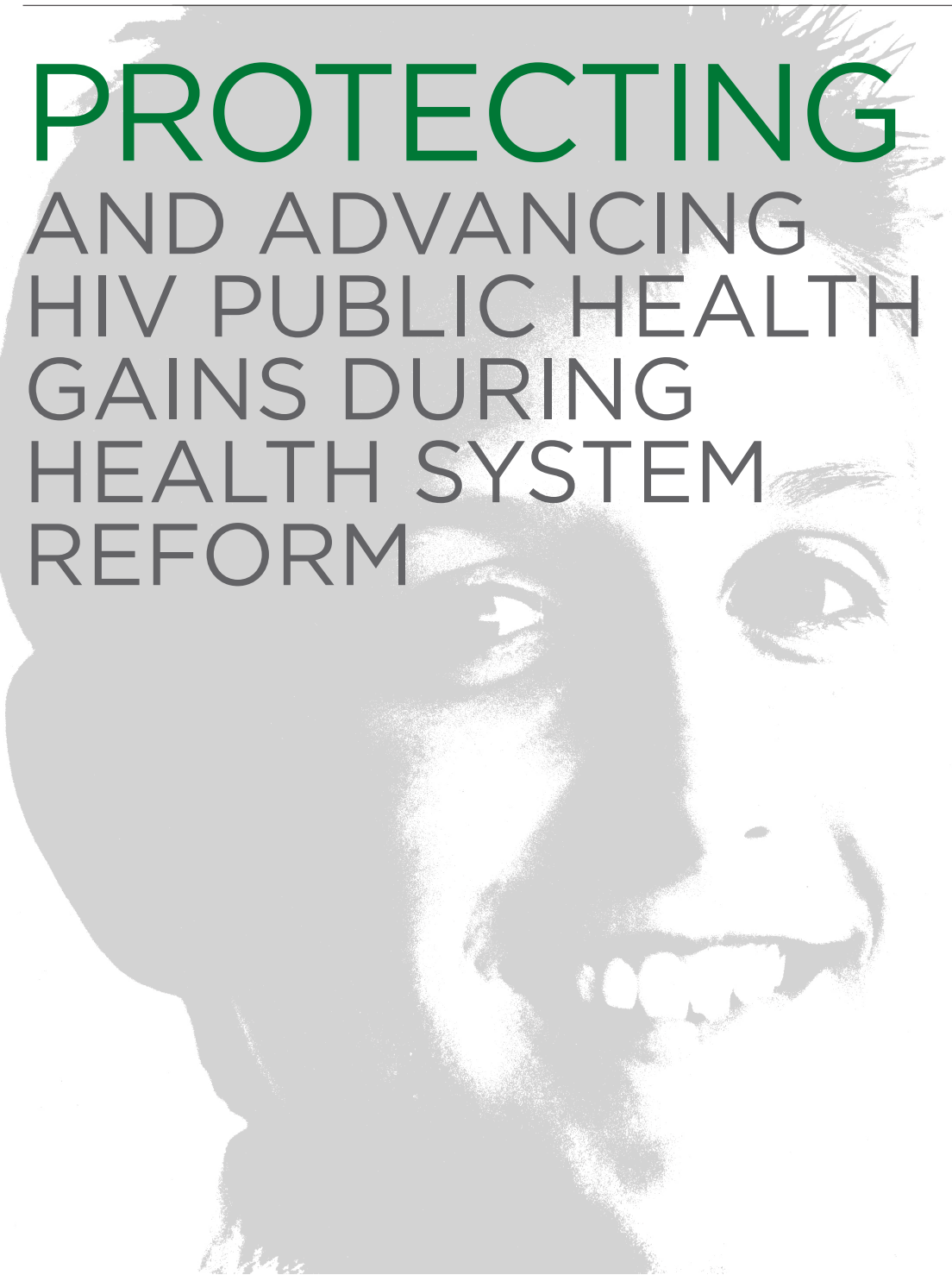


MARCH 2017

THE RYAN WHITE HIV/AIDS PROGRAM

PROTECTING

AND ADVANCING
HIV PUBLIC HEALTH
GAINS DURING
HEALTH SYSTEM
REFORM



MARCH 2017

Prepared by **Jeffrey S. Crowley**, **Sean Bland**, and **Connie Garner**

This issue brief was developed independently of, but informed by an expert consultation held in Washington, DC in October 2015 of approximately 30 diverse stakeholders, including people with HIV, HIV medical and non-medical providers, Ryan White grantees, and federal HIV policy and program staff. The project is guided by an advisory group consisting of:

Deloris Dockrey, Hyacinth AIDS Foundation
Ernest Hopkins, San Francisco AIDS Foundation
Connie Garner, Foley Hoag
Ann Lefert, National Alliance of State and Territorial AIDS Directors
Bill McColl, AIDS United
Carl Schmid, AIDS Institute
Naomi Seiler, Milken Institute School of Public Health, George Washington University
Andrea Weddle, HIV Medicine Association

In addition to the advisory group, the authors thank the following for reviewing drafts of this report or consulting on technical issues. These include: Lindsey Dawson and Jen Kates of the Kaiser Family Foundation and Patrick Sullivan of Emory University.

The views expressed in this issue brief are those of the authors and not necessarily those of advisory group members, expert consultation participants, or external reviewers.

*This project is supported by a grant from **Gilead Sciences**.*

AT A TIME OF POTENTIALLY SIGNIFICANT CHANGE IN THE UNITED STATES (US) HEALTH SYSTEM,

this issue brief examines the changing role of the Ryan White HIV/AIDS Program and how it supports Medicaid, Medicare, and private insurance to prevent HIV transmission and reduce health care spending.

HIV continues to be a major health threat in the US. While it is rarely front-page news lately, the US has the most serious HIV epidemic among high-income nations, with 1.2 million Americans living with HIV.¹ Important progress has been made, however, due to significant federal and other investments in care and treatment, prevention, and research. After remaining stable since the mid-1990s,

the number of new HIV infections fell by nearly 20% from 2008 to 2014.² People with HIV are living longer, and there are more effective treatment options that are easier to take and have fewer side effects than ever before. With effective antiretroviral therapy (ART), individuals with HIV can lower the amount of HIV virus circulating in their bodies to below the limits of detection. When this is

THE RYAN WHITE HIV/AIDS PROGRAM'S IMPACT

The Ryan White HIV/AIDS Program is a federal program that provides medical care, prescription drugs, and support services to more than a half a million uninsured and underinsured people living with HIV/AIDS in the US.

- 1) The Ryan White Program increases rates of viral suppression:** 83% of Ryan White clients receiving medical care services are virally suppressed compared to only 30% of all people living with HIV in the US.
- 2) From 2010 to 2014, viral suppression rose and health disparities shrank in the Ryan White Program:** A HRSA analysis comparing program outcomes in 2010 and 2014 found increasing rates of viral suppression in all groups examined and reductions in disparities in nearly all groups.
- 3) Viral suppression prevents HIV transmission. To further reduce transmission, more people with HIV need to be engaged in care:** People who are virally suppressed do not transmit infection. The Ryan White Program supports viral suppression by ensuring access to services that keep people engaged in care and supporting regular clinical monitoring. Roughly 70% of HIV transmissions in the US arise from persons who have been diagnosed with HIV, but are not receiving regular HIV care. Greater support for the Program could enable it to reach even more people not in care.
- 4) The Ryan White Program is a critical supplement to public and private insurance:** As was the case prior to the ACA, most Ryan White clients (80% in 2015) had some form of insurance coverage, but turned to the Ryan White Program to address financial barriers to care or to fill gaps in services not covered by their insurance (see text box “Critical Services that Support Engagement in Care and Viral Suppression”).

achieved, they are considered “virally suppressed”. People who maintain viral suppression can stay healthy and do not transmit infection to others.³

Getting people with HIV diagnosed, into care and on ART as soon as possible after infection, and then ensuring that they remain on treatment and virally suppressed are the most important things we, as a

nation, can do to improve the lives of people with HIV and end the HIV epidemic in the US. This requires ensuring that all people with HIV have access to treatment and high quality medical care, as well as services and supports needed to keep them engaged in care.

The Ryan White HIV/AIDS Program is a federal program that provides primary

THE PARTS OF THE RYAN WHITE HIV/AIDS PROGRAM

Part A: Provides grant funding for medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs). EMAs and TGAs are population centers that are the most severely affected by the HIV/AIDS epidemic.

Part B: Provides grant funding to states and territories to improve the quality, availability, and organization of HIV health care and support services. Grant recipients include all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and the 5 U.S. Pacific Territories. In addition, Part B also includes grants for the AIDS Drug Assistance Program (ADAP).

Part C: Provides grant funding to local community-based organizations to support outpatient HIV early intervention services and ambulatory care. Part C also funds planning grants, which help organizations more effectively deliver HIV care and services.

Part D: Provides grant funding to support family-centered, comprehensive care to women, infants, children, and youth living with HIV.

Part F: Provides grant funding that supports several research, technical assistance, and access-to-care programs. These programs include:

- The **Special Projects of National Significance (SPNS)** Program that supports the demonstration and evaluation of innovative models of care delivery for hard-to-reach populations;
- The **AIDS Education and Training Centers (AETC)** Program that supports the education and training of health care providers treating people living with HIV through a network of eight regional centers and three national centers;
- The **Dental Programs** that provide additional funding for oral health care for people with HIV through the HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnership Program; and
- The **Minority AIDS Initiative** that provides funding to evaluate and address the impact of HIV/AIDS on disproportionately affected minority populations.

ESSENTIAL ROLES OF THE RYAN WHITE HIV/AIDS PROGRAM

- 1) Access to HIV Care:** The Program ensures access to lifesaving HIV care to uninsured and underinsured people living with HIV
- 2) Integrated Care:** The Program provides insurers and providers with models and evidence for how to provide integrated care bringing together physical and mental health services that support lifelong engagement in HIV care.
- 3) Monitoring HIV Outcomes:** The Program supports state and local health departments to innovate in building data and monitoring systems that enable medical and non-medical providers, health plans, health departments and others to work together to improve patient outcomes
- 4) Equipping Workforce to Stay Current:** The Program trains medical and non-medical providers to provide current HIV medical and supportive care to the diverse HIV population
- 5) Nationwide Capacity to Provide High Quality Care:** The Program ensures that capacity to deliver HIV medical care exists in all parts of the US

medical care, HIV treatment, and support services to more than a half a million uninsured and underinsured people living with HIV/AIDS in the United States. Designed to coordinate with other programs, fill gaps in the health system, and prevent the duplication of services, the Program functions as the payer of last resort for HIV care. It strives to ensure that a system of care is available to all people with HIV in all parts of the country by providing grants and technical assistance to states, territories, local jurisdictions, community providers and others to respond to the unique needs of a specific jurisdiction.

THE RYAN WHITE HIV/AIDS PROGRAM IMPROVES HEALTH AND SAVES LIVES

Effective ART and access to health care keep people with HIV healthy, prevent

transmission, and save lives. After increasing in the early years of the HIV epidemic, the number of AIDS deaths peaked in the US in 1994 or 1995, just before the introduction of effective ART regimens, and then dropped significantly since that time. HIV remains in the top 10 leading causes of death, however, for Americans age 25 to 44, especially among Black Americans.⁴ In 2014, there were 12,333 deaths in the US among persons diagnosed with HIV and slightly more than half were directly attributed to HIV.⁵ Since the introduction of effective ART in the mid-1990s, there was uncertainty over when to initiate treatment (i.e. right away or after waiting as long as possible until certain clinical indicators of immune decline were observed). Questions also were raised over whether continuous ART was truly necessary or whether individuals could interrupt treatment for periods of time. Thanks to randomized controlled trials (RCTs) funded by the National Institutes of Health (NIH),

CRITICAL SERVICES THAT SUPPORT ENGAGEMENT IN CARE AND VIRAL SUPPRESSION

Given how important continuous care and ART are for health outcomes and prevention, a critical role of the Ryan White Program is to ensure that funded programs are actively monitoring engagement in care and taking active steps to address issues that cause people to fall out of care. One study of people with HIV in the US and Canada estimated that as many as 25% of people churn in and out care in a 12-month period.*

The following are services that enable people to overcome barriers and challenges to remaining in continuous care and maintaining HIV viral suppression, which protects health and prevents onward transmission:

- **Case management, care coordination, and insurance navigation:** The health system is confusing for many people, but this is especially so for people with HIV and other health problems such as mental health or substance use issues, for which they need ongoing services, often from multiple providers. Additionally, other life stressors such as housing or financial instability can create huge barriers to care. Among other roles, Ryan White-funded case managers assess clients for health insurance eligibility, enroll them in available forms of insurance coverage and coordinate billing across payers.
- **Medical transportation, emergency housing, and legal services:** Transportation includes bus tickets, gas vouchers, and taxi or car sharing arrangements. Many people living with HIV also require housing and related legal services and find it almost impossible to prioritize health care when they have these significant unmet needs.
- **Mental health and substance abuse treatment and oral health services:** Insurance covers some mental health services, substance abuse treatment, and dental services, but established limits are often inadequate for a patient population dealing with two or three concurrent diagnoses. Even in the most heavily resourced jurisdictions, providers report that inadequate capacity to deliver adequate mental health and substance abuse services are among the biggest challenges to keeping their HIV patients engaged in care. Moreover, oral health is an integral aspect of quality HIV care.
- **Cost-sharing assistance:** Even when programs such as Medicaid and the Medicare prescription drug program have reduced cost-sharing for low-income populations, these programs may offer inadequate protection for people with HIV given the higher than average use of prescription drugs and other services. The AIDS Drug Assistance Program (ADAP) and other parts of the Ryan White Program can be used to pay co-insurance or co-payments for prescription drugs, laboratory services, or doctor visits in order to prevent these costs from impeding access to continuing care.

science tells us that it is important to treat HIV as soon as possible after diagnosis and to maintain continuous ART. The Strategies for Management of Antiretroviral Therapy (SMART) Study, published in 2006, highlighted the critical importance of continuous ART.⁶ The study found more than a doubling of the risk of death for persons not receiving continuous ART. In 2015, the Strategic Timing of Antiretroviral Treatment (START) Study definitively answered the question of when to initiate treatment, indicating immediate treatment should be offered. The study found that persons who received immediate treatment were 57% less likely to develop serious injury or die than those who deferred treatment until their disease had progressed.⁷

It is not a simple matter to get people into care, keep them engaged with regular, specialized HIV care, and keep them on ART and healthy over the long term.⁸ The Ryan White Program, however, plays an important role in achieving these goals. Since its inception, the Program has engaged people living with HIV and affected communities in program planning and service prioritization. This role in decision-making has been at the heart of the Program's vibrancy over the years, and ultimately, its success. In fact, people with HIV who receive Ryan White Program services are more likely to be virally suppressed and experience other positive health outcomes than other people with HIV. Whereas the CDC estimates that only 30% of people with HIV in the US are virally suppressed,⁹ 83% of persons receiving a Ryan White ambulatory care medical service are virally suppressed.¹⁰

The Program achieves these outcomes by supplementing insurance coverage, when it is available, to provide critical services that support the monitoring of HIV and engagement in care that are either not covered by or insufficiently covered by insurance. The Program also can pay co-payments or other cost sharing that can be a barrier to continuous engagement in care and ART; it supports networks of care by training and equipping the clinical and non-clinical workforce to provide quality care to people with HIV; and it works with states, territories, local jurisdictions, and providers to monitor HIV clinical and other outcomes.

THE RYAN WHITE HIV/AIDS PROGRAM HELPS TO REDUCE THE SIZE OF THE HIV EPIDEMIC

The majority of HIV transmissions in the US arise from persons who have been diagnosed with HIV, but are not in care. The Ryan White Program builds the networks of different kinds of clinical and non-clinical providers working together to enable people to remain engaged in care. It also supports monitoring, along with CDC surveillance data, to identify and intervene with persons who have stopped engaging in care. Greater support for the Ryan White Program may allow the Nation to do even more to increase engagement in care in order to keep reducing the number of new infections.

With routine HIV screening, diagnosis of HIV infection has improved. It is estimated that only 13% of people living with HIV in the US are unaware of their infection. The CDC estimates, however, that nearly

VIRAL SUPPRESSION is when individuals with HIV on antiretroviral therapy (ART) reduce the amount of HIV virus circulating in their blood below the limits of detection. Such individuals are sometimes called “undetectable.”

Roughly **SEVEN IN TEN HIV TRANSMISSIONS** arise from persons diagnosed with HIV who are not receiving regular HIV care. The Ryan White Program bolsters efforts across the health system to engage people with HIV in regular HIV care.

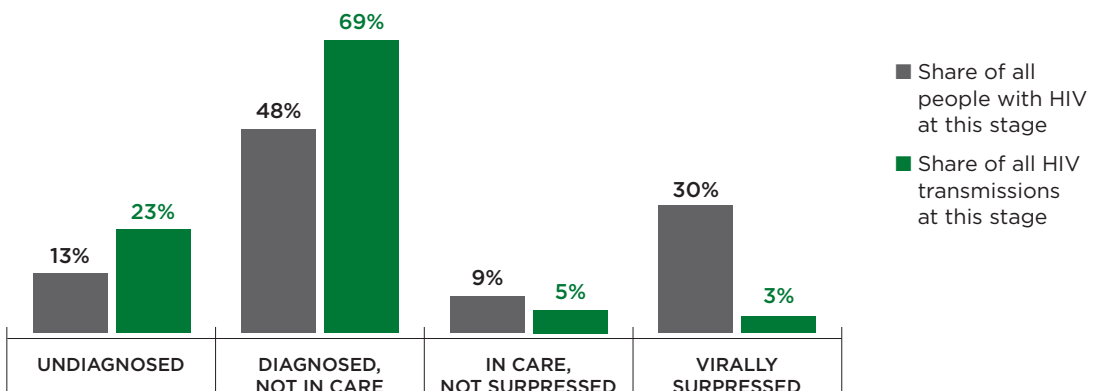
half (48%) of people with HIV have been diagnosed, but are not receiving ongoing HIV care. They further estimate that these individuals are responsible for roughly seven in ten (69%) HIV transmissions in the US (Figure 1).

Just as the SMART and START studies provided important information on the benefits of ART for people living with HIV, another RCT supported by the NIH, called the HIV Prevention Trials Network 052 (HPTN 052) Study, found that the risk of transmitting HIV declined by 96% in persons who received immediate ART instead of delayed ART.¹¹ Named by *Science Magazine*

as the biggest scientific breakthrough of 2011,¹² HPTN 052 provides a high weight of evidence of the effectiveness of ART at stopping HIV transmission.¹³ In 2016, another important study was published. The Partners of People on ART—A New Evaluation of the Risks (PARTNER) Study is a European observational study of serodiscordant partners (one partner was HIV positive and one was HIV negative) that had enrolled couples from 14 countries. It published an analysis that found that when the HIV positive partner was taking ART and virally suppressed, even when regularly engaging in condomless sex, there were zero transmissions from the HIV positive partner.¹⁴

FIGURE 1. HIV TRANSMISSIONS ALONG THE HIV CARE CONTINUUM IN THE UNITED STATES AND PUERTO RICO (2012)

The majority of HIV transmissions could be prevented by getting all diagnosed persons into HIV care; many of these individuals already have health insurance coverage



Source: Frieden TR, Foti KE, Mermin J. Applying public health principles to the HIV epidemic—How are we doing? *N Engl J Med.* 2015;373(23):2281-2287.

Note: In care means receiving at least two HIV specialty care visits per year at least 90 days apart.

THE RYAN WHITE PROGRAM CAN HELP BEND THE HEALTH CARE COST CURVE

Because engaging individuals living with HIV in care and treatment leads to fewer transmissions, the Ryan White Program can help to bend the national health care cost curve.

The medical cost saved by avoiding one HIV infection is estimated to be \$229,800.

CDC estimates that the annual number of new infections has declined over time. **There were 8,700 fewer infections in 2014 when compared to 2008.** The cost savings from averting just this many infections adds up to nearly \$2 billion in avoided health care expenditures.

National cost savings would grow exponentially if these trends toward declining incidence are maintained.

Incidence estimates are based on: HIV Incidence: Estimated Annual Infections in the U.S., 2008-2014. Centers for Disease Control and Prevention Fact Sheet. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-incidence-fact-sheet_508.pdf. Accessed February 21, 2017. Cost estimates are based on: Schackman BR, Fleishman JA, Su AE, et al. The lifetime medical cost savings from preventing HIV infection in the United States. *Med Care*. 2015;53(4):293-301.

To achieve these results, individuals must remain in care and on ART and have their viral load carefully monitored to ensure that they remain durably virally suppressed over time. Recently released data from the CDC, however, examined durable viral suppression in 33 jurisdictions in the US.¹⁵ The study found that in 2014, only about half (48%) of people living with diagnosed HIV had durable viral suppression, i.e., all viral load measures were suppressed during the defined time period (<200 copies/mL). These data emphasize the need to bring even more people into care and spotlight the role of the Ryan White Program in providing supplementary coverage of medical services to facilitate more regular viral load monitoring and to fund services that enable people to remain engaged in care and on treatment so that they can maintain durable viral suppression.

Just as before the Affordable Care Act (ACA) was enacted, the majority of Ryan White Program clients are insured and receive additional services through the AIDS Drugs Assistance Program (ADAP), a component of the Part B grant program to states and territories, or other parts of the Ryan White Program. These additional services, whether more frequent laboratory monitoring or support services that enable people to remain engaged in care (see text box “Critical Services that Support Engagement in Care and Viral Suppression”), create a comprehensive system of care that achieves better outcomes than insurance coverage alone.^{16,17} In addition, insurance coordination and support have proven cost effective. Therefore, the Ryan White Program is both a safety net and a cost effective conduit to coverage. Amidst reforms to the broader health system, it

is necessary to preserve the Ryan White model to safeguard the improvements in health outcomes for people living with HIV and the corresponding public health gains of reduced HIV transmission.

THE RYAN WHITE HIV/AIDS PROGRAM REDUCES HIV-RELATED HEALTH DISPARITIES

The National HIV/AIDS Strategy for the United States (Strategy) was released in 2010 and updated in 2015 to guide the Nation's efforts through 2020.¹⁸ It was developed with extensive public input and engagement from federal agencies to provide an evidence-based roadmap for all stakeholders to align their efforts around the goals of reducing HIV incidence, increasing access to care, and reducing HIV-related health disparities. Addressing HIV-related health disparities is critical because the US health care system is highly variable and produces uneven health outcomes for many different populations and in different places of the country. While people living with HIV are found in all parts of the country and come from all walks of life, the epidemic exacerbates nearly all pre-existing disparities, which in turn often act to further concentrate the impact of HIV within groups and communities. Certain groups, including gay and bisexual men, transgender people, and Black and Latino communities, have been particularly impacted. Therefore, a central goal both of the Strategy and the Ryan White Program is to reduce HIV-related health disparities so that health outcomes improve and HIV transmissions are reduced in all regions of the country and among all groups in terms of age, race, gender, risk group, and other characteristics. A recent study published in *Health Affairs* by the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) documented the Program's progress on this front.¹⁹ Over the 2010 to 2014 period,

viral suppression increased among all groups of Ryan White clients examined and health disparities declined for most groups (Figure 2). Notably, health disparities did not decline among transgender people and those with unstable housing during this time, suggesting areas requiring continued emphasis.

THE RYAN WHITE HIV/AIDS PROGRAM CONTINUES TO EVOLVE AND ADAPT

First enacted in 1990 as an emergency response to a burgeoning public health crisis, the Ryan White Program has been reauthorized by Congress four times with bipartisan support, most recently in 2009.²⁰ Each of the Program's four reauthorizations has brought changes to accommodate new and emerging needs.²¹ Although the Program's authorization has now lapsed, it has continued functioning under its prior authority and has been funded through annual Congressional appropriations.

At some point, the Congress may wish to revisit the shape and structure of the Ryan White Program in light of current needs. Given the supplementary nature of the Program in responding to gaps left by other programs, policy makers may choose to first resolve some of the larger questions over the future direction of the US health care system including policy decisions related to the funding and structure of Medicaid, Medicare and the private insurance system before significantly changing the Program. The Ryan White Program is critical in ensuring that people living with HIV can continue to access HIV treatment and care, and may be needed more than ever as the larger health system evolves.

Since the last reauthorization, several new developments in the health care environment and in HIV science have occurred and a future reauthorization may

seek to account for these developments. As discussed, several important studies have shown that people with HIV should be encouraged to initiate ART immediately on diagnosis (federal clinical treatment guidelines now reflect this)²² and studies have shown that if we can support people to remain virally suppressed, it is possible to stop transmission to others. Further, the development and refinement of population-level metrics (such as for all people with HIV in the US, or in a state, city, or clinic) to monitor the stages of HIV care from diagnosis with HIV, to linkage to HIV medical care, engagement in care, initiation of ART, and achievement of viral suppression—also known as the HIV care continuum—are increasing accountability from Ryan White Program grantees and enabling a more effective targeting of

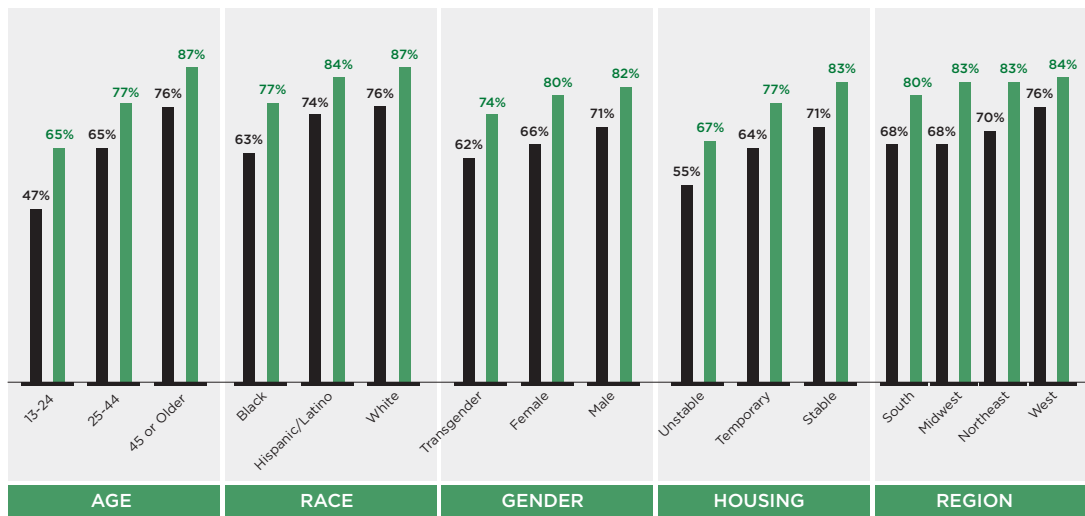
resources and tailoring of responses to yield improvements in HIV outcomes, including rising rates of viral suppression.²³

The ACA has increased access to health insurance coverage for people living with HIV.²⁴ As a result, many states and local jurisdictions have begun re-orienting their Ryan White programs to provide enhanced supports to promote engagement and retention in care, such as expanded substance abuse and mental health treatment services, insurance navigation assistance, and cost-sharing assistance, to ensure that pharmacy, laboratory, and doctor visit co-payments do not become a barrier to care.

HAB often has led the way in leveraging the Strategy to focus on improving health

FIGURE 2. VIRAL SUPPRESSION RATES IN THE RYAN WHITE PROGRAM BY DEMOGRAPHIC GROUP

■ 2010 ■ 2014



Source: Doshi RK, Milberg J, Jumento T, Matthews T, Dempsey A, Cheever LW. For many served by the Ryan White HIV/AIDS Program, disparities in viral suppression decreased, 2010-2014. *Health Affairs*. 2017;36(1):116-123.

Note: The overall proportion of Ryan White HIV/AIDS Program clients with virally suppressed HIV increased from 69.4% in 2010 to 81.5% in 2014. Disparities in age and between Blacks and Whites decreased between 2010 and 2014 but persisted. Although absolute viral suppression rates for transgender people and those with unstable housing improved between 2010 and 2014, disparities were not reduced.

SOUTHERN US IS HIT HARD BY HIV

The southern United States has the highest rates of new HIV infections and the largest number of people living with HIV. Most Southern states have not expanded Medicaid. This lack of access to health care, compounded by high poverty rates and lower educational attainment, further increases the vulnerability of people living with HIV. As a result of these barriers, southern states lag behind the rest of the country in HIV outcomes, although regional disparities within the Ryan White Program

are shrinking. Death rates among people living with HIV in some Southern states are three times higher than those living in other parts of the country.*

A critical role of the Ryan White Program is to tailor responses to HIV to specific populations. Importantly, this includes a focus on using data to identify which groups and sub-groups are most heavily impacted and have the poorest outcomes, whether this means highlighting the needs of Black women who are very disproportionately

impacted by HIV compared to White women or bringing attention to the unique needs of people who inject drugs. Recognizing the different types and levels of need on the basis of geography is also a significant aspect of the Program. This includes supporting different approaches to meeting needs in urban and rural areas, and it means acknowledging and responding to large health care inequities (not limited to people with HIV) across regions of the country.

*Southern states lag behind rest of nation in HIV treatment testing. AIDS.gov website. <https://aidsinfo.nih.gov/news/1633/southern-states-lag-behind-rest-of-nation-in-hiv-treatment-testing>, December 6, 2015. Accessed March 10, 2017.

outcomes across the population. HAB leadership in recent years has been critically important in helping the field of HIV service delivery adapt to unfolding technology and new coverage options, while embracing a heightened focus on using data to better monitor and improve population-level outcomes. Key HAB initiatives include:

- **Client-level Data:** Since 2010, HAB has published client-level data that allows federal administrators, grantees and sub-grantees, and the public to assess the numbers and types of clients receiving services and their HIV-related outcomes.²⁵ A comprehensive annual client-level data report has now been released in 2015 and 2016, providing particularly rich data access.
- **More Tailored Approaches for Underserved Populations:** The HIV epidemic is heavily concentrated among key populations. There has been a welcome emphasis within HAB on funding technical assistance to develop tailored approaches to serving young gay and bisexual men (especially young Black and Latino gay men) and transgender women, two groups that have remained at extremely high risk even as HIV diagnoses have declined in all other groups (including people who inject drugs, heterosexual women and men, and older gay and bisexual men). In the past, efforts to tailor models of care to serve young gay and bisexual men and transgender women have been limited.

RESEARCH SHOWS that people with HIV with private insurance, Medicaid, or Medicare are more likely to be virally suppressed if they also receive services from the Ryan White Program.

- **Strengthened Policy Guidance on the Ryan White/Health Insurance Interface:**

Many Ryan White clients live on limited incomes and even when covered by insurance, without the support provided by the Ryan White Program, would be unable to afford to access critical services. As opportunities for people with HIV to gain insurance have increased under the ACA, grantees have raised numerous questions regarding how to best support engagement with coverage in the most cost effective way, while complying with the payer of last resort provision and other Ryan White Program requirements. Because the Ryan White legislation has such a strong payer of last resort provision and a core emphasis of the Program is to prevent the duplication of services, a key component of HAB's program oversight and its audits is to ensure compliance with these requirements. Therefore, this has necessitated HAB dedicating significant resources to working with grantees to monitor HIV outcomes as people are transitioned to new insurance coverage and to providing technical assistance and policy guidance to assist grantees so that they remain in compliance with HAB policies.²⁶ Moreover, the Ryan White Program has long supported insurance continuation in which funds (primarily ADAP funds) have been used to purchase comprehensive insurance coverage in place of providing drugs alone when it is cost effective. HAB also has issued policy guidance on this topic to clarify expectations and allowances around insurance purchasing.

- **Updated Workforce Training Initiatives:**

Experienced HIV medical providers deliver higher quality and more cost effective HIV care. National studies predict a significant shortfall of medical providers with the appropriate expertise to care for people with HIV within the next five years.²⁷ The AETC program is the component of the Ryan White Program with lead responsibility for workforce training and capacity building. The program supports 5 national centers or initiatives and a network of 8 regional AETCs.^{28,29} In 2015, HRSA updated its guidance for the AETC program that marked a significant update and refocusing of the program on emphasizing the HIV care continuum to achieve the goals of the National HIV/AIDS Strategy. The new direction of the program also is intended to strengthen collaboration across the network and reduce duplication of activities.

CONCLUSION

THE RYAN WHITE HIV/AIDS PROGRAM HAS BEEN REMARKABLY SUCCESSFUL.

Indeed, the investments in building clinical and non-clinical capacity to serve people with HIV throughout the United States, combined with the refinements to the Program through successive reauthorizations and strong administrative leadership of the Program, have served the country well. **The Program has led the way in the development of integrated models of care that other parts of the US health system are seeking to replicate, and the Program has enabled states, territories, and local jurisdictions to mount flexible responses to their unique epidemics, while also raising the standard of care and expectations for population-level outcomes for everyone.**

As the Program transforms to more effectively meet needs in an evolving health care environment, future consideration could be given to how the Program could be shaped to demand even greater accountability from grantees to increase population-level HIV viral suppression by leveraging program data to address populations and communities with the most urgent needs. Consideration also could be given to expanding funding to enable it to reach even more people with HIV, especially those who have been diagnosed, but are not receiving ongoing HIV care. Moreover, additional investments may be considered for working with states and local jurisdictions to build stronger monitoring systems to better identify and respond in real time to persons at risk for disengaging from care. Policy makers also may consider a role for the Ryan White Program in expanding access to pre-exposure prophylaxis (PrEP) for high-risk HIV negative individuals. Moreover, because of the success of the Program, some policy makers, providers, and advocates have questioned whether the Ryan White Program model, or the Program itself, could assist with responding to related health challenges other than HIV, such as Hepatitis C, that may benefit both from the integrated care models and the provider networks established by the Ryan White Program.

Over the last two and a half decades, the Ryan White Program has proven its ability to be flexible and responsive to changing needs. As the wider health system continues to change, it is critically important that policy makers retain their strong support and funding for this Program that is leading the Nation's efforts to care for people living with HIV and reduce the number of new HIV infections.

THE LIVES OF INDIVIDUALS WITH HIV AND OUR NATION'S PUBLIC HEALTH DEPEND ON IT.

ENDNOTES

- 1 HIV in the United States: At a Glance. Centers for Disease Control and Prevention website. <https://www.cdc.gov/hiv/statistics/overview/atag glance.html>. Updated December 2, 2016. Accessed February 19, 2017.
- 2 HIV Incidence: Estimated Annual Infections in the U.S., 2008-2014. Centers for Disease Control and Prevention Fact Sheet. https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-incidence-fact-sheet_508.pdf. Accessed February 21, 2017.
- 3 See comment from Dr. Carl Dieffenbach, Director, Division of AIDS Research at the National Institute of Allergy and Infection Disease in an interview with AIDS.gov on November 16, 2016 available at https://www.youtube.com/edit?video_id=MGSTO2CSFrU: "If you are durably virologically suppressed you will not transmit to your partner... I'll say this again, for somebody who is in a discordant couple, if the person [with HIV] is virologically suppressed, 'durably' --means there is no virus in your system, hasn't been for several months -- your chance of acquiring HIV from that person is ZERO, let's be clear about that: ZERO. If that person the next day stops therapy for two weeks and rebounds, your chance goes up. That's why we talk about durable viral suppression. ...You're as virologically suppressed as good as your adherence. That's the message."
- 4 Centers for Disease Control and Prevention. Mortality Slide Series: HIV Mortality. <https://www.cdc.gov/hiv/pdf/library/slidesets/CDC-HIV-EPA5-Mortality-Slides-2013.pdf>. Accessed February 19, 2017.
- 5 HIV in the United States: At a Glance. Centers for Disease Control and Prevention website. <https://www.cdc.gov/hiv/statistics/overview/atag glance.html>. Updated December 2, 2016. Accessed February 19, 2017.
- 6 The Strategies for Management of Antiretroviral Therapy (SMART). Study Group. CD4+ count-guided interruption of antiretroviral treatment. *N Engl J Med*. 2006;355(22):2283-2296.
- 7 The INSIGHT START Study Group. Initiation of antiretroviral therapy in early asymptomatic HIV infection. *N Engl J Med*. 2015;373(9):795-807
- 8 For a discussion of the challenges in keeping individuals engaged in HIV care over their lifespan and the structural components of a health system needed to support this engagement, see Crowley JS, Amico KR, Mugavero, M. *Curbing the HIV Epidemic by Supporting Effective Engagement in HIV Care*. October 2016. http://www.amfar.org/uploadedFiles/amfarorg/Articles/On The Hill/2016/DC-2016-Engagement-Policy-Report_081916-October.pdf. Accessed February 10, 2017.
- 9 Frieden TR, Foti KE, and Mermin J. Applying public health principles to the HIV epidemic — How are we doing? *N Engl J Med*. 2015;373(23):2281-2287
- 10 Health Resources and Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report 2015*. December 2016. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/2015rwhapdatareport.pdf>. Accessed February 10, 2017.
- 11 Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med*. 2011;365(6):493-505.
- 12 Cohen J. Breakthrough of the year. HIV treatment as prevention. *Science*. 2011;334(6063):1628.
- 13 Fauci AS, Marston HD. Ending the HIV/AIDS pandemic — Follow the science. *N Engl J Med*. 2015;373(23):2197-2199.
- 14 Rodger AJ, Cambiano V, Bruun T, et al for the PARTNER Study Group. Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy. *JAMA*. 2016;316(2):171-181.
- 15 Crepaz N, Tang T, Marks G, Hall I. Viral-load dynamics among persons with diagnosed HIV: United States, 2014. Paper presented at: Conference on Retroviruses and Opportunistic Infections 2017; February 13-16, 2017; Seattle. Abstract 31.

- 16 An analysis conducted jointly by staff of the CDC and HRSA using data from the 2009 through 2011 cycles of the Medical Monitoring Project (MMP) found that health care facilities receiving funding from the Ryan White Program were more likely to provide a broad range of critical services than facilities providing HIV care that did not receive Ryan White Program funding. These services include mental health, substance abuse treatment, case management, adherence counseling, transportation assistance, and risk reduction counseling. The same study also found that for persons with HIV with incomes at or below the poverty level, those receiving services at facilities receiving funding from the Ryan White Program were significantly more likely to achieve viral suppression compared with HIV care facilities not receiving Ryan White Program funding. See Weiser J, Beer L, Frazier EL, et al. Service delivery and patient outcomes in Ryan White HIV/AIDS Program-funded and -nonfunded health care facilities in the United States. *JAMA Intern Med.* 2015;175(10):1650-1659.
- 17 An additional CDC/HRSA analysis of MMP data covering 2009 to 2012 found that people with HIV and insurance had higher rates of viral suppression when they also received assistance from the Ryan White Program. This association held true for persons with HIV with private insurance, Medicaid, Medicare, and dual eligibles receiving both Medicaid and Medicare. See Bradley H, Viall AH, Wortley PM, Dempsey A, Hauck H, Skarbinski J. Ryan White HIV/AIDS Program assistance and HIV treatment outcomes. *Clin Infect Dis.* 2016;92(1):90-98.
- 18 *The National HIV/AIDS Strategy for the United States: Update to 2020.* July 2015. <https://www.aids.gov/federal-resources/national-hiv-aids-strategy/nhas-update.pdf>. Accessed February 10, 2017.
- 19 Doshi RK, Milberg J, Jumento T, Matthews T, Dempsey A, Cheever LW. For many served by the Ryan White HIV/AIDS Program, disparities in viral suppression decreased, 2010-2014. *Health Affairs.* 2017;36(1):116-123.
- 20 Crowley JS, Kates J. *Updating the Ryan White HIV/AIDS Program for a New Era: Key Issues and Questions for the Future.* April 2013. <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8431.pdf>. Accessed February 10, 2017.
- 21 In the Program's first reauthorization in 1996, just after the emergence of successful combination ART, Congress created a separately funded line item for the AIDS Drug Assistance Program (ADAP) under the Part B program of grants to states and territories. Congress also provided new requirements for prioritizing funding for women, infants, children and youth. In 2000, Congress first initiated a process for incorporating counts of HIV cases, in addition to AIDS, which began the longer shift toward using living HIV/AIDS cases when determining funding allocations. It also put a renewed emphasis on early intervention services, in order to help people with HIV learn their status and get into care. The 2006 reauthorization, made numerous changes including prioritizing access to comprehensive health care by requiring that 75% of most funding be used for a defined set of "core medical services" (also known as the "75/25 rule") and requiring the Secretary of HHS to develop a list of antiretrovirals to serve as a "minimum formulary" for ADAPs. The most recent reauthorization, the Ryan White HIV/AIDS Treatment Extension Act of 2009, P.L. 111-87, included provisions designed to strengthen Ryan White's role in helping to identify undiagnosed people with HIV and established a new annual national HIV testing goal. The bill had specific authorization levels until 2013.
- 22 Panel on Antiretroviral Guidelines for Adults and Adolescents. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents.* Department of Health and Human Services. <https://aidsinfo.nih.gov/guidelines>. Accessed February 10, 2017.
- 23 See, e.g., City and State Profiles. AIDSvu website. <https://aidsvu.org/local-statistics/>. Accessed February 10, 2017.
- 24 Kates J, Dawson L. *Insurance Coverage Changes for People with HIV under the ACA.* February 14, 2017. <http://kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>. Accessed on February 21, 2017.
- 25 Health Resources and Services Administration. *Ryan White HIV/AIDS Program Annual Client-Level Data Report 2015.* December 2016. <https://hab.hrsa.gov/sites/default/files/hab/data/datareports/2015rwhapdatareport.pdf>. Accessed February 10, 2017.

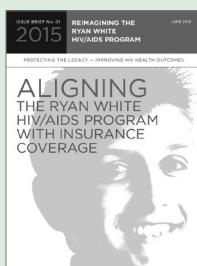
- 26 Policy Notices and Program Letters. Health Resources and Services Administration website. <https://hab.hrsa.gov/program-grants-management/policy-notices-and-program-letters>. Updated October 2016. Accessed February 10, 2017.
- 27 Weiser J, Beer L, West BT, Duke CC, Gremel GW, Skarbinski J. Qualifications, demographics, satisfaction, and future capacity of the HIV care provider workforce in the United States, 2013-2014. *Clin Infect Dis*. 2016;63(7):966-975.
- 28 AIDS Education and Training Center (AETC) Program. Health Resources and Services Administration website. <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-f-aids-education-and-training-centers-aetc-program>. Updated January 2017. Accessed February 10, 2017. <https://aidsetc.org/aetc-program/national-centers>
- 29 AIDS Education and Training Center (AETC) Program. Health Resources and Services Administration website. <https://hab.hrsa.gov/about-ryan-white-hiv-aids-program/part-f-aids-education-and-training-centers-aetc-program>. Updated January 2017. Accessed February 10, 2017.

THE RYAN WHITE POLICY PROJECT

seeks to generate and evaluate ideas for adapting the Ryan White HIV/AIDS Program to be maximally effective in a changing health system.

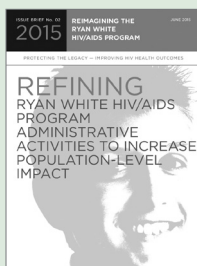
OTHER RESOURCES FROM THE RYAN WHITE POLICY PROJECT

In 2015, the Ryan White Policy Project released three policy briefs related to policy questions tied to strengthening the Program as the health system changes. These can be found at <http://bit.ly/ryanwhitepolicyproject>



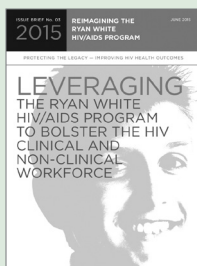
ALIGNING THE RYAN WHITE HIV/AIDS PROGRAM WITH INSURANCE COVERAGE

Originally built as a standalone system, the Ryan White Program has evolved to a complement to the insurance system. Nonetheless, as the health system seeks to better integrate services and design more effective and efficient care delivery models, this report offers strategies for better aligning the Ryan White Program with insurance to ensure that people with HIV do not get left behind.



REFINING RYAN WHITE HIV/AIDS PROGRAM ADMINISTRATIVE ACTIVITIES TO INCREASE POPULATION-LEVEL IMPACT

The Ryan White Program has always looked and acted differently than other parts of the health system. This report provides recommendations for ways to streamline existing planning and monitoring activities to retain critical aspects of community engagement. It also forcefully calls for increased Ryan White Program investments to build health department data management systems and capacity to better partner with Medicaid, Medicare, health plans, and HIV prevention programs to monitor engagement in care and intervene when care is interrupted.



BOLSTERING THE HIV CLINICAL AND NON-CLINICAL WORKFORCE

Generations of dedicated HIV care providers and community partners have built today's HIV care system. While more must be done to better reach underserved populations and communities, the need is great to bolster and sustain the existing HIV care workforce. This report offers recommendations for building upon recent changes to the AIDS Education and Training Center (AETC) program and other efforts to support clinical and non-clinical providers.

RYAN WHITE WAS AN INDIANA TEENAGER



with hemophilia who was diagnosed with HIV in 1984. He was an object of fear and he faced extreme discrimination when he attempted to attend school in the early years of the HIV epidemic. He was one of the first people that the Nation came to know as living with HIV and he was a prominent champion for an inclusive response toward all persons living with the virus. Ryan died of AIDS in 1990 before he was able to complete high school. His mother, Jeanne White Ginder continues to advocate for HIV/AIDS

issues and educate the public about the impact of this disease.

Later in 1990 when the Congress enacted the first comprehensive national response to HIV, pulling together a few smaller and more targeted initiatives, they named the law the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The Program has had bipartisan support and has been reauthorized in 1996, 2000, 2006, and 2009. Today, the Program works with cities, states, and local community-based organizations to provide services to more than a half a million people living with HIV.

The passion, perseverance, and dedication to providing a caring response to all people in the United States living with HIV as embodied by the Ryan White HIV/AIDS Program is a lasting legacy of Ryan White and the many other people living with HIV and their friends, families, and care providers over the course of the epidemic. The Program has become an indispensable linchpin in the Nation's response to the HIV epidemic in the United States.

**O'NEILL
INSTITUTE**
FOR NATIONAL & GLOBAL HEALTH LAW

GEORGETOWN LAW

<http://bit.ly/ryanwhitepolicyproject>