV positive, but I deserve to be here just as much as everybody else, and my peer health navigator has shown me that every day.’” She explained that, as a transgender woman of color living with HIV, “Sometimes I need to hear from somebody else that I got it, that I can do this.” According to Dr. Reback, the peer health navigator component of the project helps participants “remove the barriers so they can reach the milestones and create enough self-efficacy so they’re able to sustain it on their own.”

### RWHAP Transgender Clients, 2014



Data source: 2014 Annual Client-Level Data Report.

Focus group findings revealed that the two primary needs of transgender women of color living with HIV in the community were transportation, which is arranged by the peer health navigators, and money. The contingency management component of *The Alexis Project* was developed to respond to participants’ need for non-cash monetary incentives to obtain and sustain HIV care. The contingency management intervention provides increasingly valuable voucher points for attending HIV medical visits and reaching and sustaining other HIV medical milestones. For example, project participants receive voucher points for their first HIV medical appointment, additional points for picking up HIV medications, and more points for obtaining lab work. In addition, each time participants go to their 3-month medical appointment, they receive increasingly valuable voucher points. Participants also receive voucher points when they provide documentation that their viral load has been reduced by a certain amount. Voucher points can be redeemed for gift cards. Women in the program who attend all appointments and reach all HIV milestones can receive a total of \$500 in non-cash voucher points.

### **Text Me, Girl! Intervention**

The Friends Community Center also conducts a text messaging intervention called *Text Me, Girl!* This intervention is designed to improve linkage, retention, and health outcomes among HIV-positive transgender women aged 18–34. *Text Me, Girl!* is one of the demonstration projects funded through the SPNS Program initiative “Use of Social Media to Improve Engagement, Retention, and Health Outcomes along the HIV Care Continuum.” *Text Me, Girl!* responds to the multiple challenges faced by young transgender women, including discrimination, stigmatization, and social and economic marginalization, which are obstacles to regular HIV care and the use of the antiretroviral therapy (ART) medication that results in viral suppression. *Text Me, Girl!* accommodates the transient lifestyle of many young transgender women by providing an easily accessible, private, and portable method for helping them to stay engaged in their HIV care.

“From the very get-go, we’ve been trying to collect the data and utilize it to maximize services and to ensure that what we are providing to our participants is what they need and what they want.”

— Dr. Kimberly Kisler, *The Alexis Project Director*

Participants in *Text Me, Girl!* receive three automated messages each day over a 10-hour timeframe for 90 days. Each day, participants receive a message about physical and emotional health while living with HIV, another message about linkage/retention in care, and a third message about ART adherence and viral suppression. These messages represent each stage on the HIV care continuum. In addition, one message each day is based on Social Support Theory, another on Social Cognitive Theory, and a third on the Health Belief Model, so that participants are exposed daily to three proven theories of behavior change. The content of the 270 unique messages that participants receive during the intervention period has been tailored to the culture and language of young transgender women. Each message was tested in focus groups of transgender women and members of a transgender-specific community advisory board. Based on feedback received during the group sessions, messages were revised and ultimately approved by focus group participants.

## ■ USING DATA TO IMPROVE CARE

*The Alexis Project* and *Text Me, Girl!* demonstrate how formative, qualitative data collected through focus groups are crucial to the planning and design of effective HIV care interventions for priority populations. “From the very get-go, we’ve been trying to collect the data and utilize it to maximize services and to ensure that what we are providing to our participants is what they need and what they want,” explained Dr. Kimberly Kisler, *The Alexis Project Director*.

Data are also critical to the monitoring, evaluation, and continual improvement of RWHAP-funded activities. The Friends Community Center maintains several databases of both aggregate and individual-level, as well as quantitative and qualitative, information on project participants, their HIV care and treatment activities, progress toward project goals, and outcomes. Information from these program databases is used to develop a process evaluation report that is submitted to the Transgender Evaluation and Technical Assistance Center (TETAC) every six months. The program evaluator and TETAC staff examine this report to identify patterns and trends. Friends Community Center staff members also regularly examine program data to identify patterns that suggest a need for more in-depth, qualitative data collection to explain findings. According to Ms. Prudence Mendiola, Evaluator, “When we notice patterns that things are happening, I’ll come back and I’ll ask them [peer health navigators] for more qualitative information.” Once the underlying reasons for the patterns are identified, interventions can be modified to improve client services. For example, Ms. Mendiola noted, “We’re finding that when people are getting into housing, they’re becoming medication-adherent.” This type of information allows the program to focus resources on areas of need (e.g., housing) to help clients achieve program goals. Ms. Mendiola explained that, within the constraints of the program, “To the best of our ability, when we see something that works, we run with it. And when we see something that doesn’t, then we try and fix it or move on.” She also emphasized the

importance of data to identify problems. “There are sometimes numbers that don’t look as great, they’re not quite where we want them to be. But, I think those numbers are just as important as the ones that look that fantastic, because that really helps us highlight where there is more need.”

Ms. Alamilla explained how data can be used not only to guide program activities, but also to help individual clients. “Once she collects the data, we’re able to see what is missing on a certain participant, what is going on, what stage of the intervention she is in.” Dr. Kisler added that “being able to have access to that data, and in particular, all of the information that we collect through the participant files, really gives us the opportunity to identify folks that we need to do a little bit more reaching out to.” For example, a review of participant files found that large amounts of information about milestones were missing for certain participants in *The Alexis Project*. The peer health navigators attempted to contact those participants who were missing information. In most cases, the peer health navigators found that these participants had been going to appointments and reducing their viral load. Dr. Kisler pointed out that “sometimes missing data was actually lots of really exciting data because, when we found participants, they were actually doing the intervention and they were doing it without needing assistance from us after the initial involvement.” Followup activities that were triggered by the concern about missing data led to a significant increase in the number of participants found to be linked to care and who had achieved viral suppression.

Data collected through routine program monitoring and evaluation activities are not the only types of data that can be used to inform program activities and improve care. Observational data collected during visits to partner sites can be used to inform efforts to build capacity and cultural competency. For example, Dr. Reback noted that “when we had our very first site visit with our ETAC [Evaluation and Technical Assistance Center] and with HRSA [Health Resources and Services Administration], we went to see the medical facilities that we were partnering with. As we walked through the halls of the medical facilities and



In response to an observation that provider clinics lacked images of transgender individuals, Friends Community Center obtained supplemental RWHAP funding to develop posters that promote HIV care for transgender women of color living with HIV. (Source: [www.friendscommunitycenter.org/posters.html](http://www.friendscommunitycenter.org/posters.html))

in the waiting rooms, there was not one poster for transwomen, and yet this was a medical facility—all the medical facilities—who claim that they work with transwomen, and they want to work with transwomen, and they say they're culturally competent and culturally sensitive.” In response to this observation, the center obtained supplemental HRSA funding to develop posters that promote HIV care for transgender women of color living with HIV.

## ■ LESSONS LEARNED AT FRIENDS COMMUNITY CENTER

Friends Community Center staff emphasized the importance of data in identifying and responding to the needs of vulnerable populations. According to Ms. Mendiola, “The more information we gather on underserved, marginalized, or at-risk populations, the better. We capture as much as possible and put it out there so that we can make a difference.” For example, many RWHAP recipients have used data to document the link between housing and retention in/adherence to HIV care and treatment. “Housing is such a major lacking resource...and such a major factor in people’s well-being as far as lowering the viral load,” said Ms. Mendiola.

Dr. Reback highlighted the importance of using data to document and share program successes. “You might have the best intervention, the most original, innovative, novel intervention that works and is highly successful. And you know it, and your participants know it, and your staff know it. But without the data, nobody else knows it. And without the data, it cannot be replicated and it cannot be scaled up.” The expectation is that the data collected through the two RWHAP-funded SPNS Program projects at the Friends Community Center will eventually allow these types of interventions to be expanded to transgender populations living with HIV in other locations.



Women & Children Medical Case Managers, Melinda Garza (left) and Rebecca Garcia (right), discuss agency services available to clients.

## CASE STUDY

### *Coastal Bend Wellness Foundation (CBWF)*

Coastal Bend Wellness Foundation (CBWF) is a federally qualified, community-based health center located in Corpus Christi, Texas. CBWF receives two RWHAP SPNS Program grants under Part F:

- *Project WELLNESS WEB 2.0*, which has developed and will implement, evaluate, and disseminate an innovative Internet-based model to increase HIV awareness, engagement, retention in care, and viral suppression among youth and young adults who are difficult to reach through traditional communication channels.
- Practice Transformative Model (PTM), which applies an interdisciplinary team-based approach to CBWF's clinical care practice to optimize human resources, efficiently deliver HIV care and treatment services, and improve health outcomes for all RWHAP clients.

In addition, through the Texas Department of State Health Services, CBWF receives RWHAP Part B funds as a subrecipient of the East Texas Administrative Agency (Houston Regional HIV/AIDS Resource Group, Inc.). These funds are provided to multiple organizations in the region to improve the quality, availability, and organization of HIV health care and support services.

CBWF serves 12 mostly rural counties in southeastern coastal Texas. The center offers primary health care, mental health and substance abuse programs, HIV and sexually transmitted infection (STI) testing and counseling, and education and linkage to HIV care and treatment. According to Chief Executive Officer Bill J. Hoelscher, "Our goal is to provide comprehensive services for people living with HIV/AIDS by



assisting them through the continuum of care. For those who do not know their HIV status, we seek to provide them with that awareness. For those who are not HIV positive, we seek to give them the education and skills they need to avoid infection.”

In the region served by CBWF, youth and young adults (aged 13–34) account for 57 percent of all new HIV diagnoses. Blacks/African Americans and Hispanics and Latinos account for 79 percent of all new HIV infections among Texas residents in this age group. Approximately 70 percent of CBWF’s clients are Hispanics and Latinos and/or men who have sex with men (MSM). Although many clients are youth, CBWF also treats a growing number of clients who are aged 65 and older.

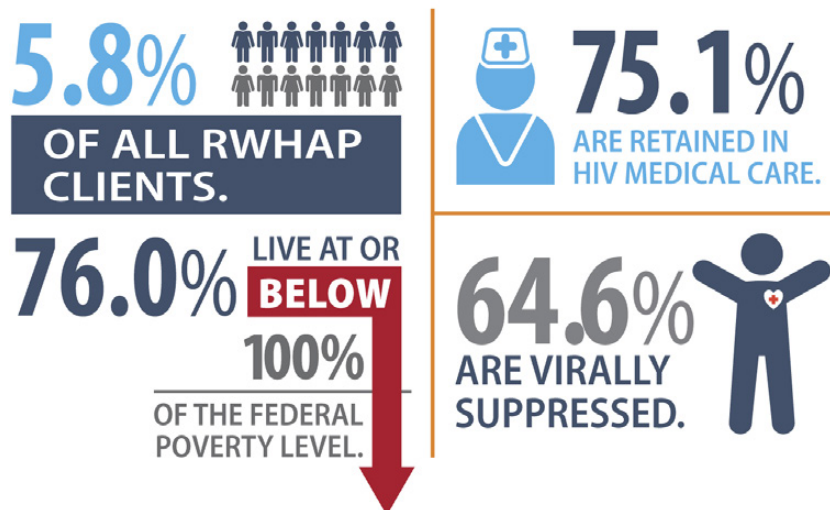
### **Project WELLNESS WEB 2.0**

Under the SPNS “Use of Social Media to Improve Engagement, Retention, and Health Outcomes Along the HIV Care Continuum” initiative, *Project WELLNESS WEB 2.0* is expanding CBWF’s use of social media networks and platforms to more effectively communicate with underserved and out-of-care PLWH—primarily racial and ethnic minority populations—aged 13 to 34, at the following points along the HIV care continuum:

- (1) HIV status awareness and diagnosis—Leveraging the CBWF testing services through a variety of social media platforms to reach at-risk youth and young adults.
- (2) Linkage to care—Adapting the Anti-Retroviral Treatment and Access to Services (ARTAS) approach via text messaging and other social media platforms to engage recently diagnosed and out-of-care youth into HIV care. ARTAS is an individual-level, multi-session intervention that takes place within 90 days of an HIV diagnosis to link individuals to medical care.<sup>21</sup>
- (3) Engagement in care—Training community peer volunteers to reach out to eligible individuals within their social networks and engage in care and case management.
- (4) Retention in care—Increasing and sustaining clinic staff-patient communications and linkage to ancillary services through various social media platforms to minimize the likelihood of patients’ dropping out of care.

CBWF uses data to improve social media outreach by ensuring that the right messages are reaching the right audiences at the right time. User data—regularly collected through online surveys and social media metrics/analytics—inform staff members how clients are accessing CBWF’s online content. This enables staff to quickly revise and refine content and channel strategies to ensure that key messages are effectively reaching and engaging audiences.

### **RWHAP Youth and Young Adult (aged 13–24) Clients, 2014**



Data source: 2014 Annual Client-Level Data Report.

CBWF works closely with the University of California, Los Angeles, ETAC to evaluate the overall effectiveness and impact of *Project WELLNESS WEB 2.0*. In addition to the social media outreach data, the ETAC is assessing overall processes, impact, and outcomes of the project using client-level Ryan White HIV/AIDS Services Report (RSR) data and electronic health record (EHR) data. Although the enhanced social media marketing efforts began in late 2015, CBWF already is seeing success in that a number of youth have been identified as high-risk individuals or living with HIV.

## ■ PRACTICE TRANSFORMATIVE MODEL PROJECT

The Practice Transformative Model (PTM) project is funded under the SPNS Program initiative “System-Level Workforce Capacity Building for Integrating HIV Primary Care in Community Health Care Settings.” CBWF is one of 15 funded demonstration sites for this four-year initiative to design, implement, and evaluate system-level changes in staffing structures to improve health outcomes along the HIV care continuum.

The PTM project at CBWF integrates the patient-centered medical home model of care to provide HIV-positive patients with primary care, HIV care, and behavioral health services, all under one roof. When a client comes through the doors, all appointments to provide necessary medical, mental health, substance abuse, and social services are made for that day, because clients do not always return or do not return right away.

## ■ USING DATA TO IMPROVE CARE

CBWF collects and analyzes both qualitative and quantitative data from multiple sources to inform and improve services provided through SPNS and RWHAP Part B. For example, CBWF uses ARIES, the Texas Department of State Health Services database, to identify the number of clients being served, services provided (e.g., housing, mental health, transportation), and medication adherence. In addition, every client’s EHR is monitored for barriers to engagement in care and health outcomes, including nonadherence to medication protocols, evidence of substance abuse, and missed appointments. Case managers contact clients to explore the reasons for these findings and to identify possible solutions, such as transportation or substance abuse treatment.

CBWF also regularly analyzes data from its accounting system to assess funding streams and to identify services that are in greatest demand. Service or program budgets are then adjusted to meet the greatest needs and expand or improve the service. Vulnerable populations or locations with a new or increasing need for specific HIV care services are identified through analysis of county health department surveillance data and ZIP code data to identify “hot spots,” where STI cases might be increasing. In addition, tracking of outcome data for particular services informs staff of services they need to strengthen—such as outreach and support—for a particular population served by the program. For example, CBWF staff members are seeing an increase in HIV among clients aged 65 and older and who now have to manage other

chronic conditions as well, such as diabetes, cancer, and dementia. Mr. Hoelscher is exploring strategies for improving services for older PLWH.

CBWF frequently uses qualitative data to increase the capacity of its staff to serve clients. For example, meeting minutes with staff and employee self-evaluation surveys often inform staff training or professional development needs. In particular, CBWF looks for trends that might affect staff interactions with specific populations. “For instance, we started seeing more transgender people come in for services and received an upset phone call and complaint from one transgender client that the correct pronoun was not used with them. When we looked into the situation we discovered there were a few other instances when this happened,” explained Mr. Hoelscher. He noted that client feedback can even influence the décor and environment of CBWF facilities. “People didn’t like the lobby because it made them feel very uncomfortable as it was very ‘HIV-heavy.’ They thought that when they came in people assumed they had HIV, but people did not want this to be the assumption. So we changed around the lobby, such as changing posters and pictures to be less HIV-focused.”

## ■ LESSONS LEARNED AT CBWF

Mr. Hoelscher concluded by emphasizing the importance of partnerships to provide high-quality HIV care and support services. For example, CBWF works with multiple mental health providers to identify clients who might have fallen out of both HIV and mental health care. CBWF also collaborates with churches in many of the 12 counties it serves to provide HIV education and testing at a wide range of locations. The Red Cord Initiative is another example of a successful partnership between CBWF and multiple community organizations, including the Corpus Christi Police Department and Nueces County District Attorney’s

Office, to intervene where women are arrested for prostitution. CBWF’s Red Cord Initiative provides these women with HIV testing and medical care and connects them to social service resources. Mr. Hoelscher highlighted the role of data in demonstrating the need for new services, which has led to new partnerships and funding sources for CBWF.

The collection and analysis of multiple qualitative and quantitative data sources has greatly influenced and shaped all aspects of clinical care, mental health and social services, staff development and training, community outreach and education, and clients’ overall experience at CBWF. “We are melding everything together for one outcome, which is the health of the people we serve. We have become a health



CBWF provides HIV testing through its partnerships.

home for clients,” said Mr. Hoelscher. As CBWF continues to grow and strives to improve its client services, Mr. Hoelscher would like to expand data management and quality assurance activities. He emphasized, however, that data are not useful unless translated into care. According to Mr. Hoelscher, all data must “go somewhere to help people.”

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