



# **Ending HIV in America**

*Policy and Program Insights From  
Local Health Agencies and Providers*

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**BIPARTISAN POLICY CENTER**

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## DISCLAIMER

This report is the product of BPC staff. The findings and considerations expressed herein do not necessarily represent the views or opinions of the Bipartisan Policy Center's founders, its board of directors, or the individuals who participated in interviews, who are listed in the Appendix.

<b>4</b>	<b>Executive Summary</b>
<b>6</b>	<b>Introduction</b>
<b>10</b>	<b>Report Objectives and Methods</b>
10	Objectives
10	Methods
<b>11</b>	<b>Jurisdiction and Provider Profiles</b>
11	Bronx, New York, and Montefiore Medical Center
13	Clark County, Nevada, and Aid for AIDS Nevada
14	Duval County, Florida, and Jacksonville Area Sexual Minority Youth Network (JASMYN)
15	Kansas City, Missouri, and KC CARE Health Center
17	Montgomery, Alabama, and Medical Advocacy and Outreach (MAO)
18	Richmond, Virginia, and Capital Area Health Network
19	Seattle, Washington, and The Madison Clinic at Harborview Medical Center
21	Scott County, Indiana, and Dr. William Cooke, Foundations Family Medicine
<b>23</b>	<b>Findings</b>
23	Access to Services
	<i>The Ryan White program</i>
	<i>Changes in the health care system</i>
	<i>Access to services in rural areas</i>
29	Facilitators and Barriers to HIV Response
	<i>HIV surveillance and data use</i>
	<i>Socioeconomic status and unmet social need among people living with, or at risk of, HIV</i>
	<i>Stigma and discrimination</i>
38	Targeted Programming Efforts
	<i>Young MSM of color</i>
	<i>Maternal health, perinatal transmission, and pediatric care</i>
	<i>HIV prevention through the use of pre-exposure prophylaxis (PrEP)</i>
	<i>HIV and substance use disorder</i>
<b>50</b>	<b>Policy Considerations</b>
<b>52</b>	<b>Conclusion</b>
<b>53</b>	<b>Appendix: Project Interviewees</b>
<b>54</b>	<b>Endnotes</b>

# Executive Summary

Since the 1980s, over 700,000 Americans have lost their lives due to the human immunodeficiency virus (HIV). Today, there are an estimated 1.1 million people living with HIV in the United States, with just under 40,000 new cases each year. Thanks to the marvels of modern medicine and public health achievements, HIV is now largely a chronic disease for many with the condition. Unfortunately, health disparities exist, and the epidemic has evolved to become highly heterogeneous across not only populations, but geographically. Federal spending for the domestic HIV epidemic totaled an estimated \$28 billion in fiscal year 2019, and the President's 2020 budget requests an additional \$291 million for the U.S. Department of Health and Human Services (HHS) to eliminate new HIV infections in the United States.

The purpose of this Bipartisan Policy Center study is to understand the challenges and opportunities to end the HIV epidemic from the vantage point of frontline health care providers and local health agencies in eight diverse jurisdictions distributed geographically around the country: Seattle, Washington; Bronx, New York; Kansas City, Missouri; Jacksonville (Duval County), Florida; Clark County, Nevada; Scott County, Indiana; Richmond, Virginia; and, Montgomery, Alabama. BPC sought a balance among rural- and urban-focused epidemics; state Medicaid expansion status; and political party of the state legislature and governor. BPC compiled key epidemiologic data from each jurisdiction and conducted 16 qualitative interviews with local health officials and providers.

The findings can be categorized into three areas. First, with respect to access to HIV services, the Ryan White Program continues to provide crucial support for low-income people living with HIV and could also be a model for serving individuals at high risk for HIV. Medicaid expansion in 37 states and the District of Columbia has increased access to care for many with HIV, while non-expansion states closely overlap with the regions that are experiencing elevated rates of new HIV diagnoses. There are distinct barriers in rural settings, which are not dissimilar from the broader challenges of accessing health care services in rural America.

Second, with respect to the facilitators and barriers to the HIV response, surveillance efforts are critical to informing HIV programming, but there are often challenges in real-time communications and data exchange. Molecular HIV surveillance holds promise in identifying clusters of infection in local communities. Barriers addressing HIV include poverty and unmet social needs among people living with, or at risk of, HIV. Partnerships with community-based organizations to address social needs can assist in supporting the clinical care plan. Stigma also impedes the HIV response by contributing to HIV risk; stigma-reduction campaigns consistent with local cultural norms may be effective.

Third, with respect to targeted programming, efforts to reach young Men who have sex with Men (MSM) of color are underway across the country given that this population is highly impacted by HIV, but more attention and resources are needed. Elimination of perinatal transmission in the United States is within grasp, though it requires improved coordination across programs and payors; in addition, young people living with HIV remain an important priority for the U.S. health care system. HIV prevention, through the use of pre-exposure prophylaxis (PrEP), has great potential; however, individual, health system, and provider barriers must be overcome. Finally, co-occurring substance abuse epidemics have the potential to exacerbate the HIV epidemic, and thus access to evidence-based treatment and harm-reduction strategies for at-risk individuals are important.

Based on the findings of this study, and consistent with the administration's HIV initiative, BPC offers the following for consideration by federal, state, and local policymakers to achieve the goal of reducing new HIV infections by 90 percent in 10 years.

- 1. Continue to support the Ryan White program.** Funding increases would permit state and local programs to invest more deeply in addressing the social determinants of health that stand in the way of full access to HIV care—access that researchers have found reduces productivity losses and overall costs of illness.
- 2. Expand insurance coverage.** Stakeholders engaged in ending the epidemic at the local, state, or national level should support the expansion of insurance coverage in all states.
- 3. Improve access to care in rural areas.** Federal and state governments should aggressively invest in innovative approaches to increasing access to preventive and care services, including through telehealth, which has been shown to reduce costs and improve access for a variety of health conditions for rural patients.



4. **Invest in public health infrastructure, workforce, and surveillance.** The federal government and states should invest in the public health infrastructure and human resources necessary to maintain robust and interoperable HIV surveillance systems, while strengthening the overall public health system; in addition, increased funds should be directed to efforts to integrate HIV service providers into surveillance systems, allowing data to inform their linkage and retention efforts as well as other provider activities.
5. **Address unmet social needs.** Funding for initiatives such as the Housing Opportunities for People With AIDS program is critical to support people living with HIV; in addition, policymakers at the federal and state levels should consider making some or all of the new funds under the recent federal HIV strategy as flexible as possible to permit innovative local solutions to address social determinants of health.
6. **Reduce stigma.** Addressing HIV requires a policy environment that supports people living with or at risk of HIV; the federal government should consider the impact of policies that harm LGBTQ people, immigrants, women, and other populations.
7. **Target programs and resources for youth.** Federal and state policymakers should assess if there are adequate funds in the Ryan White Program and Centers for Disease Control and Prevention grants to support this population with a range of social services and peer supports, as well as HIV prevention and care.
8. **Maintain focus on maternal health, vertical transmission, and pediatric care.** Efforts should be made to ensure that specialty obstetrical, maternal and pediatric infectious disease care remain widely available, especially in rural areas of the country with fewer health facilities and subspecialty services; in addition, dedicated efforts should be focused on reducing racial disparities in new infant infections, including increased access to case management, mental health, and substance abuse services for pregnant mothers.
9. **Prioritize equitable access to PrEP.** PrEP should be prioritized as part of comprehensive primary care and federal funding streams, with a focus on men of color who have sex with men and women of color; all efforts should be made to increase awareness and access to PrEP.
10. **Increase programs to address HIV and substance use disorders.** Congress and states should consider broader implementation of evidence-based harm-reduction interventions, such as syringe service programs, which are effective in HIV prevention and do not increase drug use.

# Introduction

The emergence of the human immunodeficiency virus (HIV) in the United States began with the diagnosis of a series of unusual infections in gay men in 1981. The new disease struck fear in communities and eventually led to the deaths of hundreds of thousands of Americans, many of whom had been in their healthy prime just months or years before.

Though the government was slow to respond early in the epidemic, historic advocacy and extraordinary science led to the development of a new field of HIV medicine. U.S. agencies came to play important roles in this early response. The National Institutes of Health (NIH) led work to understand the newly discovered virus and worked with scientists and the pharmaceutical industry to target vulnerable elements of its function in order to slow the progression of HIV-related illness. The Food and Drug Administration (FDA) created new pathways to shorten approval times for promising new compounds. In 1996, new class of breakthrough antiretroviral medications (ARVs) launched, turning HIV into a survivable infection for those with access to treatment.

In 1990, Congress enacted the first comprehensive funding bill to address HIV, named in honor of Ryan White, a 13-year-old boy with hemophilia who became HIV-positive from a blood transfusion.<sup>1</sup> The Ryan White Comprehensive AIDS Resources Emergency Act (RWCA) quickly became the centerpiece of the federal government's efforts to support care and treatment for individuals with HIV. Administered through the Health Resources and Services Administration, RWCA funding focuses on low-income, uninsured, and underserved populations to ensure their access to lifesaving HIV medication and essential support services such as transportation, childcare, and psychosocial support. Congress has since reauthorized the RWCA with bipartisan support four times, and the RWCA has evolved to remain responsive to the unmet needs among people living with HIV. Meanwhile, the 2010 Affordable Care Act led to an expansion of insurance coverage, including the expansion of Medicaid in 33 states, which provided further access to services for those living with or at risk of HIV.

The Office of National AIDS Policy developed the first National HIV/AIDS Strategy in 2010.<sup>2</sup> Broad consultation with diverse jurisdictions, communities, and advocates led to a cohesive set of targets for testing expansion, treatment, reductions in mortality, and new infections with HIV. The strategy was revised in 2015 to further reflect important scientific and policy shifts, including an NIH trial that demonstrated a 96 percent decrease in transmission of HIV infection among people on early treatment; the 2012 introduction of pre-exposure prophylaxis (PrEP), a drug combination that prevents acquisition of the virus; and changes in the health financing landscape after the Affordable Care Act (ACA).<sup>3</sup> State and local health departments play a pivotal role in the implementation and coordination of the National HIV/AIDS Strategy and in the overall HIV response.

## THE CURRENT STATE OF THE U.S. HIV EPIDEMIC

Today, an estimated 1.1 million people are living with HIV in the United States, and the number of new infections, which reached a peak in 1995, has plateaued at under 40,000 per year over the last several years.<sup>4</sup> Over 700,000 Americans have lost their lives due to HIV since its emergence in the 1980s, and nearly 6,000 people still die due to HIV each year in the United States.<sup>5,6</sup>

The U.S. HIV epidemic has evolved to become highly heterogeneous across not only populations, but geographically. The epidemic is most pronounced among men who have sex with men (MSM), who account for 67 percent of new infections.<sup>7</sup> Infections are also concentrated among black and Latinx Americans, who represent 44 percent and 26 percent of new infections, respectively.<sup>8</sup> Young black and Latinx MSM ages 13 to 24 and 25 to 34 have the highest overall rates of HIV infection.<sup>9</sup>

A comprehensive review found that the higher rate of HIV among African American MSM is not due to higher rates of risk behavior; most studies found that African American MSM were in fact less likely than other MSM to engage in high-risk practices.<sup>10</sup> Late diagnosis or undiagnosed HIV, along with higher rates of sexually transmitted infections (STIs), which facilitate HIV transmission, do contribute to the disparity. In addition, racism, homophobia, stigma, and a lack of access to health insurance can pose barriers to HIV prevention and care for MSM of color.<sup>11</sup>

Although HIV is sometimes considered an epidemic of coastal cities, over 50 percent of new diagnoses occurred in the South in 2017, and over 20 percent of new diagnoses in the South and the Midwest occurred in rural or suburban areas.<sup>12</sup>



An estimated 5,000 women living with HIV become pregnant each year, a number that is expected to grow as the number of women living with HIV continues to increase, although new infant infections have fallen significantly. In the United States, 80 percent of perinatal infections occur in infants of African American or Latinx mothers, in part reflecting disparities in access to care.<sup>13</sup> The same disparities often complicate the care of infants born with HIV, who will need lifelong treatment.

While HIV transmission linked to injection drug use has declined, the U.S. opioid epidemic has led to outbreaks of HIV in jurisdictions across the country. Driven initially by pill forms of opioids, the epidemic has resulted in a surge of injection drug use that has increased risks of blood-transmittable infections such as HIV and hepatitis C (HCV).

The epidemic in the United States has matured, with people living longer lives with effective HIV treatment. Nearly 50 percent of those living with known HIV infection in the United States are over 50 years of age.<sup>14</sup> Older individuals face increased risks of cardiovascular disease and cancer and require careful management of their HIV and co-morbidities.

## THE CURRENT U.S. RESPONSE TO HIV

Federal spending for the domestic HIV epidemic totaled an estimated \$28 billion in fiscal year (FY) 2019, about 75 percent of which (\$21.5 billion) was allocated for care, \$3.1 billion for cash and housing assistance, \$2.6 billion for research, and \$900 million for prevention.<sup>15</sup> The majority of domestic spending is for beneficiaries of Medicaid and Medicare, whereas discretionary spending—including for the RWCP (\$2,383.8 million), the Centers for Disease Control and Prevention (CDC), the U.S. Department of Housing and Urban Development’s Housing Opportunities for People with AIDS program, and the NIH—accounts for about 25 percent of the total.<sup>16</sup>

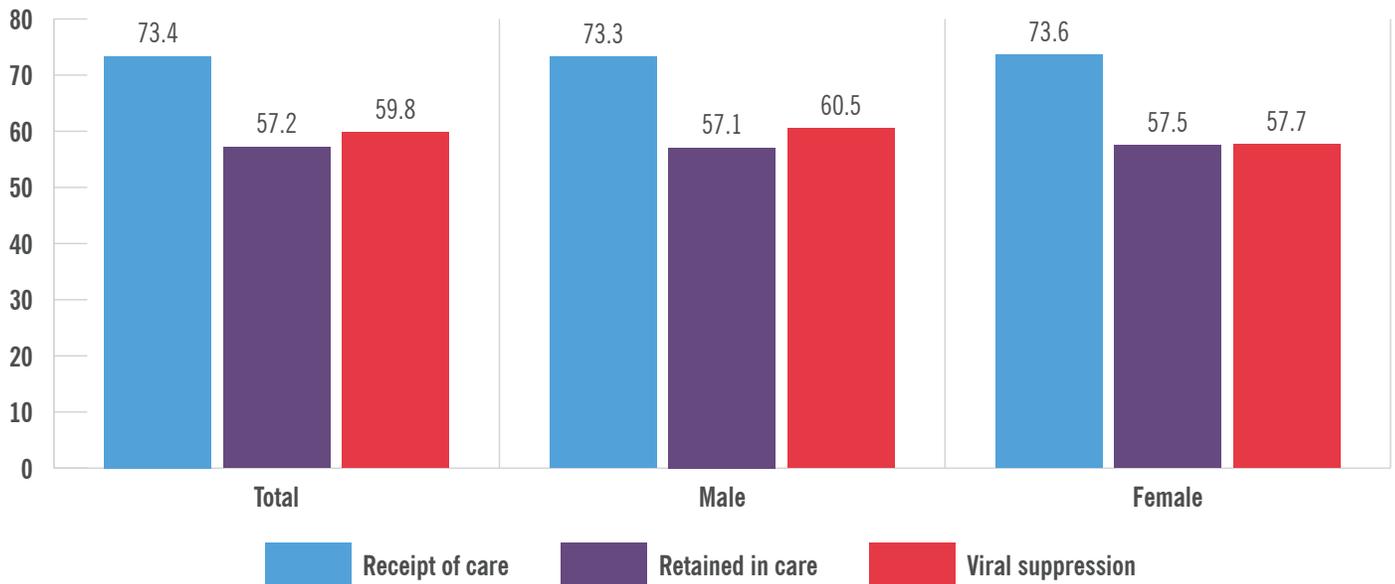
**Table 1: Domestic Federal Funding for HIV/AIDS, FY 2018-FY 2019**

Federal Funding for HIV/AIDS, FY 2013 – FY 2019 (a) (US\$ Millions)		
Program/Account	FY 2018	FY 2019
Ryan White Program (c)	\$2,318.8	\$2,318.8
ADAP (non-add)	\$900.3	\$900.3
CDC Domestic Prevention (& Research)	\$788.7	\$788.7
National Institutes of Health (domestic) (d)	\$2,430.7	\$2,455.0
SAMHSA	\$181.0	\$181.0
Department of Veterans Affairs (VA)	\$1,160.4	\$1,204.1
HOPWA	\$375.0	\$393.0
Other domestic discretionary (e)	\$410.8	\$410.8
<b>Subtotal Discretionary</b>	<b>\$7,665.4</b>	<b>\$7,751.4</b>
Medicaid	\$6,070.0	\$6,340.1
Medicare	\$10,320.0	\$11,040.0
Social Security Disability Insurance (SSDI)	\$2,099.0	\$2,099.0
Supplemental Security Income (SSI)	\$580.0	\$580.0
Federal Employees Health Benefit (FEHB)	\$211.0	\$211.0
<b>Subtotal Mandatory</b>	<b>\$19,280.0</b>	<b>\$20,270.0</b>
<b>Total Domestic</b>	<b>\$26,945.4</b>	<b>\$28,021.4</b>

Source: Kaiser Family Foundation<sup>17</sup>

It is estimated that of the 1.1 million people living with HIV in the United States, 14 percent have yet to be reached with HIV testing and are therefore unaware of their HIV status.<sup>18</sup> In 2015, of those diagnosed with HIV in the United States, 73.4 percent were linked to HIV care, 57.2 percent were retained in care, and 59.8 percent had undetectable levels of virus in their bloodstreams (“viral suppression”), the best marker of successful HIV treatment.<sup>19</sup>

**Figure 1: HIV Care Continuum for People Diagnosed with HIV, 2015**



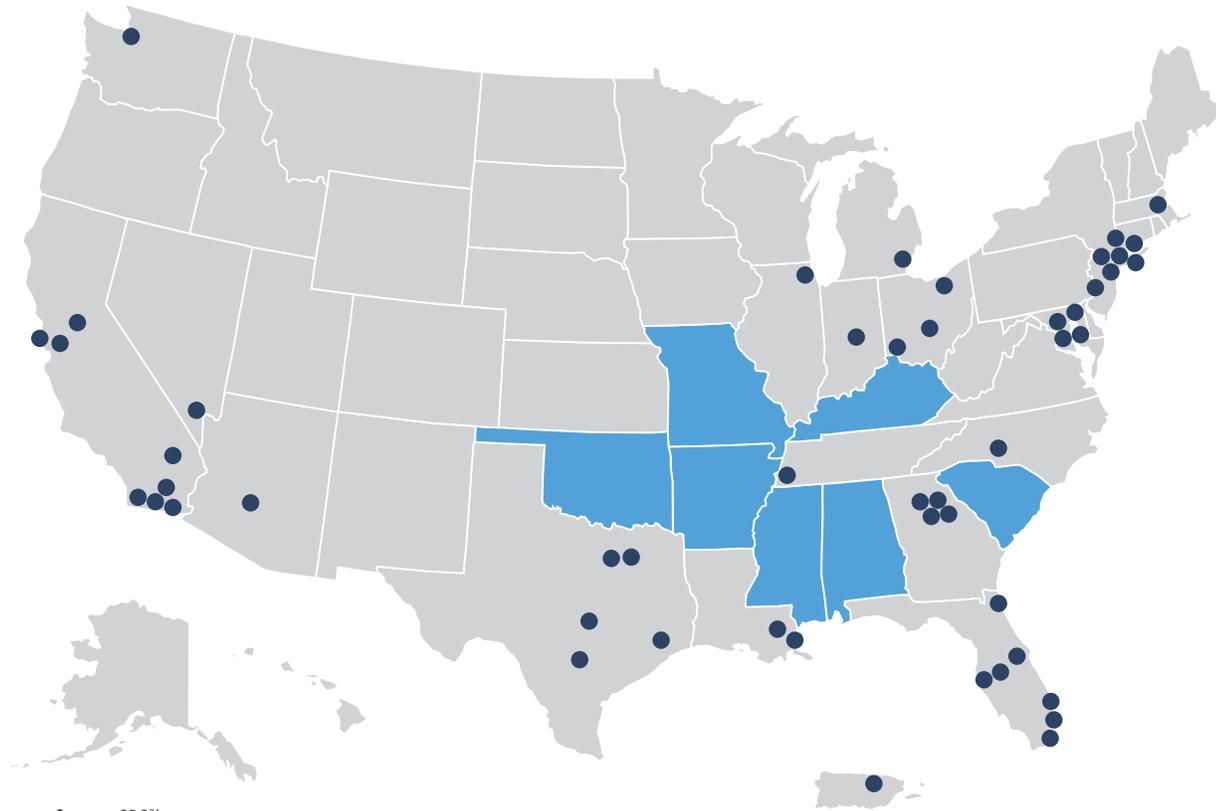
Source: CDC<sup>20</sup>

In his 2019 State of the Union address, the president announced a new federal commitment to end the HIV epidemic in the United States within 10 years. The administration subsequently released an official proposal to reduce new HIV infections by 75 percent in five years and by at least 90 percent in 10 years.<sup>21</sup> The plan relies on five key pillars: early diagnosis; rapid and effective treatment; evidence-based prevention, including PrEP; rapid response to new HIV clusters; and “HIV HealthForce” teams of local health workers responding in each jurisdiction.<sup>22</sup>

To meet its ambitious targets, the new federal strategy proposes to focus resources on the 48 counties with the highest rates of new HIV diagnoses, plus San Juan, Puerto Rico, and Washington, DC, as well as seven rural states that have heavy HIV burdens.<sup>23</sup>



**Figure 2: Target Jurisdictions for New Federal HIV Strategy**



Of the jurisdictions studied in this report, four are in counties targeted by the new federal plan: the Bronx (Bronx County), Seattle (King County), Las Vegas (Clark County), and Jacksonville (Duval County); and two more, Montgomery, Alabama, and Kansas City, Missouri, are in rural states that are part of the federal plan.

The implementation phase of the new plan began July 1, 2019, with \$1.5 million grants to four highly burdened jurisdictions to accelerate their local response.<sup>25</sup> CDC also announced a \$19.5 million planning grant program for the target jurisdictions, as well as a grant for a national technical-assistance provider, with awards to be announced by September 30, 2019.<sup>26</sup> The Health Resources and Services Administration has also released three funding opportunity notices for RWCA-funded jurisdictions to implement strategies to reduce new HIV infections in the areas targeted by the national initiative.<sup>27</sup>

# Project Objectives and Methods

## OBJECTIVES

The goals of this project were:

- To highlight new and emerging trends in the domestic HIV epidemic, with a focus on under-reported epidemics in the South, Midwest, and among particular risk groups; and
- To provide illustrative policy, financing, and public health program challenges and opportunities facing health departments, health systems, and community-based providers.

## METHODS

The BPC team purposefully selected eight diverse jurisdictions distributed geographically around the country from among the regions with the highest rates of HIV infection. The team sought to balance rural- and urban-focused epidemics; jurisdictions with enough cases to receive direct Ryan White Part A funds (see the Ryan White section for further discussion) and those with fewer cases; Medicaid expansion status; and political party of the legislature and governor. The current administration's announcement of greater support for specific jurisdictions came *after* BPC's selection process; Table 2 shows which of the selected jurisdictions are part of the new federal plan.

BPC undertook a quantitative analysis summarizing key epidemiologic data and trends from each locality, including geospatial data/maps of HIV prevalence, select service delivery points, and other variables. In each jurisdiction, the team conducted interviews with local or state health officials and HIV service providers (16 total interviews, see Appendix). BPC developed key themes from the literature searches and the transcribed interviews, and described illustrative examples of select policy, financing, institutional/systems, and public health program challenges and innovations.

**Table 2: Characteristics of Jurisdictions Selected for Inclusion in the Report**

Jurisdiction	County ranking, newly diagnosed with HIV per 100,000, 2016-AIDSVu	Absolute number of people living with HIV (county), 2015-AIDSVu	State ranking, prevalence per 100,000, 2015-AIDSVu	U.S. region	Ryan White Part A recipient?	Medicaid expansion state	State legislative control	Governor	Focus region of Trump administration HIV Plan?
Seattle, WA	350	6,484	30	Northwest	Yes, EMA	Yes	DEM	DEM	Yes, in top 48 counties
The Bronx, NY	31	26,666	2	Northeast	Yes, EMA	Yes	DEM	DEM	Yes, in top 48 counties
Kansas City, MO	162 (Jackson County, MO)	2,677	26 (MO)	Midwest	Yes, TGA	No	REP	REP	Missouri is 1 of the 7 rural states
Jacksonville (Duval County, FL)	49	5,788	5	South	Yes, TGA	No	REP	REP	Yes, in top 48 counties
Clark County, NV	126	7,422	14	West	Yes, TGA	Yes	DEM	DEM	Yes, in top 48 counties
Scott County, IN	3	150	31	Midwest	No	Yes	REP	REP	No
Richmond, VA	10	2,077	20	Mid-Atlantic/South	No	Yes	REP	DEM	No
Montgomery, AL	21	1,343	21	South	No	No	REP	REP	Yes, Alabama is 1 of the 7 rural states



# Jurisdiction and Provider Profiles

The eight jurisdictions addressed in this report reflect a broad range of settings and HIV epidemiology. This section outlines the state of HIV in each and highlights the role of the selected provider in addressing HIV. Corresponding maps (data in figures 4 to 11, courtesy of AIDSVU) depict the HIV prevalence rates for individuals ages 13 and older in each jurisdiction where data availability and population size permit. Counties and zip-code tabulation areas are displayed as “Suppressed” where prevalence is too low to protect the identify of individuals living with HIV.<sup>28</sup>

## THE BRONX, NEW YORK, AND MONTEFIORE MEDICAL CENTER

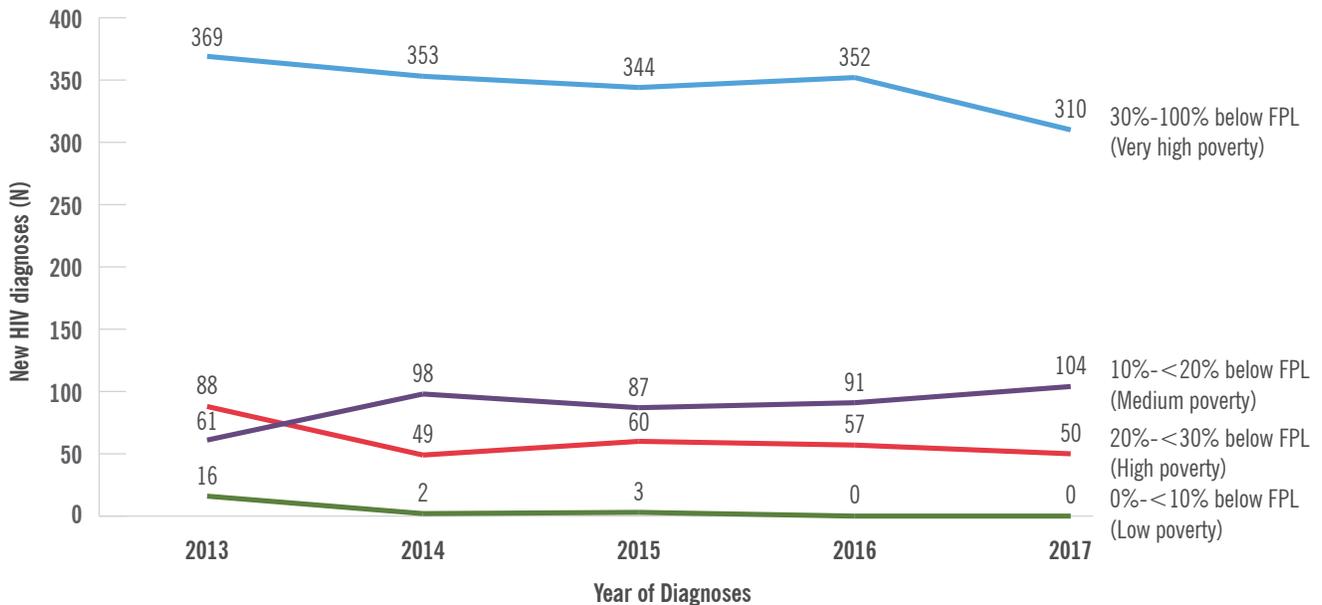
The Bronx, one of New York City’s five boroughs, is the third most densely populated county in the United States. It has a highly diverse population of over 1.4 million people,<sup>29</sup> representing 17 percent of New York City’s total population.<sup>30</sup>

The Bronx has been hit hard by HIV for decades.<sup>31</sup> Today, over 2.2 percent of Bronx residents are living with HIV (see Figure 4 for prevalence rates). From 2013 to 2017, rates of new HIV diagnoses in the Bronx declined overall but increased among people ages 30 to 39.<sup>32</sup> Blacks and Latinx, who make up most of the population in the Bronx, continue to account for most new HIV diagnoses.<sup>33</sup>

The Bronx is part of the New York Eligible Metropolitan Area, which receives direct Ryan White Part A funding to support services for income-eligible, uninsured or underinsured people with HIV.<sup>34</sup> New York City is also one of seven cities receiving direct HIV-prevention funding from CDC, and Bronx County—along with New York (Manhattan), Kings County (Brooklyn), and Queens County—is targeted to receive resources under the new federal initiative.

In the Bronx, as in many parts of the nation, HIV is strongly associated with poverty, with the number of new HIV diagnoses highest in neighborhoods with extreme severe poverty.<sup>35</sup>

**Figure 3: Number of New HIV Diagnoses by Area-Based Poverty Level in the Bronx**



**Between 2013 and 2017, the number of new HIV diagnoses was highest in neighborhoods with very high poverty in the Bronx.**

Source: NYC Department of Health and Mental Hygiene<sup>36</sup>

There are a broad range of services available in the Bronx for people living with HIV.<sup>37</sup> The largest provider is the AIDS Center at Montefiore Medical Center, which offers primary medical care, counseling, testing, mental health care, HCV co-infection treatment, dermatology, nephrology, substance use disorder services, social work case management, pharmacy, food pantry, and other services.<sup>38</sup> The AIDS Center serves approximately 3,400 people living with HIV.<sup>39</sup> Montefiore also has an adolescent HIV program, serving some patients exposed perinatally but primarily those who became HIV-positive as youth; the center also provides HIV programs at community clinics around the Bronx and at its substance use treatment program (methadone) sites.<sup>40</sup>

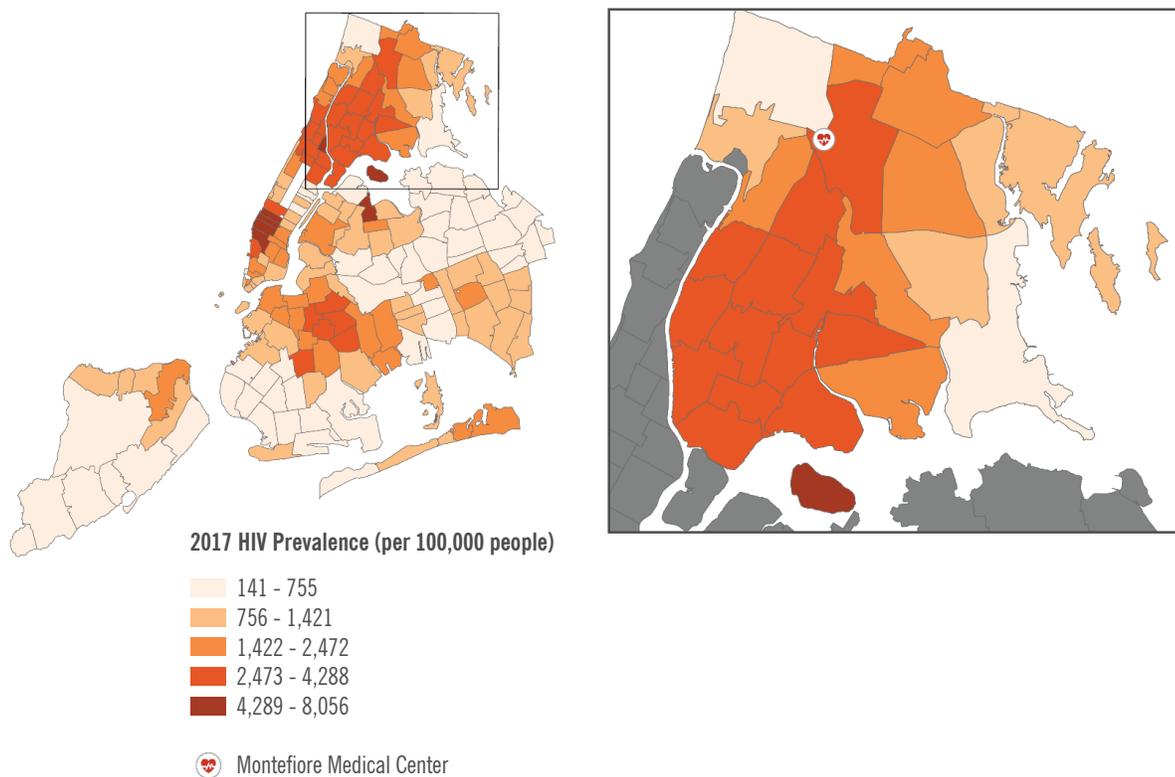
To serve harder-to-reach patients in a sex-positive and affirming environment, the Montefiore AIDS Center opened the Oval Center at Montefiore, a sexual health clinic that offers STI screening and treatment, HIV testing, pre- and post-exposure prophylaxis (PrEP and PEP), contraceptive and fertility care, LGBTQ health services like hormonal care, and HIV care to LGBTQ individuals ages 16 to 30—all with the goal of offering services across “the spectrum of risk.”<sup>41</sup>

Despite the attention and resources directed to HIV in the Bronx, poverty and other structural factors continue to pose enormous challenges to prevention and treatment:

“The Bronx is the poorest urban county in the United States. . . .That is definitely affecting our patients’ ability to navigate things, to stay on insurance plans, to stay in care, to get places, to have adequate food, to not be dependent on others, to find adequate shelter. Those are major issues for our patients. . . . Also, family structures are a big challenge, especially among LGBTQ individuals, . . . particularly when they’re dealing with poverty and sometimes poor educational status [or] immigration and undocumented status. Those all exacerbate each other.”

—Dr. Barry S. Zingman, Montefiore AIDS Center

**Figure 4: HIV Prevalence in the Bronx, New York, 2017**



Value could be inflated if correctional institution is located in this area.



## CLARK COUNTY, NEVADA AND AID FOR AIDS NEVADA

Las Vegas is the county seat and population center of Clark County, Nevada. In 2017, there were an estimated 9,834 people living with HIV in the city of Las Vegas (see Figure 5 for prevalence rates).<sup>42</sup> As in most of the country, prevalence is higher among African Americans, with prevalence among black males 2.3 times higher than among white males, and among black females 7.7 times higher than white females.<sup>43</sup>

Las Vegas receives Ryan White Part A funds, with the Las Vegas Transitional Grant Area (TGA) serving Clark County as well as neighboring portions of Nevada and Arizona.<sup>44</sup> Clark County is one of the 48 counties targeted for greater resources under the new federal HIV strategy.<sup>45</sup>

The Southern Nevada Health District (SNHD) is a large local health authority, serving a region that is coterminous with Clark County. The SNHD provides traditional public health services, as well as a broad range of clinical services, including HIV care, family planning, STI care, tuberculosis care, and immunization, through clinics across the county.<sup>46</sup> SNHD's Office of AIDS provides counseling, evaluation, case management, outreach, and prevention programs, supported in part by Ryan White Part B funds from the state and Part A funds from Las Vegas's status as an Eligible Metropolitan Areas (EMA).<sup>47</sup> The SNHD pharmacy also serves as the pharmacy for the Ryan White AIDS Drug Assistance Program (ADAP) for the state and has a mobile van to provide oral health and immunization services to some of the more remote rural portions of the county.<sup>48</sup>

AID for AIDS Nevada (AFAN) is the largest and oldest AIDS service organization in Nevada, providing advocacy and support services for about 1,300 clients per year across southern Nevada.<sup>49</sup> AFAN's services include medical case management, medical transportation, education and prevention, housing assistance, mental health services, nutritional services, and HIV testing.<sup>50</sup> The organization receives a mix of funding from Ryan White Part A and B, and from the Housing Opportunities for People with AIDS program, in addition to private donations.<sup>51</sup>

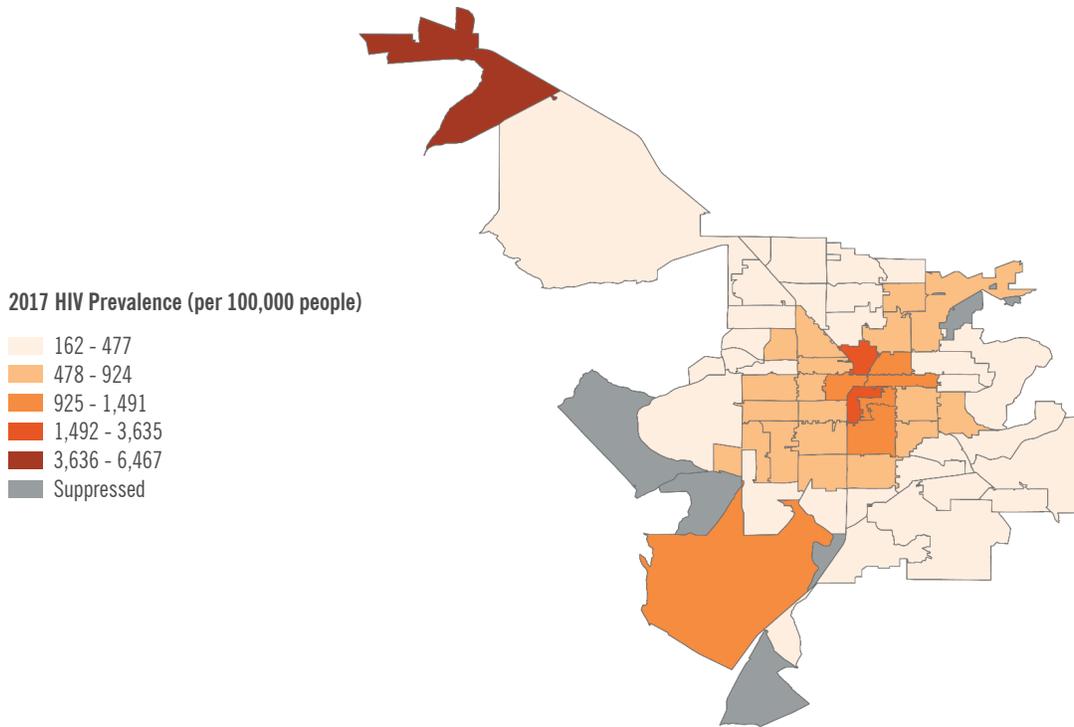
Las Vegas's population has grown significantly in the past decade, and hundreds of thousands of visitors come to the city every year, creating a transient population and particular social challenges for people living with HIV:

"I think some of the challenges that we have . . . are some clients that transfer from out of state, and they still don't have an address that is stable, so we can't verify a lot of the stuff. You have to remember that this is still a very transient state, and especially the city. People come here and it's cheaper than in many other places. . . . They come here and when they come here, oftentimes, they stay in these transition places where they're not able to get settled here and then they have to stay in couch-surfing for a while . . . or they live in their car."

—*Antioco Carrillo, AFAN*

Along with other services, AFAN helps clients living with HIV move toward some level of housing stability so they are better situated to address their health.

**Figure 5: HIV Prevalence in Las Vegas, Nevada, 2017**



## **DUVAL COUNTY, FLORIDA, AND JACKSONVILLE AREA SEXUAL MINORITY YOUTH NETWORK (JASMYN)**

Florida is one of the new epicenters of the HIV epidemic, third behind only Washington, D.C. and Georgia in rates of new diagnoses. Across the state, seven counties are experiencing high enough rates to be considered under the new federal HIV strategy.

Jacksonville, Florida, the seat of Duval County in the northeast corner of the state, reflects many of the factors contributing to Florida’s epidemic, as well as those of the South overall. As of 2017, there were an estimated 7,258 people living with HIV in Jacksonville (see Figure 6 for prevalence rates); while African Americans comprise 30 percent of the city’s population, they make up nearly two-thirds of people living with HIV.<sup>52</sup> Unlike many other jurisdictions in the country, Jacksonville has seen rising rates of new HIV diagnoses in recent years.<sup>53</sup>

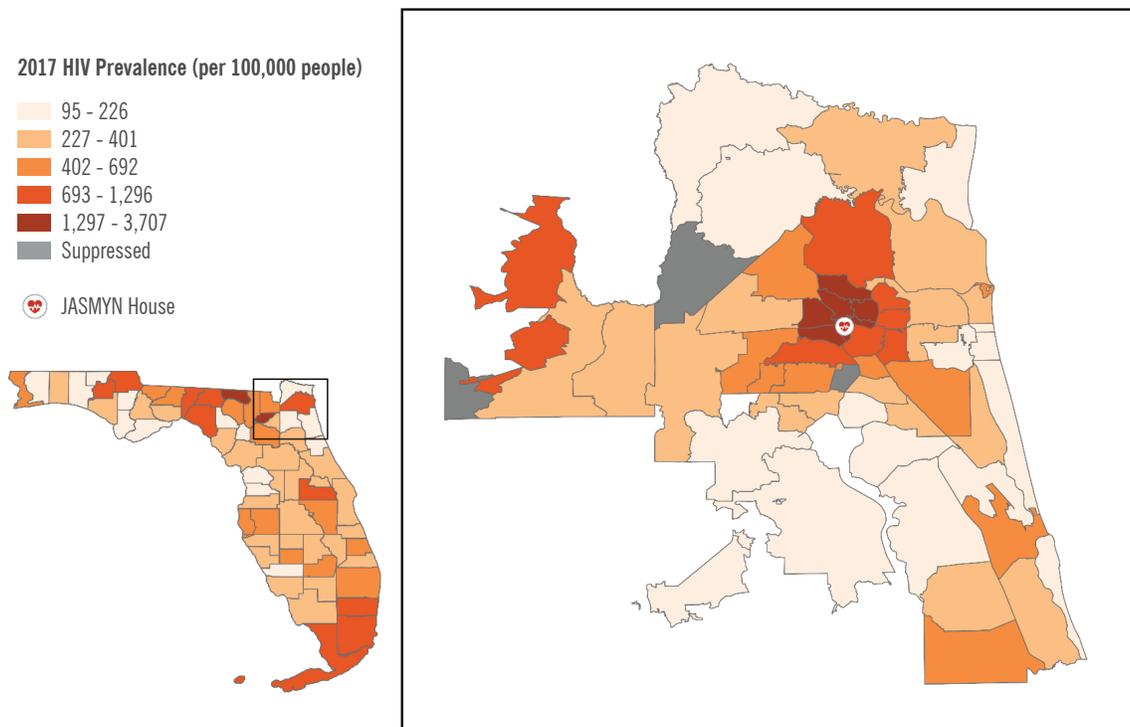
Jacksonville receives direct Ryan White Part A funds as a TGA. It includes all of Duval, Clay, Nassau, and St. Johns counties, which vary from urban to rural.<sup>54</sup> Joseph Mims, the HIV/AIDS program administrator for the Florida Department of Health in Duval County, described a “tight network” of collaborating agencies and planning councils that work to ensure people living with HIV can access a seamless set of services.<sup>55</sup>

One of the many providers in the region, the Jacksonville Area Sexual Minority Youth Network, or “JASMYN,” offers services for LGBTQ youth ages 13 to 23.<sup>56</sup> JASMYN offers a range of youth development programs, along with HIV testing, a weekly sexual health clinic, and care coordination.<sup>57</sup> The organization receives funding from a range of sources that currently includes a five-year CDC grant as well as a partnership with Duval County schools to promote safe schools.<sup>58</sup>

JASMYN has a growing focus on housing services. As discussed in the section on unmet needs (see page 34), housing is closely linked both to HIV risk and to the ability of people living with HIV to adhere to care and treatment. JASMYN is also currently developing a new building as a “front door” for case-management services and for services such as showers and lockers for homeless youth.<sup>59</sup> Across the United States, LGBTQ youth are particularly likely to become homeless because of issues related to family acceptance; in Jacksonville, a JASMYN staffer estimates, as many as 60 percent of homeless youth identify as LGBTQ.<sup>60</sup>



**Figure 6: HIV Prevalence in Jacksonville, Florida, 2017**



## KANSAS CITY, MISSOURI AND KC CARE HEALTH CENTER

Kansas City is the largest city in Missouri, making up part of the Kansas City metropolitan area that crosses the Missouri-Kansas line. It has a population of nearly half a million people.<sup>61</sup> In 2017, in the Kansas City HIV care region (which includes seven Missouri counties), there were 3,817 people living with HIV; over 84 percent were male.<sup>62</sup>

The HIV Services Division of the Kansas City Health Department (KCHD) receives Ryan White Part A funds for the Kansas City TGA, which includes seven counties in Missouri and four in Kansas.<sup>63</sup> Within the TGA, the RWCA can be used to help pay for premiums and cost-sharing assistance for people living with HIV who are insured through their state marketplaces. Because both Kansas and Missouri are non-expansion states for Medicaid, RWCA funds also support care for low-income people living with HIV who fall into the Medicaid gap.

KCHD also receives CDC funding for HIV prevention through the Missouri Department of Health and Senior Services and through the U.S. Department of Housing and Urban Development, which funds the Housing Opportunities for People with AIDS program and the Shelter+ Care program. KCHD contracts with a variety of AIDS service organizations, community-based organizations, and federally qualified health centers to provide prevention, care, and housing services across the region.<sup>64</sup> The department is also the local surveillance hub, getting direct reports from providers and labs.

The KC CARE Health Center was an early provider of HIV care in the region.<sup>65</sup> It has evolved into a full-service federally qualified health center, offering a broad range of primary care services, including HIV care at three sites across the city; one location also provides pharmacy services.<sup>66</sup> For people living with HIV, KC CARE provides primary care, dental, psychiatry, mental health therapy, substance use disorder counseling, peer support for treatment adherence, case management, and linkage to care services. KC CARE also offers HIV education and testing, PEP and PrEP, and needle-exchange services.<sup>67</sup> In addition, it serves as the local performance site for the Midwest AIDS Education and Training Center, collaborating in capacity-building efforts related to HIV across Missouri.<sup>68</sup>

KC CARE serves approximately 1,400 people living with HIV, relying on a mix of funding that includes RWCA and CDC grants and insurance reimbursement.<sup>69</sup> Largely due to the lack of Medicaid expansion in the state, approximately 58 percent of the center's overall patient population is uninsured or self-paying.<sup>70</sup>

As described by Chief Operating Officer Dennis Dunmyer, KC CARE social workers respond to HIV-positive tests in the region:

“It could be two o’clock in the morning, somebody comes in for some medical emergency, gets an HIV test as part of that process. You get a preliminary positive. Our staff get paged, and we’ll respond in real time even at two in the morning to come talk to that person about, ‘Here’s what we need to do in terms of getting a confirmatory test,’ because a lot of this is rapid technology. . . . From there, ‘What are your options? Do you have insurance? No insurance? Here are the providers.’ This is what Ryan White services are: . . . ‘Here’s how to access ADAP or all these other resources.’”

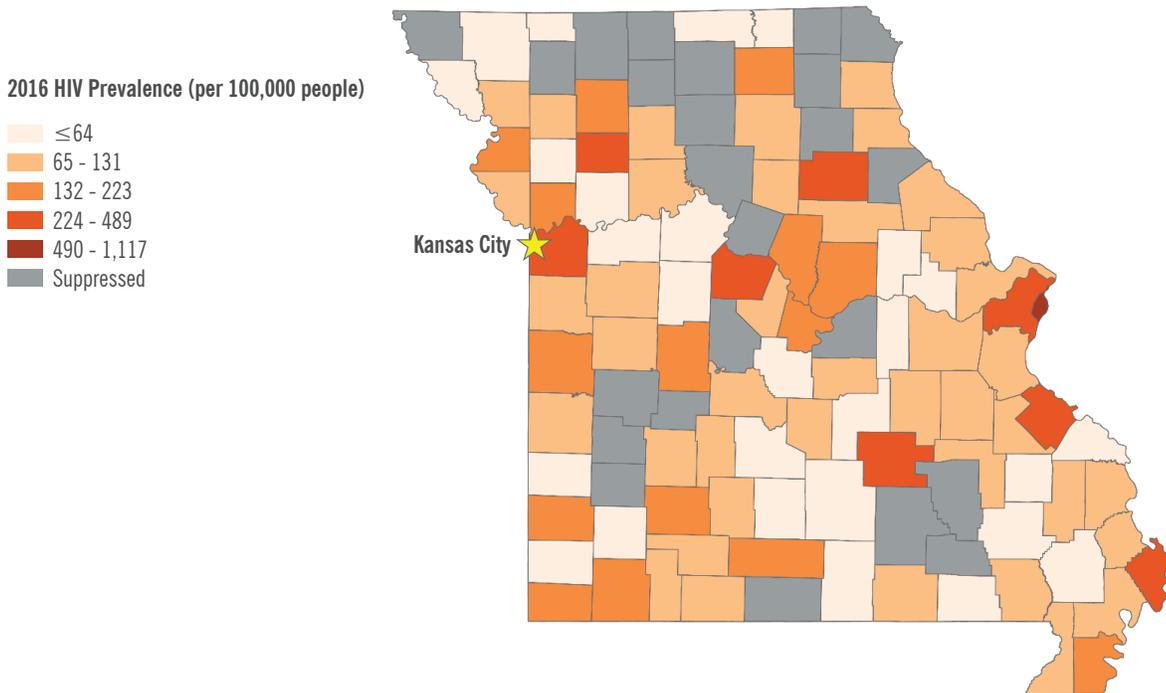
—Dennis Dunmyer, KC CARE

As a federally qualified health center offering a range of primary care and other clinical services, KC CARE can offer a streamlined, “one-stop” location for people living with, or at risk of, HIV:

“When people come to us for care, typically, we’re able to get people from initial preliminary positive to an appointment with a physician well inside of a week. About five to seven days is the outside of when we can accomplish that—and usually, that is when it’s somebody coming from somewhere else. There are a lot of [KC CARE’s preliminary] positives [who] either come from our own prevention team or from our own internal routine testing. We just walk them down to the lab, get a confirmatory, have them talk to a nurse, and come back in a couple of days to talk to the physician. Usually, [they’re] starting meds also within that five- to seven-[day] window.”

—Dennis Dunmyer, KC CARE

**Figure 7: HIV Prevalence in Kansas City, Missouri, 2016**



## MONTGOMERY, ALABAMA, AND MEDICAL ADVOCACY AND OUTREACH

Montgomery is the capital of Alabama and the county seat of Montgomery County. The city has a population of approximately 200,000,<sup>71</sup> about 59 percent African American and 37 percent white; just over 21 percent of the population lives in poverty.<sup>72</sup> As of 2016, 750 of every 100,000 people in Montgomery County were living with HIV, and 71 people were newly diagnosed in 2017.<sup>73</sup> Prevalence of HIV among African Americans is over four times higher than among whites.<sup>74</sup> Figure 8 shows overall HIV prevalence across the state, highlighting the elevated rates in Montgomery County.

Montgomery's HIV epidemic is not large enough for the city to receive direct Ryan White Part A funds. People living with HIV in the city can, however, benefit from services funded by Part B and ADAP funds coordinated by the state; the state also coordinates CDC prevention dollars statewide, including for services in Montgomery.

Medical Advocacy and Outreach (MAO), a leading HIV service provider in Montgomery, receives Ryan White Part C funds and coordinates with a Part D provider in Birmingham to serve women and infants.<sup>75</sup> MAO clients can get HIV testing and treatment, PrEP services, behavioral health services, case management, pharmacy, dental care, and maternal/infant services.<sup>76</sup> With multiple clinic locations and a range of partners, MAO provides HIV services in rural areas across southern Alabama.

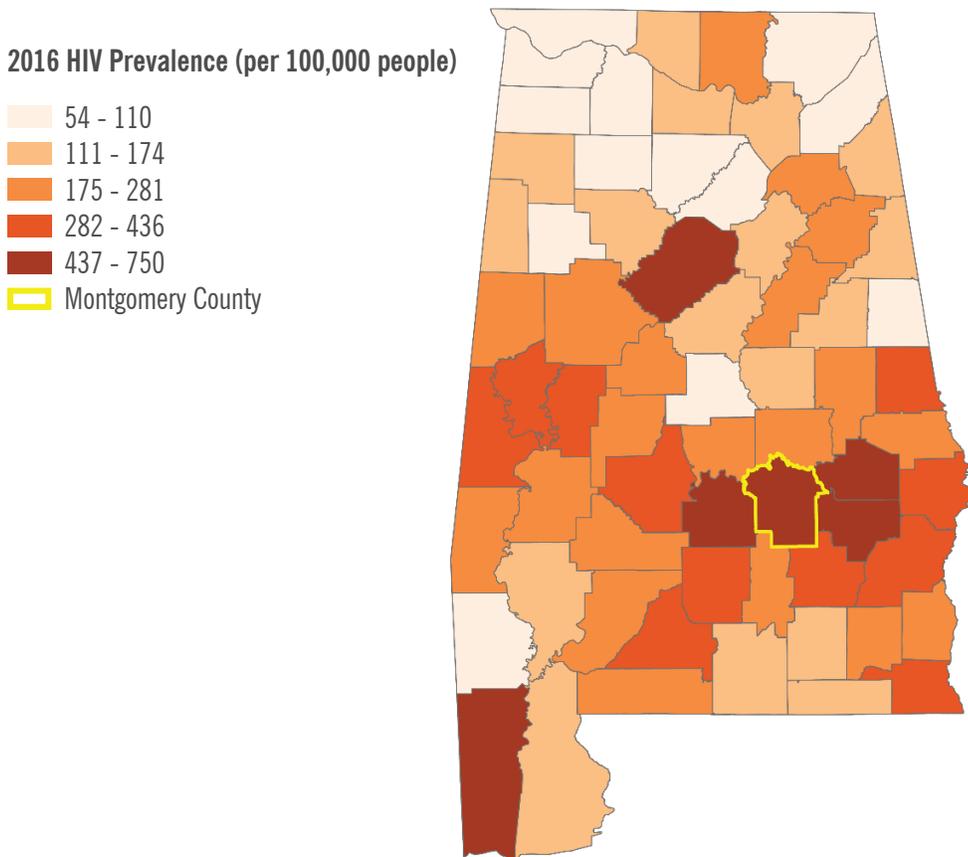
MAO has been innovative in developing telehealth services to expand access to HIV services for rural populations. Three clinics serve as hubs, with 10 satellite sites—including federally qualified health centers and public health departments—spread across the southern portion of the state.<sup>77</sup> A nurse practitioner or a physician at the hub works with nurses at the satellite sites to provide comprehensive care, including complete exams and behavioral health services, as well as a newly launched tele-legal services project.<sup>78</sup>

Efforts to address HIV in Montgomery are taking place against a backdrop of poverty, limited access to health care, and numerous challenges related to social determinants of health:

“Alabama is not only rural, but it's poor. The way I've tried to describe it is stealing a phrase from Dr. Paul Farmer called ‘the synergy of plagues,’ meaning we have a whole list of things that individually we know create poor health outcomes, but they are synergistically bad on health outcomes. So, we have very poor health literacy rates. We have very poor education in rural areas. We have absolutely no public transportation in rural areas. . . . We have high numbers of underserved medical areas, . . . not just for specialty care but also for primary care. Because in large part of not expanding Medicaid, we're having rural hospitals close. . . . We have very high rates of stigma around HIV in rural counties. We have high uninsured rates. . . . We have very, very limited mental health service coverage in the state. . . . We have very poor access in the state to substance abuse treatment. . . . We have very poor access for hepatitis C treatment. . . . All of those things . . . make it difficult to address those issues.”

—*Dr. Laurie Dill, Medical Advocacy and Outreach*

**Figure 8: HIV Prevalence in Montgomery County, Alabama, 2016**



## **RICHMOND, VIRGINIA AND CAPITAL AREA HEALTH NETWORK**

Within the Richmond metropolitan statistical area, 4,933 people were living with HIV as of 2017 (see Figure 9 for prevalence rates).<sup>79</sup> Three-quarters were men, and two-thirds were African American, though African Americans make up only one-third of the area's total population.<sup>80</sup> At 24 percent, Richmond's poverty rate is twice that of the United States overall.<sup>81</sup>

Richmond's City Health District is a local health agency under the jurisdiction of the centralized state health department. The City Health District's primary HIV focuses are on prevention, testing, and linkage to care.<sup>82</sup> The department runs an STI/HIV clinic with testing, treatment, and counseling services available, along with case management and linkage to HIV medical care.

Richmond's CDC funds for HIV prevention come primarily through the state. Because Richmond is not a Ryan White Part A jurisdiction, its care and treatment dollars are also distributed via the state.

Capital Area Health Network (CAHN) is one of the primary providers of HIV care in Richmond. As a federally qualified health center, CAHN offers comprehensive services, including primary care, mental health services, dental care, and substance use treatment. CAHN offers care regardless of insurance status and can serve people living with HIV at no charge. CAHN has six locations across the Richmond area, as well as a mobile unit.<sup>83</sup>

In addition to clinical services for patients supported with state Ryan White Part B dollars, CAHN provides other RWCA-funded services, including case management and emergency financial assistance.<sup>84</sup> CAHN also delivers PrEP, relying on a combination of patient insurance, when available, and pharmaceutical-manufacturer assistance programs.

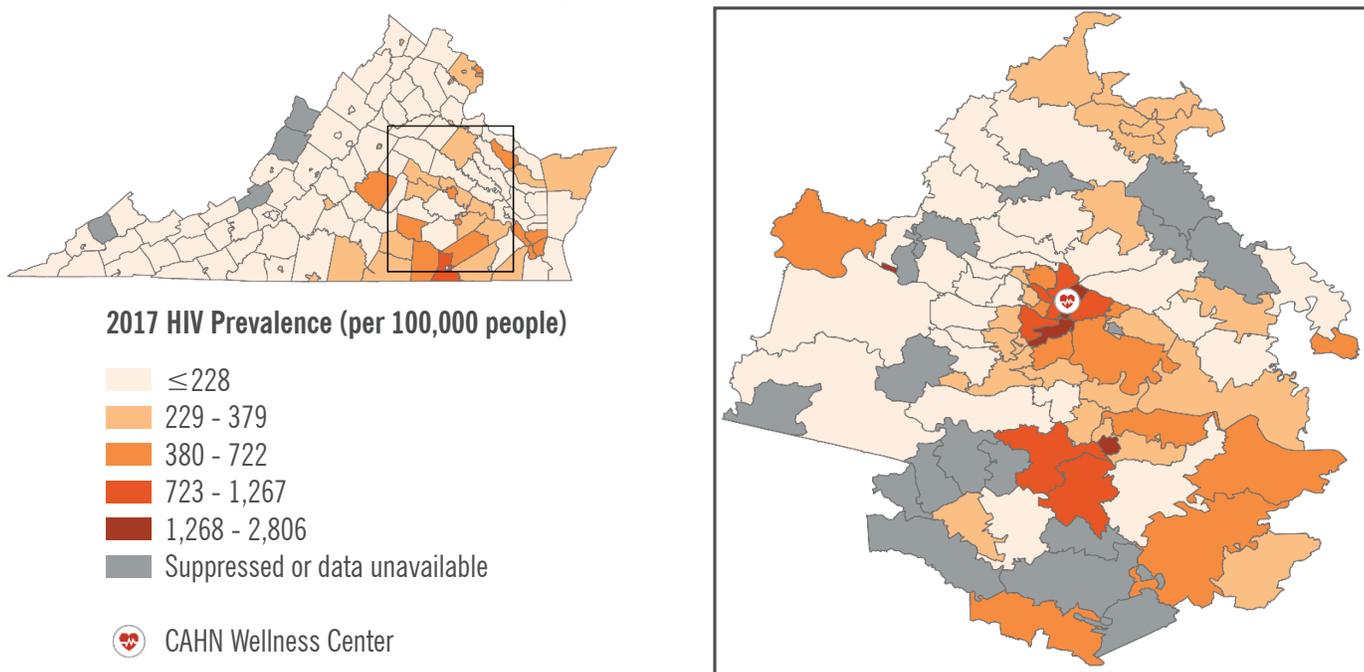
The ACA changed insurance options for CAHN’s patients significantly. Once individual insurance became available through the marketplaces, the state’s ADAP program was able to support premiums for people living with HIV. As of 2019, Virginia is also in the process of expanding its Medicaid program, which may impact as many as 40 percent of CAHN’s patients living with HIV.<sup>85</sup>

Since CAHN does not exclusively focus on HIV services, its patients are able to avoid some of the privacy or stigma concerns associated with obtaining HIV care in a relatively small community:

“Richmond’s a pretty small place. . . . You walk into people that you know, and . . . they don’t want that, so therefore they won’t go. We hope to continue with the environment that we have here where nothing’s labeled HIV, . . . you don’t know why that patient is sitting in the waiting room to be seen.”

—Phyllis Mann, Capital Area Health Network

**Figure 9: HIV Prevalence in Richmond, Virginia, 2017**



## SEATTLE, WASHINGTON, AND THE MADISON CLINIC AT HARBORVIEW MEDICAL CENTER

Seattle, the county seat of King County, is home to approximately 745,000 people.<sup>86</sup> There is less poverty there than in many of the other jurisdictions profiled in this report, with less than 10 percent of the city’s population living under the poverty line.<sup>87</sup>

Seattle and King County have been at the forefront of meeting the World Health Organization’s 90/90/90 goals for HIV: 90 percent of people with HIV knowing their status; 90 percent of people who know their status linked into care; and 90 percent of people linked into care retained in care. King County has met or exceeded the World Health Organization’s 90/90/90 goals for the past three years, and achieved 85 percent viral suppression in 2017.<sup>88</sup> In addition, the county’s HIV diagnosis rate dropped by 51 percent from 2008 to 2017.<sup>89</sup> However, disparities remain: HIV prevalence and risk are higher among black and Latinx MSM than white MSM, and viral suppression rates are lower among U.S.-born blacks, black MSM, and people who inject drugs.<sup>90</sup>

Seattle receives direct Ryan White Part A funding as part of a TGA that includes King County and two neighboring counties.<sup>91</sup> The city and King County share a combined metropolitan health department,<sup>92</sup> which administers RWCA funding and receives funding through the state to conduct prevention, surveillance, and other HIV and STI activities, including an STI clinic.<sup>93</sup> The department has also worked closely with the state department of health on developing and implementing the End AIDS Washington strategic plan.<sup>94</sup>

Because of historically high levels of insurance coverage as well as the impact of the ACA and Medicaid expansion, most people living with HIV in Seattle can access health insurance.<sup>95</sup> The RWCA provides wrap around coverage as well as support services that address barriers to care.

Seattle and King County conduct robust prevention efforts among people who inject drugs, distributing more than 7 million syringes in 2017 and supporting access to buprenorphine treatment.<sup>96</sup> That year, only 4 percent of new HIV diagnoses were among people who inject drugs who were not also MSM.<sup>97</sup> However, in 2018, public health officials identified an HIV transmission cluster among heterosexual people who use drugs and are homeless.<sup>98,99</sup> This cluster may reflect a geographic gap in the availability of syringe services and also may reflect the need for “low-threshold” HIV care in that part of the city.<sup>100</sup>

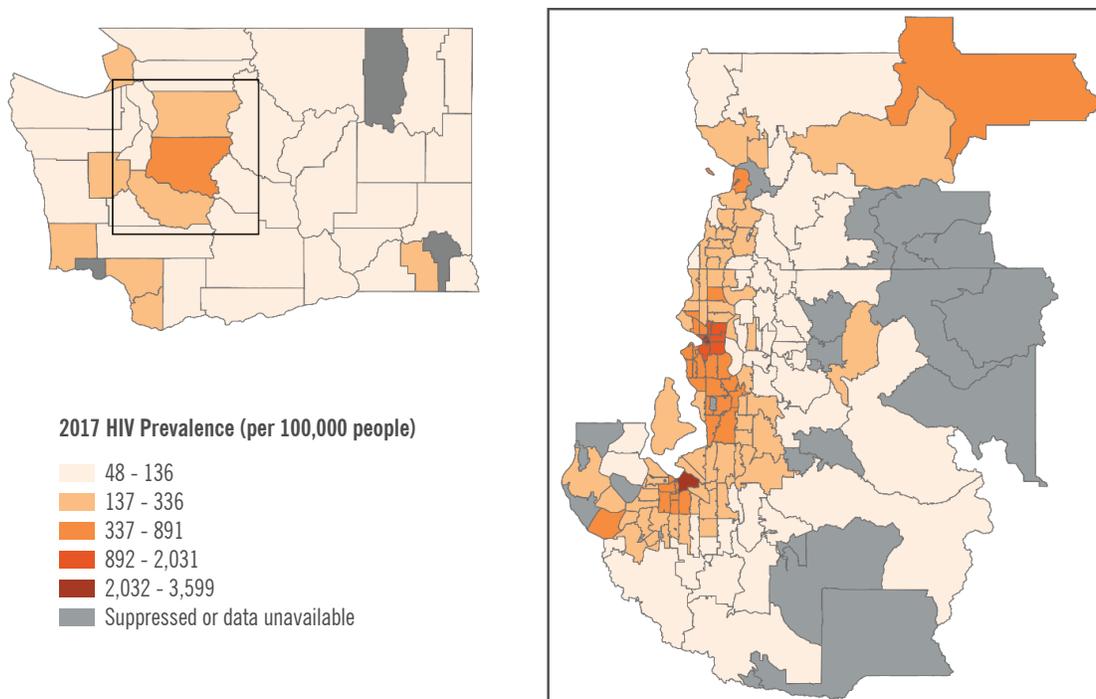
Harborview Medical Center’s Madison Clinic, the largest HIV care facility in the region, serves 3,000 clients with HIV specialty and primary care, behavioral health care, and social work, as well as PEP and PrEP counseling for people who are HIV-negative. The clinic’s services are available at the Medical Center as well as at several satellite locations and a mobile unit.<sup>101</sup> The Madison Clinic is also part of a network of clinic sites for NIH clinical research trials. Harborview receives Ryan White Parts B, C, and D funding, as well as state funding.

Together, Seattle, King County Health, and Harborview run the Max Clinic, a high-needs clinic with intensive services and resources available for patients who have challenges engaging in standard medical care.<sup>102</sup> The Max Clinic provides:

- High-intensity outreach support, with a team of nonmedical and medical case managers;
- Low-threshold incentivized care, including walk-in access to primary HIV and urgent care, case managers, and psychiatrists;
- Incentives, such as food, small amounts of cash, or cell phones to support patient communication;
- Coordinated HIV care across the Max Clinic, the Madison Clinic, and the public STI clinic located at Harborview; and
- Collaboration, with community-based organizations as well as the King County jail release program.<sup>103</sup>

Despite high rates of comorbidities and complex barriers to care, 80 percent of Max Clinic patients achieved viral suppression at one point in, or for a sustained portion of, 2016.<sup>104</sup>

**Figure 10: HIV Prevalence in Seattle, Washington, 2017**



## SCOTT COUNTY, INDIANA, AND DR. WILLIAM COOKE, FOUNDATIONS FAMILY MEDICINE

Prior to 2014, rural Scott County, Indiana, had averaged fewer than five new HIV cases per year. By then, like much of the nation, Scott County and the surrounding region were experiencing a surge in opioid use, with people in the area favoring a pain medication called Opana that could be crushed and injected.<sup>105</sup> Health officials had already observed increases in HCV, another blood-borne infection also transmissible via shared needle use.<sup>106</sup>

A new cluster of HIV diagnoses in January 2015 quickly led health officials to identify an unprecedented outbreak. As new diagnoses rose, the Indiana Department of Health and CDC became involved. Ultimately, 215 HIV infections were diagnosed in the outbreak, out of a total county population of 24,000. Cases were concentrated in white young adults, and largely associated with injection drug use and with transactional sex for drugs or money.<sup>107</sup> As one resident told *The New York Times*, “Everyone we grew up with got H.I.V. in a matter of months.”<sup>108</sup>

Two months after the HIV outbreak was identified, then-Governor Mike Pence signed an order permitting the distribution of clean syringes in Scott County, and eventually the rate of new infections subsided.<sup>109</sup>

Experts have argued that earlier implementation of syringe services and other interventions could have prevented or mitigated the outbreak and that Scott County’s experience in 2015 should serve as a lesson for counties facing similar outbreak risks.<sup>110</sup> Subsequent to identification of the Scott County outbreak, CDC conducted an analysis of the factors that would put similar jurisdictions at high risk of HIV or HCV outbreaks, and identified a total of 220 counties across the country.<sup>111</sup>

Today, Scott County’s health department has established a range of HIV-prevention and -treatment programs.<sup>112</sup> Routine testing is offered in the department’s offices five days per week, and testing is available in a mobile unit, recovery treatment centers, and the local jail. The department partners with a clinic on a bimonthly basis to offer a one-stop shop for care coordination, case management, and referrals to an infectious disease doctor.

Because Indiana has expanded Medicaid, nearly all people diagnosed with HIV in the county are able to gain immediate access to comprehensive health coverage.

The department runs a needle-exchange program—now one of nine in the state—with CDC funding from the state health department. Because CDC funds cannot be used to purchase syringes, an AIDS service organization based in Indianapolis supplies syringes to programs around the state. In addition, three providers in the county prescribe PrEP for HIV prevention, though barriers to uptake persist.

Dr. William Cooke is a private primary care physician in Austin, Indiana, and is the primary provider of HIV clinical services in Scott County. He began serving patients with HIV during the outbreak and continues to offer HIV care in addition to HCV and substance use disorder treatment services. His team at Foundations Family Medicine includes another physician, three nurse practitioners, and a physician’s assistant, each certified in family medicine but also expert in a range of areas to serve the needs of Scott County, which, like many rural areas, lacks adequate specialty care. Cooke also employs a peer recovery specialist and a public health nurse who engage in health promotion and outreach, including on the practice’s mobile HIV testing unit.

The 2015 HIV outbreak posed major challenges to Cooke’s clinic, but he was driven to serve the newly diagnosed:

“It was devastating that year. Growing up in Indiana, I was born the same year and month—one day apart from—Ryan White. I watched what was happening with him and kind of felt connected. . . . I wanted to make sure that I carried that on. When this outbreak occurred, I was shocked that people were still responding with the same sort of stigma from the ’80s. . . . People knew that I had stepped up to offer care for HIV, and we were getting angry phone calls. . . . We were seeing about 14,000 visits a year. We were looking at about 150-180 HIV patients. It was a very small minority, but I felt it was very important. It took a big sacrifice, losing a fair amount of business early on.”

—Dr. William Cooke, Foundations Family Medicine

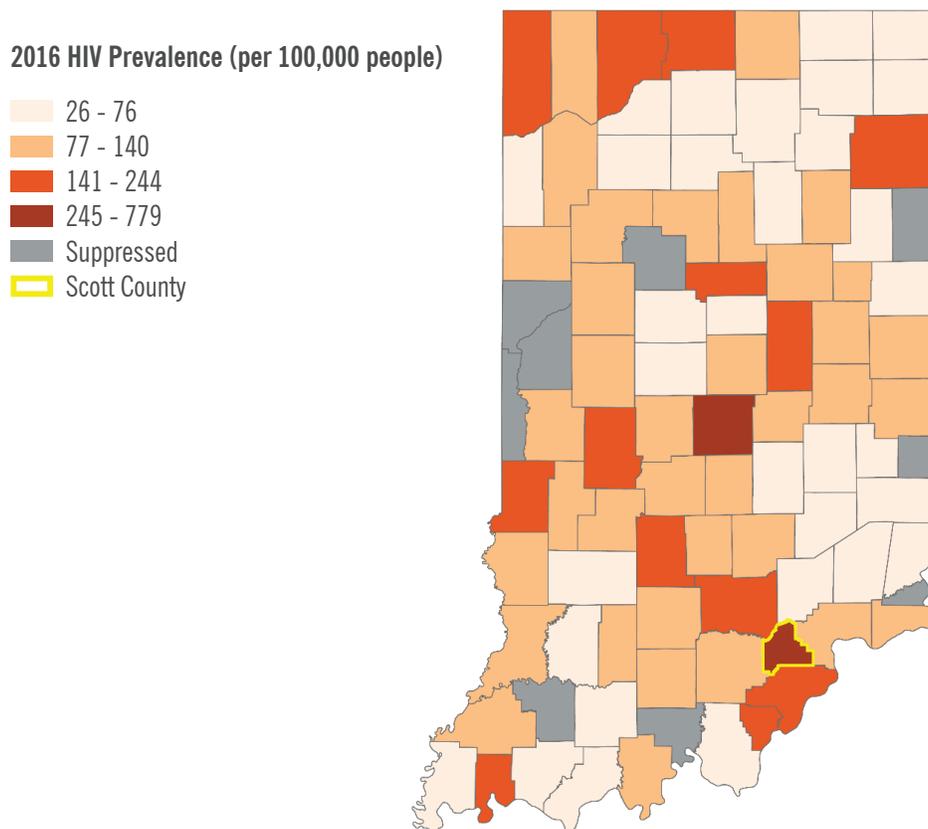
Today, much of that stigma has receded. However, among his patients, Cooke still sees a mix of social determinants that drive vulnerability to HIV and hinder access to services. Major challenges include transportation, social isolation, and a lack of social-service programs, including homeless shelters. Further, he notes, criminalization and stigma surrounding drug use exacerbate isolation and decrease people’s willingness to seek testing and services.

When asked his advice for health officials and providers in other counties at high risk of HIV and HCV outbreaks, Cooke said:

“Prevention is pennies versus responding to an outbreak. They will definitely wish they had done something, after the fact. The opportunity is now.”

—Dr. William Cooke, Foundations Family Medicine

**Figure 11: HIV Prevalence in Scott County, Indiana, 2016**



# Findings

The themes and findings that emerged from the research and interviews for this project are presented across three broad categories: (1) access to services, (2) facilitators and barriers to HIV response, and (3) targeted programming efforts. These themes are connected back, where possible, to the federal policies, funding, and programs that support the U.S. HIV prevention and care response.

## 1. ACCESS TO SERVICES

Individual and community access to HIV services is influenced by HIV-specific programs and policies, as well as by broader changes in the health care system. Interviewees discussed the RWCA's coverage of care and treatment services for people living with HIV, the positive impact of broader access to individual insurance and to Medicaid in expansion states, and distinct barriers to HIV prevention and care services in rural areas. Their views reflected shared beliefs in the importance of robust RWCA dollars integrated with accessible and affordable private and public health insurance, as well as the need to address HIV in the context of larger problems in the rural health care system.

### The Ryan White program

Congress enacted the Ryan White Comprehensive AIDS Resources Emergency Act in 1990. Few HIV treatments were available at that time, and those that existed were often out of reach financially. Recognizing that HIV was both a human crisis and a national public health disaster, Congress created the program to support care and treatment services for low-income people living with HIV (see text box, “The Structure of the RWCA”).

The Ryan White program is, by statute, the “payer of last resort”: No funds can be used to support a service if other payment, such as insurance coverage, is available. In addition to preventing duplication and waste, this requirement reflects the program's role of addressing gaps in care—essentially, acting as a wraparound for unmet needs among people living with HIV.

The Ryan White program has evolved with the HIV epidemic and with changes to the national health care system. Fortunately, with the advent of a combination of ARV treatment, the range of treatment options for HIV has expanded significantly.

The program has also seen policy and programmatic changes. One significant shift has been the use of AIDS Drug Assistance Program funds to purchase insurance. Every state receives ADAP dollars, which were initially used to purchase drugs to treat HIV and opportunistic infections. Over time, it became apparent that in some cases it would be more cost-efficient to use ADAP funds to purchase comprehensive health insurance for Ryan White enrollees. Today, most states use ADAP funding to cover health insurance premiums and cost sharing for Ryan White enrollees.

The RWCA allows states and localities to address nonclinical needs that impact the ability of HIV patients to access care and stay healthy. The program covers a set of core medical services such as outpatient ambulatory care and mental health and substance use treatment, as well as a set of support services that are “needed for individuals with HIV/AIDS to achieve their medical outcomes.”<sup>113</sup>

### The Structure of the RWCA

The Ryan White program funds HIV care and treatment programs through five parts:

**Part A:** funds medical and support services for cities and counties hardest hit by the HIV epidemic, including eligible metropolitan areas and transitional grant areas.

**Part B:** provides funds to all states and territories for medical and support services, including AIDS Drug Assistance Program funds.

**Part C:** early intervention services and capacity building grants for clinics and other community-based organizations.

**Part D:** grants to organizations that provide medical and support services for women, infants, and youth affected by HIV.

**Part F:** a set of funds for provider training, technical assistance, special projects, dental care, and the Minority AIDS Initiative.

**Table 3: RWCA Core Medical and Support Services**

Core Medical Services	Support Services
• Outpatient Ambulatory Health Services	• Non-Medical Case Management Services
• AIDS Drug Assistance Program Treatments	• Child Care Services
• AIDS Pharmaceutical Assistance	• Emergency Financial Assistance
• Oral Health Care	• Food Bank/Home Delivered Meals
• Early Intervention Services (EID)	• Health Education/Risk Reduction
• Health Insurance Premium and Cost Sharing Assistance for Low-Income Individuals	• Housing
• Home Health Care	• Other Professional Services
• Home and Community-Based Health Services	• Linguistic Services
• Hospice Services	• Medical Transportation
• Mental Health Services	• Outreach Services
• Medical Nutrition Therapy	• Psychosocial Support Services
• Medical Case Management, including Treatment Adherence Services	• Referral for Health Care and Support Services
• Substance Abuse Outpatient Care	• Rehabilitation Services
	• Respite Care
	• Residential Substance Abuse Services

Source: Public Health Service Act<sup>14</sup>

By statute, states and Part A localities must commit at least 75 percent of their Part B funds to core medical services. However, grantees may receive a waiver of this requirement if they can show that HIV drugs and care are accessible in the jurisdiction.<sup>15</sup> A growing number of jurisdictions, particularly where health insurance coverage rates have increased post-ACA, have received this “75/25” waiver, allowing them to focus funding on support services that are deeply connected to access.

The RWCA enjoys bipartisan support and has been reauthorized four times. The jurisdictions addressed in this report reflect a range of RWCA experiences. As noted above, all states receive Ryan White Part B funds, and many health departments indirectly receive some of that Part B funding. In addition, Seattle and New York City receive direct Part A funding as eligible metropolitan areas, and Kansas City, Clark County, and Duval County City receive Part A funding as TGAs. Meanwhile, many of the providers interviewed for the project receive Part C funding for clinical services and/or part D funding for women, children, and families.

The local perspective on RWCA planning is influenced by the type of jurisdiction within the Ryan White framework. Metropolitan areas that directly receive Part A funding are required by statute to have planning councils, including community and consumer representation, that set priorities and allocate Part A funds to be spent by the region’s department of health. Jurisdictions that don’t receive Part A funding are dependent on their states’ allocations of Part B funding, including ADAP dollars.



## Crucial access to HIV services

Interviewees report that the RWCA is still crucial for people living with HIV. First, the program can directly cover necessary medical care for people who are uninsured. In states with limited insurance coverage (see “Medicaid expansion,” below), this population can include a considerable portion of low-income people living with HIV. Even in states with high rates of insurance coverage, the program serves as a gap filler: covering care for people without insurance (such as those awaiting the next open-enrollment period for marketplace coverage), covering services that aren’t covered by insurance (for example, mental health visits beyond an annual number of visits covered by insurance), or supporting a small subset of people living with HIV who face challenges that make it difficult to maintain health insurance coverage.

“Sometimes patients who have particularly hard lives and are particularly marginalized, especially those who are homeless and have substance use disorders, have frequent lapses in coverage.”

—*Health department official*

As noted above, Ryan White program ADAP funds can also fund insurance coverage for people who could not otherwise afford premiums and cost sharing.

In addition to providing access to health services directly or through insurance, Ryan White funds support a range of services that help people living with HIV find, and remain connected to, care. Interviewees from multiple jurisdictions described the importance of RWCA-funded case managers in coordinating clinical and social-support services for their clients. These case-management services are often not covered by private or public insurance but are vital for addressing the complex health needs of many people living with HIV. For example, as described below in the section on Maternal Health and Transmission, Ryan White case managers help women living with HIV navigate multiple providers and payors to remain healthy and prevent perinatal transmission.

## Ryan White as a model for serving people at high risk

Several interviewees pointed to the Ryan White program as a model for how comprehensive services could be offered to reduce risk among people who are HIV-negative but highly vulnerable to transmission. Mental health and substance use treatment, outpatient services, case management, and other services could help reduce HIV risk, averting infection and reducing the human and economic costs of new cases. Meanwhile, the same social and structural factors that pose barriers to care and treatment for people living with HIV—including poverty, racism, homophobia, and transphobia—also elevate HIV risk for those who are negative.

“Ryan White and their linkage-to-care folks have long been ahead of the curve in terms of trying to address the underpinning issues that impair an individual’s ability to engage in care.”

—*Health department official*

Because RWCA funds can only be used to support services for people living with HIV, jurisdictions and providers must work to stretch limited prevention and social-support dollars to address social determinants of health in a meaningful way for people who are vulnerable to HIV infection.

“Right now, . . . if you are HIV-positive, there are a relative wealth of services that are available to folks, and we don’t have those parallel services available to HIV-negative folks.”

—*Health department official*

## Changes in the health care system

The health care system has been changing rapidly across the country, largely in ways that have helped states and localities better serve people living with, or at risk of, HIV.

### Access to private insurance

Historically, individual insurance was often inaccessible for people living with HIV; many were excluded entirely, charged exorbitant rates, or denied care for preexisting HIV infection. New national consumer protections under the ACA—including guaranteed issuance and a prohibition on exclusions for preexisting condition—have made private health insurance accessible to people living with HIV nationwide. There are premium subsidies for people who are living between 100 and 400 percent of the federal poverty level and cost-sharing assistance for those living between 100 and 250 percent of the federal poverty level, making individual insurance more affordable.

Ryan White program ADAP dollars, as noted above, can be used to help support the purchase of health insurance for people who are living with HIV if that purchase is more cost-effective than purchasing drugs directly.<sup>116</sup> A number of jurisdictions and providers reported that once subsidized individual insurance became available on the marketplaces, they were able to shift RWCA enrollees to comprehensive health insurance. Because insurance covers clinical services as well as drugs, Ryan White programs can save money on outpatient medical care and target funds toward persistent barriers to care. In addition, health insurance can cover all care, including services unrelated to HIV, whereas RWCA dollars can only support HIV-related care.

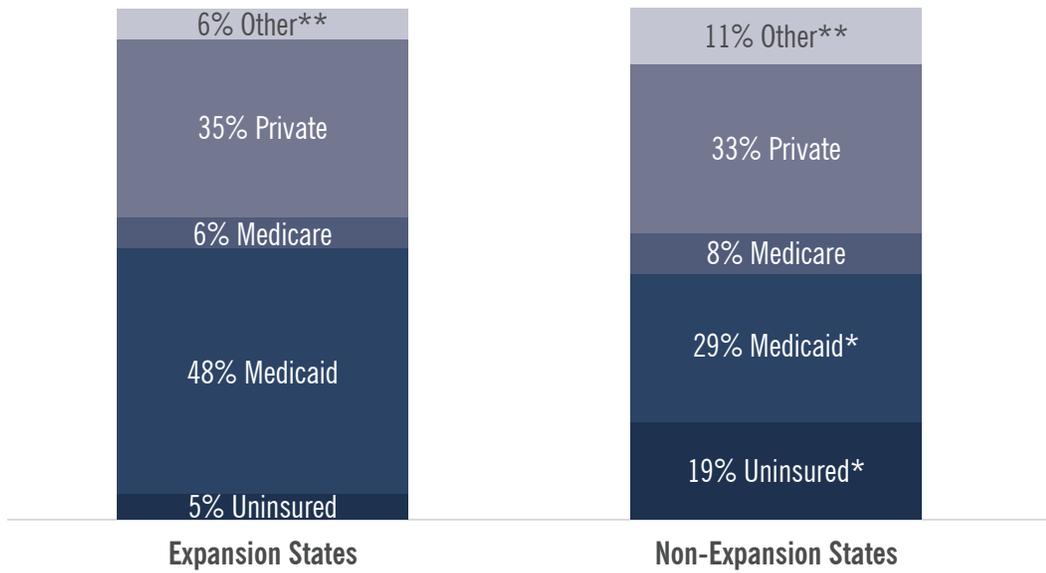
### Medicaid expansion

Because expanding Medicaid is a state-by-state decision, the landscape for public insurance access is a patchwork. Where Medicaid hasn't been expanded, there is an insurance gap for people between 0 and 100 percent of the federal poverty level who do not qualify for subsidized individual coverage. Unfortunately, states with this coverage gap closely overlap with the regions experiencing elevated rates of new HIV diagnoses.





**Figure 15: Insurance Coverage Among Nonelderly Adults with HIV in Medicaid Expansion and Non-Expansion States, 2015**



Source: CDC/Kaiser Family Foundation analysis of the MMP<sup>119</sup>  
 \*Coverage rates in expansion vs. non-expansion states, significantly different ( $p < 0.5$ ).  
 \*\*Due to small sample size, finding should be interpreted with caution

### Access to services in rural areas

Despite the prominence of the epidemic in urban epicenters, HIV exists across all parts of the country, including suburban and rural areas. In the South, 23 percent of cases are in suburban or rural areas; as are 21 percent in the Midwest.<sup>120</sup> Studies have found rural residences are associated with lower HIV testing rates, later diagnosis, later adoption of the newest medications, and higher HIV-related mortality.<sup>121</sup>

### Distinct barriers in rural settings

Among the health departments and providers participating in this project, the majority serve jurisdictions that are at least partly rural, including Scott County, Kansas City, Las Vegas, Montgomery, and Jacksonville. Health officials and providers from these areas described a range of distinctly rural challenges to HIV prevention and care.

Interviewees in both urban and rural settings reported on the ongoing stigma related to HIV, but those serving rural areas noted that the “small town” nature of their areas heightens people’s concerns about privacy. Similarly, in various settings, interviewees said that transportation was a potential barrier, but interviewees in rural populations in particular noted distinct challenges posed by a lack of any public transportation services.

“I think the only challenge in the rural areas, because it is so small, people who are positive, they have a lot of stigma because the people they’re going to see are usually their neighbors and friends. . . . [T]hey have to come to the city.”

—Health department official

“When you go into rural, there’s just tons and tons of stigma, and we hear from some of our patients who will drive pretty good distances. They don’t really want to get their HIV care in their rural hometown, because everybody knows their business and they don’t want their doctor to be there, if they even have a doctor that’s available for them.”

—Provider



“Transportation is our biggest issue that we have, it’s one of our biggest barriers out here. Anytime we have a meeting, transportation always comes up.”

—*Health department official*

“Transportation has to be one of the top. In urban settings, you tend to have public transit that can help get people to testing sites or to access care. . . . In rural settings, it seems like . . . there’s this mistrust of people coming to your house, and there’s lack of transportation to get them to a testing site or a clinic.”

—*Provider*

One interviewee noted that the inclusion of rural states in the new federal HIV strategy could help address the fact that smaller rural areas haven’t always received adequate levels of funding:

“[T]he majority of HIV is not in one urban area. It’s throughout these more-small rural [areas] where they’ve never sent the money out. [W]hat we’ve done is to still work with the communities and reach out to the youth and others, but we’re doing it all for almost no money.”

—*Provider*

## **The broader rural health care challenge**

Shortages and trends affecting the HIV response in rural areas are part of a broader pattern of limited access to care.

“One of our problems is, in a lot of rural [parts of the state], our health provider shortage for primary care of any type is just horrible. It’s nonexistent; in some places, there are no physicians or nurse practitioners around.”

—*Provider*

“We are projected to lose between 12 and 18 hospitals in the state . . . this year and in 2020 if we don’t expand Medicaid. Those hospitals are closing. They’re predominantly in rural areas. In areas that . . . already have a lack of medical care. It’s going to get worse, and with rural culture, rural people tend not to go to doctors already as regularly because of a variety of reasons. . . . I don’t think . . . that’s been adequately addressed as a nation because, honestly, the nation still focuses on cities.”

—*Provider*

A number of jurisdictions and providers nationally, such as MAO (see page 17), are engaged in telehealth programs to extend HIV-prevention and -care services to people in rural settings and other hard-to-reach populations. However, as one interviewee noted, a lack of broadband access in some rural areas can limit the effectiveness of this approach.

“[W]e do still have some parts of our state [where] broadband access is not available. It does limit a lot of individuals who live in some of those very rural areas to know what’s available. They can’t get on the computer. They can’t use the telephone.”

—*Health department official*

## **2) FACILITATORS AND BARRIERS TO HIV RESPONSE**

Discussions with interviewees covered a broad set of factors that either support or hinder efforts to respond to the HIV epidemic. Existing and developing approaches to HIV surveillance data can improve public health and clinical efforts to reach and retain patients, though gaps in integrating data into care remain. Meanwhile, many of the interviewees pointed to unmet social needs, including housing, food security, and transportation, that underlie HIV risk and hinder access to care, and that must be addressed as a core element of efforts to prevent and treat HIV. Meanwhile, across all types of jurisdictions, interviewees described how persistent stigma—related to HIV, sexual orientation, gender identity, race, and other factors—continues to stymie response efforts.

## HIV surveillance and data use

Modern HIV surveillance efforts involve coordination among providers, laboratories, and local, state, and national public health departments. All states require providers and laboratories to report HIV diagnoses, and nearly all also require labs to report CD4 and viral-load results, which reflect the course of the illness and the impact of treatment.<sup>122</sup> All states use a standardized, confidential reporting system to report HIV diagnoses and AIDS (now “HIV stage 3”) diagnoses to CDC.<sup>123</sup> CDC does not receive names or other identifying information. CDC does receive information on demographic characteristics like race, sex, and age; the route of transmission, if known; and immune status and viral load.<sup>124</sup>

### Data to inform HIV programming

Both health departments and providers at the local level were enthusiastic about the importance of shared data to inform both population-level and clinical efforts to address HIV.

For example, Alabama’s state department of health publishes HIV continuum-of-care data for each public health region within the state, including the Central District, where Montgomery is located.<sup>125</sup> In addition, the state provides clinic-specific continuum data to each RWCA provider in the state; providers have decided to share this data among themselves to compare outcomes and learn from other clinics’ efforts.<sup>126</sup> MAO (see page 17), a Montgomery provider, reported that the quarterly meetings to review data—including viral-suppression data, patient status in care, and other markers—have been very useful in guiding clinical care.<sup>127</sup>

The department also provides surveillance data—protected by the terms of a data agreement—to clinics to help identify and reengage patients who have dropped out of care.<sup>128</sup> MAO staff described this Data-to-Care effort from the clinical perspective:

“Data-to-Care is a project that is ongoing between the Ryan White clinics and the state health department surveillance division. . . . [It] allows us to submit a list of our patients . . . that we have as being out of care. The surveillance department is able to run the list through several different databases. . . . [T]hey have access to surveillance data for other states, as well as for all of the clinics in the state. They then send us the list back to say, “Okay, this patient is deceased, or this patient is living in another state, . . . or this patient is in care in another facility, they can come off your list.” And then you can really drill down to the patients that are truly out of care. . . . We can actually concentrate resources to the patients that really need it for reengagement.”

—Ashley Tarrant, MAO

MAO also described a Data-for-Care initiative that uses data on missed visits to stratify patients by risk and provide enhanced contacts to ensure that high-risk patients remain in care by addressing barriers such as transportation or childcare.<sup>129</sup>

In another innovative example, Dennis Dunmyer of KC CARE Health Center described using surveillance data from the city health department to target outreach programs in “hot spots” of HIV risk in the city:

“[A]s an organization, I would say we’ve gotten substantially better at being smarter and utilizing that surveillance data to really think about where we’re doing targeted testing . . . and trying to identify specific geographic areas down to neighborhoods. . . . We established a couple of years ago a quality measure that . . . is the percentage of outreach events that occur in what we’ve identified as our hotspot zip codes. That number’s gone up over time, in terms of more and more of those events are in those zip codes.”

—Dennis Dunmyer, KC CARE Health Center

### Other CDC HIV Surveillance

In addition to nationwide surveillance, CDC funds other targeted HIV surveillance projects, including:

- Incidence surveillance: 25 state and local health departments receive funding to collect and analyze data that permits an estimation of new HIV infections at the national level.
- Medical Monitoring Project (MMP): 23 jurisdictions have conducted MMP surveillance, combining clinical and behavioral information to characterize risk behaviors, care utilization, and other characteristics among adults living with HIV.



Joseph Mims from the Florida Department of Health in Duval County described multiple ways that surveillance data from the state informs the local response across prevention, treatment, and outreach efforts.

“Definitely, our surveillance data from the Florida Department of Health in Tallahassee drives what we do. We get that data, we look at it, and we determine what services are needed when it comes to prevention. . . . Outside of that, when it comes to care, we look at our viral-load suppression rate. Where are we, and which patients aren’t reaching viral-load suppression? Which patients aren’t we retaining in care and how can we address barriers?”

In this area, we just launched our mobile medical clinic that will take you from prevention all the way through care. We are hoping it will alleviate some of the problems that we have with transportation and make it more accessible for people to get into care. . . . For that, we’ll utilize our data systems to see where we have a large population of people who are falling out of care.”

—Joseph Mims, Florida Department of Health in Duval County

### Challenges in conveying data to providers

Despite progress, some providers described gaps in how data is translated into action at the provider level.

“It’s things like, where are clusters of new infections coming from and how to get that data to treatment programs in the area in real time so we could do more outreach, for example. Or [be] a little more user-friendly to clinical programs around high-impact, rural areas that could be actionable in terms of trying to do county-level or community-level outreach and organizing around testing and getting people into care. There’s still some gaps on how to make that kind of information usable in real time for clinics or for programs like ours.”

—Provider

“We still have very limited and arcane methods of tapping into surveillance as well as genetic linkages. [There are] tremendous restrictions on sharing of information between public health authorities and private entities like us. We really struggle with that. It’s very difficult for us to track down patients who are out of care because the governmental agencies really have a difficult time providing this information.”

—Provider

One health department interviewee pointed to a lack of interoperability among systems—particularly public health surveillance systems and clinical records—as blocking the timely flow of useful information to providers.

“I think there could always be more interoperability between systems. I think one of the problems that you see all throughout health care, . . . [at] that juncture between reportable diseases in the public health sector and reportable disease investigation and health care is that the two systems are not interoperable. Even in between two health care systems, the systems aren’t always interoperable. When you’re talking about somebody who’s bouncing from place, to place, to place, we sometimes are able to get a hold of where they’ve been tested before. . . . Sometimes we have to go through this very slow inter-jurisdictional thing, where we talk to another state person, and yadda, yadda, yadda. It can be very slow. That’s just for the reportable disease end of things. From the health care end of things, it’s even worse, because you don’t want somebody dropped out of care. . . . You have no idea what their CD4 count is, . . . you have no idea when they last saw a provider, . . . or you have no idea what their genotype is.”

—Health department official

### Molecular HIV surveillance

One important goal of HIV surveillance is identifying “transmission clusters,” when a set of people related by sexual activity or shared syringes become HIV-positive. People in a transmission cluster are part of a broader “risk network,” which includes people who are not HIV-positive but may be exposed to the virus. Identifying such clusters and risk networks as quickly as possible can allow providers and public health officials to intervene, linking HIV-positive people to care and other services, and connecting people who are at risk of infection to prevention services and other supports.

Historically, a number of approaches have been used to identify transmission clusters.<sup>130</sup> An increased rate of HIV diagnoses in a region might reflect a transmission cluster, though diagnoses do not themselves indicate whether transmissions are still actively occurring in a network. In most jurisdictions, when someone is diagnosed with HIV, public health workers called “disease intervention specialists” conduct contact investigations, working with the individual to voluntarily identify sexual or needle-sharing partners who may have been exposed to the virus. This approach can yield a clearer view of a network across which infections may be occurring. However, contact tracing is limited by its reliance on information that people choose to share with disease intervention specialists, as well as a growing trend of people engaging in activities with partners about whom they have limited information, such as those met through online apps.

“Molecular surveillance” is a newer approach that can in some cases help characterize transmission clusters, based on tracking the genes of the virus present in a diagnosed individual. When people are diagnosed with HIV, the virus is typically analyzed to guide clinical care. Since HIV mutates somewhat quickly, if someone is diagnosed with HIV shortly after transmission, the genes in the virus at diagnosis will be very similar to the viral genes in the person from whom they got the virus (though the approach does not allow determination of the direction of transmission). The closeness of genetic sequences can allow public health agencies to map out a “molecular cluster.”

Currently, if CDC identifies a molecular cluster, it informs the affected jurisdiction, allowing state or local public health agencies to conduct further investigation to characterize any related transmission cluster and risk network.<sup>131</sup> For example, CDC shared information about molecular clusters with the Texas Department of State Health Services to help the state and local health departments characterize the transmission clusters and guide agency and provider response efforts.<sup>132</sup>

As of March 2019, molecular surveillance had identified 145 “priority clusters” in the United States.<sup>133</sup> CDC has characterized cluster detection, aided by molecular surveillance, as crucial to the new federal strategy to end the epidemic.<sup>134</sup>

At the local level, interviewees understand the promise of molecular surveillance, though their comments reflected the newness of the approach:

“The molecular HIV surveillance . . . really takes a lot of time and effort. People are not geographically bound so much anymore. I don’t know how effective the molecular HIV surveillance will wind up being in the long run.”

—*Health department official*

“It has not been used as widespread as it is now. We’re going to be getting a sense of what’s the added value to the usual data to care work that we do. . . . In this age, where people are meeting partners online and don’t know the names of their partner, . . . this is another way to help to build those networks so that we can identify . . . clusters that may be having recent and rapid spreads. Then we can go in and send our field-services staff to intervene and to get folks who may not be diagnosed.”

—*Health department official*

## **Socioeconomic status and unmet social needs among people living with, or at risk of, HIV**

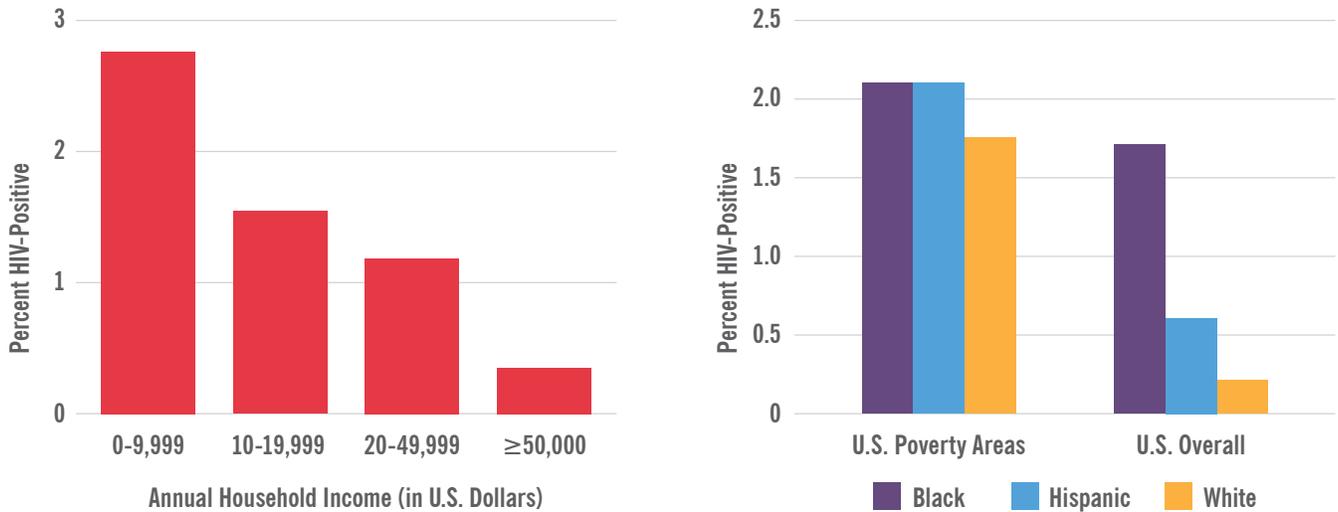
Poverty and other socioeconomic factors can affect HIV risk at both the population and individual levels.<sup>135</sup> HIV prevalence is higher in some high-poverty communities, meaning that people who engage in risk behaviors in those communities may have higher risks of HIV than people who engage in identical risk behaviors in other communities. In addition, poverty, inequality, and related factors can underlie behaviors that put individuals at risk.<sup>136</sup> For example, homelessness may lead a person to engage in transactional sex in order to secure a safe place to sleep.

In addition to affecting HIV risk, socioeconomic status can affect people’s ability to access prevention or treatment services—directly, through health insurance status, or indirectly, by creating barriers to access or by posing more pressing demands on people’s attention.

In a 2010 study, CDC researchers tried to identify the extent to which HIV was affecting poor urban areas of the United States.<sup>137</sup> Among heterosexual adults in 23 cities living in census tracts where 20 percent or more of the people lived in poverty, they found a prevalence rate of 2.1 percent, more than 20 times higher than the rate among all heterosexuals in the United States, and meeting the World Health Organization’s definition of a generalized epidemic. Prevalence was inversely related to income, a pattern than held across racial groups.



**Figure 16: HIV Prevalence Rate, by Income and Race/Ethnicity**



Source: CDC<sup>138,139</sup>

The association is not solely urban; researchers have also long identified poverty as a factor strongly affecting HIV risk and service access in rural areas of the United States, particularly in the southeastern states.<sup>140,141</sup>

### Poverty, unmet social needs, and HIV

Unsurprisingly, health departments and providers at the local level, in both rural and urban settings, described poverty as a barrier to helping individuals and communities address HIV. Within the context of poverty, they frequently mentioned three issues: housing, transportation, and food security.

“I think it’s hard to overstate the impact of poverty, and it affects all of those things. . . . Transportation is a huge issue. Housing is a huge issue. . . . They are all huge issues that adversely impact each other.”

—Provider

“[P]overty’s at the root. [T]here’s always going to be elements of racism, there’s always going to be elements of homophobia. We all know that, but the poverty, really, is a big, big issue and it still impacts us.”

—Provider

“It’s basically the same for HIV as it is for any other chronic disorder. It’s poverty level, it’s education, it’s transportation, it’s mental health services. All of those play a part into a person [who is] HIV-positive either maintaining viral suppression or refraining from obtaining HIV infection. Anytime we look at those areas, . . . our highest areas of HIV infection are in our high-unemployment areas, low education, large poverty areas, [and] high crime areas.”

—Health department official

Some interviewees offered specific examples of how poverty and intersecting challenges can increase an individual’s HIV risk, especially when intersecting with stigma. For example, LGBTQ people may be more likely to have unstable housing situations and therefore more likely to engage in transactional sex for a place to stay. Overall, as one health department official recounted:

“I’d learned that in order to have a place, they’d sleep on someone’s couch. . . . They may partake in some risky behaviors just to have a roof over their head.”

—Health department official

Others described the challenge of helping individuals engage in care when other needs are more immediately compelling.

“Trying to get someone to concentrate on a chronic medical condition when they don’t know about where they’re sleeping is almost silly.”

—*Provider*

### **Addressing unmet needs as part of the HIV response**

Rather than simply pointing to poverty and need as barriers, interviewees described addressing unmet social needs as an integral component of addressing HIV.

“[W]e know, without a doubt, how social determinants of health are related to HIV, and it can be sometimes frustrating to say over and over again, ‘HIV is related to homelessness and poverty and stigma about sexual minority status and HIV.’ Really, the more important questions for us as a field are, how do we mitigate the impact of those factors, while, of course, also trying to address them upstream?”

—*Health department official*

Some interviewees noted that it would be helpful for new funding under the recently announced federal HIV strategy to allow a focus on social determinants of health:

“To have funding that’s flexible enough that allows us to address [what] people often call social determinants of health. . . . I think a lot of our funding is around providing HIV-prevention services, and the way we operationalize that, it’s providing PrEP, . . . providing condoms, providing STI screening and treatment, but can we also support folks in getting employment and getting housing and all these other structural factors, which we know drive HIV risk if people go without them?”

—*Health department official*

### **The role of community-based organizations in addressing social needs**

Both health departments and providers noted the role of community-based organizations (CBOs) in addressing the social determinants of health that underlie HIV risk and barriers to care. Daniel Merkan from JASMYN, an LGBTQ youth-serving CBO in Jacksonville (see page 14), described the range of needs at issue.

“We address all sorts of needs that [LGBTQ youth] may have. We will work with them on a plan with individualized goals. Their plan could address all sorts of things. It could be about helping them with housing; or, it could be getting them to substance abuse treatment. It could be helping find them mental health resources. It’s sometimes about coordinating with their Ryan White case manager to stay in care. It’s often getting them basic supplies. We have a food-pantry program, hygiene products, transportation assistance, and all sorts of stuff like that. Sometimes it is helping them with access to resources to find jobs. We have programs on our campus that we don’t run all the time, everything from résumé creation to better job-interview tips. That’s one of the things that some of our corporate partners really love to bring to the table. . . . Whatever we can figure out to support young people, we try and figure out a way to do that. They really get all the things that they need to get them stable and hopefully to figure out over time how to maintain that for themselves and then grow.”

—*Daniel Merkan, JASMYN*

Another interviewee who works at an HIV clinic described how CBOs help support their work:

“We partner with one of the care-coordination grantees, and their role is that if we are having problems with a patient or if the patient needs home visits or if the patient needs [directly observed treatment], then we can reach out to our community partner, and they will attempt to reach the patient and meet those needs.”

—*Provider*



Multiple interviewees pointed to examples of CBOs that serve as a link to specific communities or populations— such as LGBTQ people, people who inject drugs, or people of certain races or ethnicities—offering a trusted source of information and support resources.

“We have really close relationships with community-based organizations that serve LGBTQ individuals, community-based organizations that serve African Americans or that service drug users. They often do education and risk assessment and testing, and then they refer them to us for STD screening, for PEP, for PrEP, or for HIV care.”

—*Provider*

## Stigma and Discrimination

“As far as the gaps and the barriers. I would say probably the largest one . . . is stigma.”

—*Ashley Tarrant, MAO Alabama*

CDC defines HIV stigma as “negative attitudes and beliefs about people living with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable.”<sup>142</sup> Stigma often drives discrimination, or “the act of treating people living with HIV differently than those without HIV,” which can include health care providers “refusing to provide care or services to a person living with HIV,” or community members shunning individuals for their HIV status.<sup>143</sup>

★ ★ ★

*HIV stigma can also intersect with racism, homophobia, transphobia, sexism, and other biases to further threaten community and individual health.*

Stigma and discrimination exist on several levels, including societal stigma of individuals based on their identity or behavior that can include laws and regulations rooted in stigma. For example, a recent survey of individuals living with HIV in the deep South states of Alabama, Mississippi, South Carolina, and North Carolina found that 36 percent had experienced at least one type of verbal abuse in the last quarter, such as being “told God [was] punishing me [for having HIV]” and being “blamed for HIV status.”<sup>144</sup> Researchers have found that societal stigma often leads to internalization of these beliefs and self-stigmatization, which can lead to depression, substance use, and related health issues.<sup>145</sup> Levels of stigma have been shown to negatively affect health-seeking behaviors (such as HIV testing or adherence to care), and stigma has been found to be related to poor HIV-medication adherence in a large meta-analysis and a synthesis of the literature.<sup>146,147</sup>

“We did have one friend who finally did come in [to the clinic], but they were told [they had HIV] several years ago, and the only reason they came in now was because they were so sick, and they felt like they didn’t want to die. They were ready to try to get some type of health [care] now. [The patient said.] ‘But I would lose my family, it’s like I would lose my family if I come in there [to the clinic]. If my family knew I was HIV-positive, I would lose them all.’”

—*Provider*

## Stigma contributes to HIV risk

Stigma and discrimination not only have negative effects on people living with HIV; they also undermine HIV-prevention efforts, particularly among those at high risk of infection. For example, stigma affects uptake and adherence to interventions such as PrEP. A recent study examining the links between stigma and PrEP uptake found a strong association between stigmatizing beliefs, such as “believing that PrEP is for people who are promiscuous,” and a lack of interest in using PrEP.<sup>148</sup> Individuals with this belief were also statistically more likely to report sexual risk-taking behavior.<sup>149</sup>

LGBTQ youth in particular face issues around family acceptance; this trend has been noted nationally, including in the South.<sup>150</sup> Family rejection can lead to youth homelessness and migration to major cities, where their risks for HIV are often amplified by their vulnerable economic and social state. According to estimates, LGBTQ youth account for 20 to 40 percent of the population of homeless youth in some cities.<sup>151</sup>

“Some families have put their kids out. Once they knew they were positive, they kicked them out and everything. We’ve been witness to that many times. It’s like: ‘You can’t come here. You can’t come back here.’ We tried to educate the parents. . . . We’ve had some parents that want to come in and talk to us to see what’s what, and what do they have to do and don’t do. They don’t have to be afraid at all. You should not have to kick your child out because you’re afraid to get it, because he can’t just give it to you like that.”

—*Provider*

“There’s still tremendous stigma about being LGBTQ, and that leads a lot of people who have unstable housing in our area, who have unstable relationships, who are often being paid for sex or have transactional sex to be able to survive, we have a lot of that.”

—*Provider*

### **Criminalization perpetuates stigma**

Thirty-three states have HIV-specific criminal laws on the books. Most of these laws emerged early in the HIV epidemic: 75 percent of the states with these laws enacted them prior to 1995 as a means of reducing HIV transmission.<sup>152</sup> However, there are now multiple effective means of reducing HIV transmission that are not taken into consideration by these laws—for example, condom use, PrEP, and HIV treatment, which have been shown in clinical trials to reduce onward transmission of HIV to nearly zero among people with a suppressed viral load. Researchers have found that HIV-specific criminalization laws and HIV-related prosecutions under other laws may not have measurable effects on sexual behavior among people living with HIV,<sup>153</sup> yet they do likely worsen stigma.

Although CDC recommends individual disclosure of HIV status, the agency notes that criminalization may hinder the public health response, and it concludes a recent analysis by stating that “states are encouraged to utilize the findings of this paper as a basis to reexamine those laws, assess the laws’ alignment with current evidence regarding HIV transmission risk, and consider whether current laws are the best vehicle to achieve their intended purposes.”<sup>154</sup> The REPEAL HIV Discrimination Act was introduced in the House in several of the last Congresses to encourage state review of HIV criminalization laws, but it has not advanced beyond committee.<sup>155</sup>

### **Established strategies to reduce stigma**

Reducing stigma requires multipronged efforts that evolve with the times, science, and public health approaches. The 2015 U.S. National HIV Strategy highlights several HIV stigma-reduction approaches, including:

- Mobilizing communities to reduce HIV-related stigma;
- Strengthening the enforcement of civil rights laws;
- Assisting states in protecting people with HIV from violence, retaliation, and discrimination associated with HIV status; and
- Promoting the public leadership of people living with HIV.<sup>156</sup>

The Jacksonville, Florida, CBO JASMYN (see page 14) focuses on reducing stigma and providing supportive environments for LGBTQ youth to stay safe, build confidence, and thrive in a diverse society. Their work has affected local ordinances and provided programs for youth in the educational, medical, and housing sectors.



“[I]n Jacksonville, we have taken some steps forward, but they haven’t been fully actualized yet. . . . [W]e finally updated our human rights ordinance to protect [LGBTQ populations] from discrimination. Other cities have had those laws on the books for 20, 30 years. During that effort, we identified many persons in the faith community that were supportive. I think that work has been valuable for laying the groundwork for further change. That was an interesting and beneficial effect from doing that policy work. It helped us identify more allies than we were ever aware of previously. . . .

[JASMYN also supports] safe-schools work. We do work to support the creation of gay-straight alliances in schools. We support the maintenance of them by bringing different leaders together from the different high schools and middle schools that have GSAs so that they can share resources and talk. Part of that includes a health-promotion piece to encourage youth to use our health resources. A lot of them tell us they still feel more comfortable coming to our clinic even though it might be a drive.”

—Daniel Merkan, JASMYN

Multiple jurisdictions described stigma-reduction campaigns that are highly variable across regions of the country due to local cultural norms. Some cities, such as New York, have adopted a “sex positive” approach:

“New York City has started to do a lot of subway and bus advertising around sexual health, PrEP, and the NYC PlaySure Network, with positive messaging around sex and images of couples of all different racial, ethnic, gender, and sexual-orientation backgrounds.”

—Dr. Barry Zingman, AIDS Center at Montefiore Medical Center

For example, ¡Listos! is an advertising campaign sponsored by the NYC Department of Health supporting delivery of effective messaging about PrEP to Latinx, who currently use PrEP at lower rates than whites.<sup>157</sup>



Image courtesy of the NYC Department of Health and Mental Hygiene

Integrating HIV and other services in clinics such as federally qualified health centers can be helpful in reducing perceived stigma that can lead to reduced health care utilization. For instance, in Richmond, Virginia, Phyllis Mann, the Wellness Supervisor for the Vernon J. Harris Medical Center noted that “being a community health center, we see many different populations. . . . It’s like, ‘If I’m going there, no one knows why I’m actually in that clinic.’”<sup>158</sup>

Stakeholders are also working to reduce stigma through scientific information. Evidence has in recent years clearly established that when a person has an undetectable viral load in their system, they have a 0 percent chance of transmitting HIV.<sup>159</sup> This fact has informed the U=U, or “Undetectable = Untransmittable” campaign, both to raise awareness about the prevention impact of treatment and to destigmatize living with HIV.<sup>160</sup>

### 3) TARGETED PROGRAMMING EFFORTS

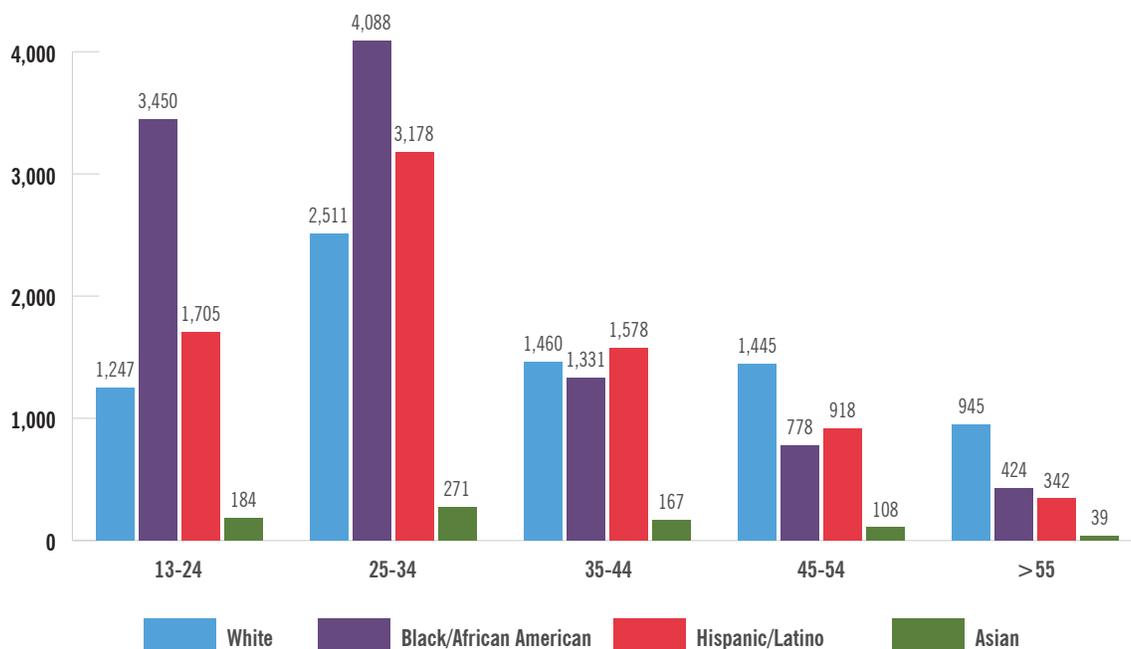
Interviewees discussed specific areas of focus in their HIV programming efforts. Across the country, young MSM of color are highly impacted by HIV; interviewees described efforts to reach this population, including ongoing challenges. Public health officials and providers also described their work to coordinate care for pregnant women living with HIV, as well as programs for children who became HIV-positive perinatally or as youth. Pre-exposure prophylaxis for HIV, or PrEP, is generating activity in all eight jurisdictions, with public health staff and clinicians reporting a range of opportunities and challenges in increasing provider and patient uptake. Finally, interviewees discussed the evolving intersection between HIV and substance use, noting the impact of the opioid epidemic as well as other drug use and the need for non-stigmatizing services to improve HIV prevention and care for people who use drugs.

#### Young MSM of color

Nationally, the population most impacted by the HIV epidemic today are young MSM of color.<sup>161</sup> Young African American MSM experienced a higher number of HIV diagnoses in 2016 than any other subpopulation, despite representing a small fraction of the population.<sup>162</sup> CDC predicts that without a significant change, African American MSM face a lifetime HIV risk of 50 percent, along with one in four Latinx MSM.<sup>163</sup>

Among MSM, nearly two-thirds of all new diagnoses in 2017 were among 13- to 34-year-olds, with the most diagnoses among 25- to 34-year-olds, and disproportionate rates among African Americans and Latinx.

**Figure 17: New HIV Diagnoses Among Gay and Bisexual Men by Age and Race/Ethnicity in the United States and Dependent Areas, 2017**



Source: CDC<sup>164</sup>



Across all races, the 13- to 24-year-old age group are the least likely to know that they are HIV-positive<sup>165</sup>; this may contribute to high ongoing incidence rates, since people who know their status are more likely to take steps to protect their partners.<sup>166</sup> This age group also has the lowest viral-suppression rate: 25 percent in 2015 compared with 51 percent across all ages.<sup>167</sup>

## Efforts to reach young MSM

Health department officials and providers from all parts of the country recognize the importance of specific efforts to reach young MSM of color, both with prevention and testing services and to ensure linkage to, and retention in, care. As one provider noted, young MSM of color can be underrepresented in prevention programs—particularly for PrEP—and then overrepresented in HIV care and treatment services.

“I’m worried about our young MSM of color, . . . young MSM, and other young sexual minorities. . . . It’s just the sense that we get from who we aren’t always seeing, like who do we see come in as a positive who we didn’t see come in for PrEP? . . . I think primarily for our PrEP program, we get a lot of white clients, and then with our linkage program for Ryan White, we get a lot of minority, African American.”

—*Health department official*

Alabama’s health department has a set of activities for outreach to young black MSM, focused around the “Start Talking Alabama” campaign.<sup>168</sup> They produced a video on PrEP featuring a correspondent who “met the demographic” and shared it on social media. Meanwhile, MAO has an outreach coordinator who focuses on college students. The experience gave them insight into how this age group digests information:

“One thing we learned was that college students want information short, sweet, and to the point. An outreach coordinator tried to give them a print brochure that gave all the information about PrEP, including the side effects, and they weren’t interested in that. They wanted something less wordy. We created a simply stated brochure that gives the nine top facts about PrEP and how it works. The 10th fact was to call our 1-800 number for more information. They seem to like that better.”

—*Alabama health department interview*

Another health department official concurred that outreach programs should reflect the young men of color they are trying to reach:

“We have another agency that receives special money that targets young men of color. They’re very effective. . . . I think the biggest thing that drives the effectiveness is making sure that they see themselves in the people who are reaching out to them.”

—*Health department official*

On the clinical side, successfully reaching young MSM of color depends in part on creating “an affirming environment”:

“We now are seeing lots of young MSM of color who are HIV-positive, and, at our sexual health clinic, 99 percent of our patients are people of color. There, it’s a mixture of MSM as well as women of color. We are trying to reach out significantly as well to women of color in the community. And we are successful reaching young men of color and women of color, I think, [by] just trying to create an affirming environment and also providing a lot of support to people.”

—*Provider*

## Reflecting young people's lived experience

The interviewees noted several ways that programs and providers should recognize the distinct needs and perspectives of young people living with, or at risk of, HIV.

First, as one provider noted, young people may have practical challenges working with health insurance and the health care system due to a lack of experience:

“It’s usually much more intensive to get young people linked into services, because developmentally, they’re not as familiar with systems like health care. . . . [G]etting somebody back into care when they’re 40 years old, probably at that point they’ve had some interactions with the health care system and are more familiar with it, and a little more independent, hopefully.”

—*Provider*

Similarly, another provider noted that it can be hard to get young adults to remain engaged in care:

“I think [there are] a lot of barriers to just coming back to a hospital when you don’t feel like you need to. Now we’re looking at doing a WhatsApp intervention or a Telegraph intervention. Something that’s text-based that we think will be easier to access for young people. . . . I mean, my sense of it is, it’s probably going to have to happen outside of the clinic; . . . those efforts are broader and need to happen on . . . some other level.”

—*Provider*

Importantly, one provider noted that some may feel alienated by efforts to “target” young MSM of color for HIV-prevention or treatment outreach:

“[O]ne of the things we’ve found in our community is that we hear, particularly pointing at feedback from young African American MSM, . . . that they’re starting to feel like they got a target on their back that we put on their back. They’re saying things like, ‘Hey, we’re more than HIV, and can you chill?’ It’s actually turning them off to testing.”

—*Provider*

This insight highlights the inherent tension in steering resources and attention toward a hard-hit group without perpetuating stigma or creating alienation from the health or public health systems.

## Maternal health, perinatal transmission, and pediatric care

Without intervention, the infants of women living with HIV will become HIV-positive between 15 and 40 percent of the time, depending on breastfeeding and other factors.<sup>169</sup> Successfully reducing HIV transmission during pregnancy, labor, and delivery has required coordinated clinical and public health interventions that allow for intensive case management. However, these efforts alone cannot eliminate perinatal HIV transmission completely. Programs and systems must consistently provide intensive and state-of-the-art prevention and care on a daily basis to an increasing population of women living with HIV and HIV-exposed children.

## Success in preventing mother-to-child transmission

Intensive efforts to date to test pregnant women, and to provide HIV treatment throughout pregnancy and breastfeeding to the mother and HIV-exposed infant, have reduced infant infections in the United States dramatically from 1,650 in 1991 to 73 in 2017.<sup>170,171</sup> However, there are pockets of the country in which perinatal transmission of HIV is increasing, such as in northern rural Florida, in which there was a 10-fold increase in new infections between 2013 and 2017 compared with the previous five-year period (10 versus one new infant infections).<sup>172</sup>

Prevention of perinatal transmission starts upstream with preventing HIV infections among women and girls, and continues across the following extensive set of activities:

- Identification of infection among women of childbearing potential;
- Assurance of adequate preconception care and family-planning services for women living with HIV;
- Early identification of HIV among pregnant women through universal prenatal screening;
- Provision of adequate prenatal care for women who have HIV infection;
- Maximal reduction of maternal viral load through appropriate use of ARV drugs;
- Cesarean delivery when maternal viral load is not maximally suppressed;
- Provision of neonatal ARV prophylaxis; and
- Neonatal replacement feeding as well as maternal support for lactation suppression.

Clinically, local health departments typically work with university teaching hospitals and others to identify and train local obstetricians who are equipped to provide “high-risk” care to pregnant women living with HIV. Work through these specialists combined with intensive case management has been successful in helping women overcome hurdles to stay on HIV medication and attend prenatal visits.

Dennis Dunmyer, the chief operating officer at KC CARE Health Center in Kansas City, Missouri (see profile page 15), estimates that in the region, approximately 25 to 30 women living with HIV become pregnant each year. Often uninsured, these women receive case management through RWCA Part D-funded family-centered case managers at KC CARE and a subcontract to a local community hospital. The women receive obstetric services at the community hospital or through an RWCA Part A-funded local university medical center. The case managers work with the obstetricians for high-risk pregnancy management. Everyone in contact with the mother trains in protocols for preventing HIV transmission; the case managers attend all prenatal appointments, and closely follow babies post-delivery, educating women on the need to avoid breastfeeding, as well as on nutrition and medication adherence.

“It’s a whole program, but it really hinges on . . . the case manager to really coordinate that care [home visits, pre- and post-natal visits] and make sure mom’s getting all that she needs and making sure she’s going to those appointments and making sure all the pieces fall into place.”

—*Dennis Dunmyer, KC CARE*

Joseph E. Mims, the program administrator for Area 4 HIV/AIDS for the Florida Department of Health in Duval County, Florida, described his county’s similar approach to intensive case management through the Targeted Outreach for Pregnant Women Act program:

“[The program] makes sure . . . our women of childbearing age get tested and linked into care. . . . We have one high-risk OB HIV provider here in this area so all of us refer to that provider. So anytime a HIV-positive pregnant woman is identified, they’re immediately linked to this one provider. . . . They will case manage that client from the date of identification to . . . after delivery, ensuring that they received the services they need, ensuring they are in for prenatal care, ensuring that at delivery the babies receive the medications they need and the mothers go home with those medications.”

—*Joseph Mims, Florida Department of Health in Duval County*

In 2012, CDC developed a framework to further intensify the reduction of new infections, in line with the global trend of adopting a goal of less than 1 percent transmission.<sup>173</sup> CDC built the framework around twin foundations:

1. Assure that HIV care includes comprehensive reproductive health, family planning, and preconception care services and that providers test women of childbearing age for HIV according to CDC recommendations.
2. Conduct comprehensive, real-time case finding of all pregnant women living with HIV and their exposed infants.

Importantly, this framework adopted a methodology from the Fetal and Infant Mortality Review program, funded by the Health Resources and Services Administration.<sup>174</sup> This approach uses the concept that cases of maternal-to-child transmission of HIV are rare and that new cases will reflect a diversity of “health systems failures” that should be treated as “sentinel events,” understood locally and ultimately matched with local solutions in order to prevent future occurrences. Opt-out testing for HIV is an essential part of the strategy, and this component was further strengthened in 2016 with the adoption by the American Medical Association of a new Common Procedural Terminology (CPT) code (80081) that includes HIV testing as part of an obstetrical panel that encourages prenatal providers to order all relevant tests by checking off a single panel.<sup>175</sup>

Fetal and Infant Mortality Review is a continuous quality-improvement methodology that many jurisdictions have adopted as it enables a richer understanding of the causes of new infant infections, ranging from late presentation for delivery without prenatal care, lack of repeat testing in the third trimester in women living in high-prevalence settings, and inconsistent adherence to HIV drugs during the course of pregnancy and breastfeeding. Many of these gaps have been closed due to the flexibilities involved in the application of RWCA funding that include intensive case management, transportation, home visits, and other services.

Despite the gains in reaching pregnant mothers and their infants, researchers studying the rise in new infant infections in northern Florida identified a number of gaps in the existing system of care provision:

“Improved access to prenatal case management and access to mental health and substance abuse services are seriously needed in rural areas. Improving pregnancy compliance with ARV therapy is crucial in preventing vertical transmission. The number of perinatal coordinators needs to be significantly increased to support compliance and provide services.”<sup>176</sup>

### **Coordination across programs and payors**

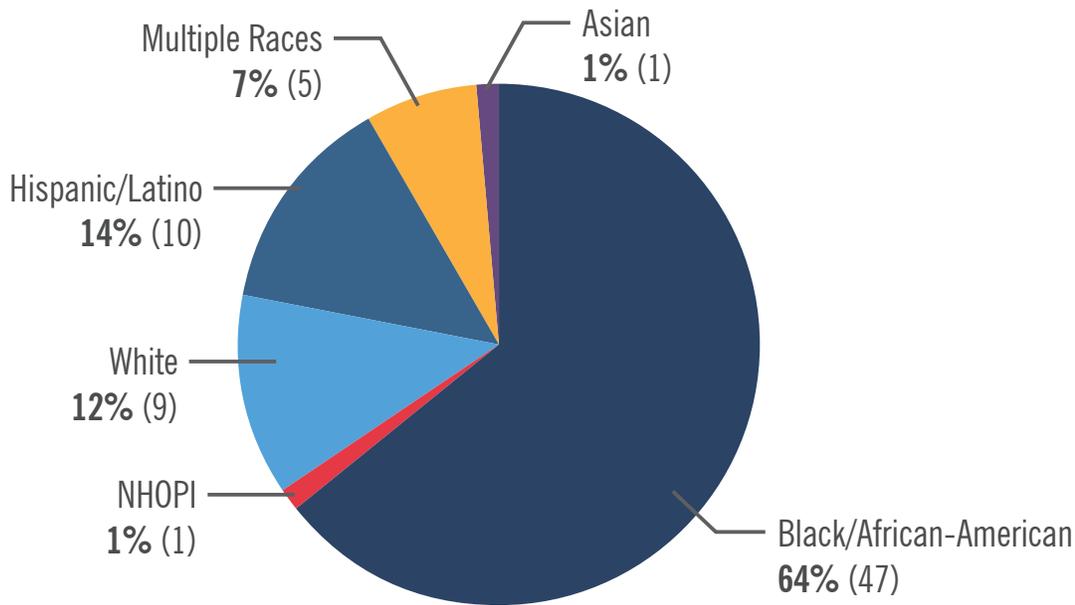
Ensuring continuity of care for women and their babies requires knowledgeable and consistent coordination across the payors and programs. For example, one health department described how low-income women living in the state are eligible for Medicaid while pregnant but must transition off of Medicaid after delivery. The state’s Ryan White program funds case managers who help women navigate their prenatal and postnatal care to protect their health and prevent transmission to the baby. Once women transition off Medicaid postpartum, they can transition back to Ryan White support for their own medical care. Part D can continue to provide wraparound support for the infants, who are typically eligible for Medicaid.

### **Persistent racial disparities**

Although infants born to African American mothers make up fewer than 15 percent of births in the United States, they represent 64 percent of infants born with HIV.<sup>177,178</sup> This disparity is rooted in multiple social and health inequities. For example, a study of babies born with HIV in Georgia, 89 percent of whom had African American mothers, found that although 74 percent of the women knew their HIV status prior to pregnancy, only 50 percent had prenatal care, substance use was common (33 percent), and uptake of ARV therapy was poor.<sup>179</sup>



**Figure 18: Diagnoses of Perinatal HIV Infections in the United States and Dependent Areas by Race/Ethnicity, 2017**



Source: CDC<sup>180</sup>

### Challenges specific to treating HIV-positive children

Children living with HIV, whether infected perinatally or later through adolescence, remain an important priority for the U.S. health care system. Treating children living with HIV involves using pediatric ARV medicine formulations that can be challenging for the child to take, along with multidisciplinary specialty HIV and supportive care. Furthermore, caregivers of infants and children living with HIV may have substantial social and medical needs of their own, further complicating the already complex process of providing comprehensive care to children with chronic non-curable illness.

Children who have grown up with HIV or who acquire it behaviorally face multiple challenges throughout adolescence. According to HHS, “Older children and adolescents now make up the largest percentage of children with HIV who are cared for at pediatric HIV clinics in the United States.”<sup>181</sup> Of the 7,125 youth newly diagnosed with HIV in 2017, 21 percent (1,723) were ages 15 to 19, and 79 percent (6,416) were ages 20 to 24, representing substantial needs for adolescent-focused services and multidisciplinary comprehensive navigation while transitioning from pediatric to adult care settings.<sup>182</sup>

As with many chronic lifelong illnesses, HIV requires daily medication adherence. There are many issues that negatively affect medication adherence in children and adolescents, including those noted in the latest HHS HIV guidelines: medication formulation; frequency of dosing; drug toxicities and side effects; child’s age and developmental stage; and psychosocial, behavioral, and sociodemographic characteristics of children and caregivers.<sup>183</sup> More specifically, stigma can affect children at school. Children living with HIV may be unable to disclose their status due to fear of stigma, thus exacerbating barriers to medication adherence. Because of these challenges, pediatric HIV providers should deliver care in family-friendly multidisciplinary environments. And given the high rates of childhood trauma as well as issues related to neurocognitive development and stigma experienced by children living with HIV, regular access to services for mental health, substance abuse, and childhood development are essential.<sup>184</sup>

For children living with HIV, challenges can be compounded by immigrant status. Children may be living apart from parents, may face language barriers in treatment, or may have experienced trafficking.

## HIV prevention through the use of pre-exposure prophylaxis (PrEP)

Scientific evidence and clinical guidelines support the use of PrEP for HIV prevention. Scientists first tested Tenofovir and Emtricitabine--combined into a pill known as Truvada--for prevention in a multi-country clinical trial for an HIV infection known as IPrEx. In this landmark trial, among HIV-negative MSM taking the pill as prescribed (seven days per week), there was a 99 percent reduction in the risk of acquiring HIV disease compared with placebo; rates of protection were lower among those with lower adherence to the medication.<sup>185</sup> PrEP has since been tested in subsequent clinical trials in a variety of populations with high risk of HIV, including MSM, sero-discordant heterosexual couples (i.e., one individual is living with HIV and the other individual is not), commercial sex workers, and injection drug users.<sup>186</sup> On the basis of these early clinical trials, the FDA approved PrEP, in the form of Truvada, for an HIV-prevention indication in 2012.

In 2014, CDC launched guidelines recommending PrEP for individuals at high risk of HIV infection.<sup>187</sup> In 2015, the World Health Organization endorsed PrEP for individuals at high risk of HIV infection (defined as three new infections per 100 person-years or higher).<sup>188</sup>

### Use lags behind need

PrEP is still in the nascent stages of implementation in the United States. Providers and municipalities are aware of PrEP, yet few have specific data on the size of the at-risk population, or the degree of PrEP and other prevention “coverage” of high-risk populations, although a number of municipalities posited estimates. It is essential to establish these targets and visibility to ensure that coverage meets all needs.

Using modeling, CDC has established that an estimated 1.1 million Americans are eligible for PrEP,<sup>189</sup> although CDC recognizes that this figure is an estimate with substantial uncertainty and may represent an underestimate. CDC has intensified efforts to raise awareness and increase the use of PrEP among those at risk for infection, including gay, bisexual, and other MSM, a group that accounted for an estimated 68 percent of new HIV infections in 2016. And there is some early progress: From 2014 to 2017, “PrEP awareness among MSM in 20 urban areas increased from 60 percent to 90 percent, and PrEP use increased from 6 percent to 35 percent.”<sup>190</sup> While use increased in almost all groups, uptake among MSM of color continues to lag.<sup>191</sup>

States and local health departments are still building demand among potential providers of PrEP. Much of the initial PrEP uptake in some settings has been among young white male professionals with private employer-based plans. For example, KC CARE estimates that 75 percent of their PrEP clientele have insurance, including private insurance, and that PrEP users are largely white, male professionals. In contrast, in the Bronx, efforts to get people on PrEP have led to substantial uptake among those without private insurance, including people on Medicaid.

Among interviewees, PrEP programs frequently report that they are lagging in reaching women; some note that there is often a perception that women are not at risk. The Florida Department of Health is working with a university-based program to study approaches to integrating PrEP into family-planning clinics that are popular with women, an approach that could serve as a good platform for driving PrEP uptake.

Multiple interviewees noted the need to reach women engaged in transactional sex and people who inject drugs with low-threshold services that are conveniently located. One jurisdiction reported a diversified portfolio of “many PrEP providers,” including STI clinics, family-planning clinics, private primary care, and community clinics, which they believe is critical for success.

### Strategies to improve uptake

Many jurisdictions have noted that training their community-based HIV testing staff on PrEP helps to drive interest and uptake. A leader within a large HIV program noted:

“[A]ll of our testers also are very educated in PrEP. As they’re out in the community, talking to folks, whether they’re doing testing or not, they’re also promoting PrEP as an option for folks, . . . having conversations with people and able to answer questions pretty intelligently about what PrEP is and what it isn’t and what it looks like, and helping them understand what their resources are in the region. . . . [And,] if they are interested in finding out, making an appointment and going down the road of getting that [established].”

—*Provider*



Some jurisdictions are implementing PrEP social-marketing campaigns. For example, New York had one PrEP social-marketing campaign focused on cis and transgender women, another on Latinx broadly, and another on Latinx MSM. New York also uses a strategy of public health “provider detailing,” in which public health representatives visit provider offices and educate and offer support to providers on STIs and PrEP.

Seattle and other municipalities are using telehealth/telePrEP, including to high-risk sites such as bathhouses. In this program, a PrEP program “navigator” can educate someone about PrEP and then connect them via phone to an experienced prescribing provider who can prescribe PrEP over the phone.

Pharmacies have substantial underutilized capacity for PrEP provision. The state of Washington, for instance, is developing a program to initiate pharmacy-based PrEP throughout the state. Even when PrEP is prescribed by a physician, pharmacists can play a role in PrEP medication management and counseling.

Various jurisdictions are also successfully using emergency departments for PrEP education and referral. This setting is particularly effective at identifying people at high risk for HIV who are presenting for *post*-exposure prophylaxis (PEP) to prevent transmission after experiencing potential exposure.

PrEP navigators have emerged as an important element of PrEP implementation, delivery, and adherence. In some settings, such as in Kansas City, PrEP navigators conduct some case management, helping people to navigate the paperwork for the manufacturer’s patient assistance programs. PrEP navigators can also help support PrEP users in adherence or in addressing barriers to uptake and use.

Many interviewees in counties or states targeted under the new federal HIV strategy listed PrEP among the activities they would like to support with new funds:

“Another area that we would certainly love to be more engaged in would be PrEP access in the state. . . . We’re starting to look at ways in which we can use those resources.”

—*Health department official*

“If we get additional money, additional resources, definitely, PrEP is on the agenda. We’re definitely going to try to push PrEP. We’re definitely going to see how we can push ending the epidemic. We’re definitely going to try to start reaching out to one of our highest populations or age groups, which is 20 to 29, . . . that have the highest infection rates.”

—*Health department official*

## **New national recommendation for PrEP in the primary care setting**

The U.S. Preventive Services Task Force (USPSTF) recommended PrEP as a preventive service in the primary care setting on June 11, 2019. The USPSTF referenced numerous randomized controlled trials that established the efficacy and safety of PrEP for men and women at high risk for acquiring HIV disease, including those who inject drugs.<sup>192</sup> As the USPSTF also noted in its statement, Truvada for PrEP is FDA-approved for adolescents weighing 35 kilograms or more.

Importantly, the USPSTF recommendation means that private insurers must begin paying for the medication without imposing cost-sharing (co-pays or coinsurance).<sup>193</sup> However, experts have pointed out the corresponding need for insurance coverage for the quarterly visits, labs, and counseling that make up the full PrEP intervention,<sup>194</sup> as well as the need to ensure that people without insurance have access to the full set of services.

The USPSTF recommendation could help further expand PrEP by prescribing beyond HIV specialists to a broader provider set, including primary care doctors. As one health department official said of the new USPSTF recommendation:

“[M]y understanding is doctors who may not know a lot about PrEP would respond to the fact that the task force is recommending [it]. It’s no longer just like, [the] ‘HIV clinic should do this.’ This is appropriate for the primary care setting.”

—*Health department official*

## Individual, system, and provider barriers

In some areas of the country, there is a perception that use of PrEP could promote promiscuity. Interviewees ascribed some of this to social, religious, and other beliefs. There are also private providers who do not want to list themselves as PrEP providers because of a perceived stigma. These and other factors may explain in part why Southern states account for over half of new HIV diagnoses yet only about 30 percent of new PrEP users.<sup>195,196</sup>

In addition, several jurisdictions noted that it matters who is doing PrEP outreach. One provider organization noted, “There is a lot of medical mistrust in the African American community, so the messenger really matters.”

A Southern provider described the challenges inherent in the local environment:

“[A partner organization] came down, and they really did struggle to try to understand why a message that worked in the areas up North was not as effective here. That’s because you need to engage folks from the area to help you translate that message. That’s just something I say out loud for a lot of programs that want to come South to really start implementing—they really do need to respect that local area a lot more than what sometimes happens.”

—Provider

PrEP does not provide protection against other STIs and blood-borne illnesses such as HCV, syphilis, and gonorrhea. As PrEP uptake has increased in the United States, the numbers of diagnosed STIs have also increased. This rise may be a consequence of increased “barrier-free” sex, in addition to increased STI testing among PrEP users. However, the rise and already-high rates of STIs also reflect the fact that U.S. STI programs are fragmented and often suffer from inadequate funding. The opportunity with PrEP is to ensure that there is requisite attention to comprehensive testing and treatment for STIs and to promote integration of these services at a wider array of service delivery points. In fact, one modeling study conducted by CDC found that implementation of the STI screening guidelines around PrEP could lead to a net *decline* in STI incidence among MSM.<sup>197</sup>

## The cost of PrEP

Most people who are candidates for PrEP can access the current FDA-approved version of the drug with a fairly-low cost-sharing burden, due to insurance coverage and the support from the manufacturer patient assistance program. However, individuals may still face financial challenges accessing the drug, as well as in paying for the ancillary services recommended for PrEP users. In addition, the cost of PrEP for state Medicaid programs and other payers could present challenges to scaling up.

Truvada’s manufacturer has a patient-assistance program for the uninsured, as well as a copay assistance program for people with private insurance, whose cost sharing for Truvada can reach thousands of dollars per year. The manufacturer of Truvada has also recently committed to donating PrEP to 200,000 people over a 10-year period.<sup>198</sup> According to a 2017 CDC analysis, of the estimated 1.2 million Americans eligible for PrEP in 2015, less than 1 percent would require assistance for the cost of the drug if they fully utilize insurance coverage and manufacturer assistance.<sup>199</sup>

## USPSTF indications for PrEP use in the United States include:

- 1. MSM who are sexually active and have one of the following:**
  - A sex partner living with HIV;
  - Inconsistent use of condoms during receptive or insertive anal sex; or
  - An STI—syphilis, gonorrhea, or chlamydia—within the past six months.
- 2. Sexually active heterosexual women and men who have one of the following:**
  - A sex partner living with HIV;
  - Inconsistent use of condoms during sex with a partner whose HIV status is unknown and who is at high risk; or
  - An STI within the past six months.
- 3. People who inject drugs who have one of the following:**
  - Shared use of needles or other drug injection equipment; or
  - Risk of sexual acquisition of HIV, as described above.

The recommendation highlights certain groups, including sex workers, bisexual men, and transgender women and men, who may be at increased risk for HIV and who providers should consider for PrEP based on the same criteria.



Cost sharing for PrEP medication for those with private insurance will be eliminated in forthcoming plan years due to the new USPSTF recommendation for PrEP. However, for now, changes in insurance and other policies can still lead to variable costs for patients.<sup>200</sup> For example, some insurance companies are no longer allowing the manufacturer assistance card to count toward enrollees' deductibles, resulting in significant cost burdens for individuals.<sup>201</sup> In addition, the perceived high cost of PrEP may discourage patients and providers from considering PrEP uptake.<sup>202</sup>

Meanwhile, the clinical visits, quarterly STI tests, and other monitoring recommended for PrEP users may result in additional out-of-pocket costs, which are compounded by lost work time and travel costs for PrEP users. The 2017 CDC analysis found that 7 percent of potential PrEP users would require financial assistance for ancillary PrEP services and care.<sup>203</sup>

For state Medicaid programs and other payers, the cost of PrEP medication varies. The average wholesale price of Truvada in the United States is over \$2,000 a month, or approximately \$24,000 per year; this represents an increase of approximately 25 percent since its approval for PrEP in 2012.<sup>204,205</sup> However, Medicaid programs receive significant rebates on Truvada from manufacturers, safety net providers, and other 340B-eligible entities through 340B. Even with discounts, costs can be substantial; for example, Massachusetts's Medicaid program expended \$22 million for Truvada in 2017, while California's Medicaid program spent \$50 million; these numbers are expected to climb with greater PrEP uptake.<sup>206</sup> These figures don't account for rebates the state receives from the manufacturer, which are undisclosed and considered proprietary information.

Some health departments are stocking up on PrEP as a strategy to provide initial supplies to people who are working through insurance or manufacturer patient assistance program processes. For example, one local health department said: "We have a supply of PrEP medication. . . . We ensure that anyone who desires access to PrEP medication has at least a 90-day supply of medication regardless of their ability to pay." Multiple jurisdictions noted the high costs of front-loading supplies of PrEP and the opportunity costs in terms of other priority public health interventions (including expenditures that could promote PrEP uptake and retention instead).

## PrEP discontinuation

While PrEP is not necessarily a lifelong practice for all users, discontinuation can hinder HIV prevention for individuals and can also make it difficult to model and measure optimal population coverage of PrEP.

Some PrEP discontinuation is related to the phenomenon of starting and stopping PrEP based on perceived or real risks of transmission, as was observed in one large cohort of American MSM.<sup>207</sup> Discontinuation can also be related to other medication adherence issues like those associated with any long-term medication. An experienced PrEP clinic in a major metropolitan area interviewed for this report estimates that 60 percent of the patients they start on PrEP discontinue it within a year. A study of young MSM starting PrEP in Chicago found 33 percent discontinuation at six months; 21 percent of those who stopped using PrEP reported difficulty getting a doctor's appointment, and another 20 percent discontinued due to insurance-related issues.<sup>208</sup> A study from Los Angeles found that at six months, 37 percent of PrEP users had discontinued PrEP and another 16 percent were lost to follow-up.<sup>209</sup>

Of great concern are the high rates of HIV seroconversion that have been noted in those discontinuing PrEP. In a Montreal study, people discontinuing PrEP had rates of HIV incidence of 3.9 new infections per 100 person-years of observation. Of those discontinuing, 13.5 percent cited side effects as the reason, 23 percent cited either abstinence or entry into a stable monogamous relationship, and 7.2 percent cited cost.<sup>210</sup>

## HIV and substance use disorder

In the early years of the U.S. HIV epidemic, cases of what soon became known as "AIDS" were identified among men who used drugs but had no other known risk factors, and among women who were sexual partners of male injection drug users. Of all cases of AIDS reported to CDC through 1985, 17 percent were among people who inject drugs; by 1995, injection drug use was cited in 30 percent of AIDS cases reported.<sup>211</sup> In the mid-1980s, over half of New York City's population of people who inject drugs were living with HIV.<sup>212</sup>

Today, new diagnoses among people who inject drugs have decreased. In 2016, approximately 5.5 percent of new HIV diagnoses were attributed to injection drug use; another 3 percent were among MSM who inject drugs (i.e., dual risk factors).<sup>213</sup> From the mid-1990s through 2014, there were declines in overall HIV diagnoses connected to injection drug use.<sup>214</sup>

## HIV, the opioid epidemic, and other substance use

The overall decline in HIV diagnoses associated with injection drug use stalled in 2015, when the nation saw a 10 percent increase in new HIV infections among white people who inject drugs, largely due to the opioid epidemic.<sup>215</sup>

While jurisdictions varied in the rate of injection opioid use, multiple interviewees expressed concern that the opioid epidemic would eventually cause higher transmission rates in their jurisdictions:

“What we are concerned about is what’s occurring in some of the counties more north of us where, . . . because they finally are shutting down the pain medicine mills, . . . heroin dealers are moving in at much cheaper rates, of course, and therefore, we’re going to see that increase. . . . It’s more isolated, but it’s going to get worse and we know that.”

—*Provider*

As one interviewee noted, syringe services programs are important even for regions where injection opioid use is not, or not yet, dominant:

“Interestingly, we still see more meth use as a percentage of use out of our needle-exchange clients. It’s less dominant than it used to be. Heroin and other opioid-based injectables are catching up.”

—*Provider*

Other patterns of drug use are associated with HIV risk even if the drugs are not injected. As one provider noted, “chemsex”—the use of certain recreational drugs to facilitate or enhance sex—is associated with higher risk of HIV, as well as HCV and bacterial STIs.<sup>216</sup> It is therefore vital that HIV policy responses, while recognizing the threat posed by increasing injection opioid use in some regions, also reflect the broad range of behaviors and experiences of people who use drugs.

## Syringe-exchange services

Syringe services programs (SSPs) have contributed to the decline in new HIV diagnoses among people who inject drugs.<sup>217</sup> These programs provide clean needles or syringes so that people who inject drugs do not share equipment; they also offer additional supplies and linkages to a range of services, including substance use treatment. The evidence has shown for decades that SSPs are effective at reducing HIV transmission, as well as HCV transmission, without increasing rates of drug use. As summarized by CDC:

“Nearly 30 years of research has shown that comprehensive SSPs are safe, effective, and cost saving, do not increase illegal drug use or crime, and play an important role in reducing the transmission of viral hepatitis, HIV and other infections. . . . Research shows that new users of SSPs are five times more likely to enter drug treatment and about three times more likely to stop using drugs than those who don’t use the programs. . . . SSPs that provide naloxone also help decrease opioid overdose deaths. SSPs protect the public and first responders by facilitating the safe disposal of used needles and syringes.”<sup>218</sup>

It is important to note that for a given individual, ending injection drug use is another effective way to avoid HIV transmission from shared equipment. However, many people are unwilling or unable to quit, or lack access to effective substance use treatment programs: In 2017, less than one in five adolescents and adults who needed substance use treatment received services.<sup>219</sup>

Despite the overwhelming evidence supporting their use, SSPs have faced political and ideological resistance at the federal, state, and local levels. Until they were recently revised in 2016, federal appropriations bills prohibited the use of any HHS funds, including HIV-prevention funds, for SSPs. Congress lifted the total spending ban, but current law still prohibits the expenditure of federal funds for the syringes themselves.<sup>220</sup>

As of 2017, SSPs remained explicitly illegal in 15 states.<sup>221</sup> However, policies are changing: Georgia, Idaho, and Florida legalized SSPs in 2019, and efforts are underway to advocate for legislative change in other states.<sup>222,223,224</sup>



Whether or not SSPs are legal in a given state, they are largely inaccessible across many swaths of the country. In 2016, CDC identified 205 counties, primarily rural, at high risk of an HIV or HCV epidemic among people who inject drugs; as of 2017, 93 percent of those counties had zero SSPs.<sup>225</sup> In some areas where SSPs are technically legal at the state level other laws—such as those criminalizing the possession of drug paraphernalia—can render program participants vulnerable to criminal penalties.<sup>226</sup>

Many of the health departments and providers interviewed for this project either provide or are supportive of SSPs. AFAN (see profile page 13) was one of the first locations in Las Vegas to have a needle-exchange vending machine, a novel approach to making clean syringes available on demand to reduce HIV and HCV transmission risk.<sup>227</sup>

“The idea that we had [was], if you make the needles open for people and leave it open for people to just access them, drug use is just going to go to the roof. . . . Really, we had not seen any of that stuff. What we did see is that even hardcore drug addicts will come and thank us because they had the ability to just get their own needles and they didn’t want to share anything with anybody else.”

—*Antioco Carrillo, AFAN*

Since the 2015 outbreak, the Scott County, Indiana, health department has established a needle-exchange program (see Scott County profile, page 21), supported by CDC funds from the state health department, along with syringes purchased by an Indianapolis-based organization. These services, along with a multi-component public health response and the provision of HIV care and substance use treatment services, led to the abatement of the outbreak.<sup>228</sup>

Dr. William Cooke notes that 98 percent of people with HIV in Scott County who are still injecting drugs are engaging in the SSP:

“I think that shows that these are people. They’re not bad people—they’re people. And when they’re not stigmatized and criminalized, and they’re offered a way to engage in care . . . that feels safe to them, they’re willing to do that. They’re really taking responsibility because they’ve been given the opportunity to.”

—*Dr. William Cooke, Foundations Family Medicine*

Overall, Dr. Cooke noted, the provision of non-stigmatizing services to people who use drugs serves both the individuals and the community:

“Stop saying ‘issues’ and start saying ‘people.’ . . . With services, crime goes down, disease transmission goes down, employability goes up, the economics of an area improve. We get so stuck on the issue— ‘it’s illegal’—and we don’t see the truth behind it, that if we invest in the people, all of that improves.”

—*Dr. William Cooke, Foundations Family Medicine*

# Policy Considerations

Based on the research and the insights gained from the interviews for this project, BPC offers the following considerations for federal, state, and local policymakers and health officials.

## ACCESS TO SERVICES

- 1. Continue to support the Ryan White program.** The Ryan White program continues to serve a vital role in supporting HIV care and treatments across a broad variety of jurisdictions. About half of all people living with HIV in the United States received at least one RWCA service in 2017.<sup>229</sup> The viral suppression rate among RWCA clients who received at least one outpatient visit was 84.9 percent—significantly higher than the national average.<sup>230</sup> Funding increases could permit state and local programs to invest more deeply in addressing the social determinants of health that stand in the way of full access to HIV care—access that researchers have found reduces productivity losses and overall costs of illness.<sup>231</sup>
- 2. Expand insurance coverage.** Lack of health insurance contributes to lower health care access and worse HIV outcomes. Stakeholders engaged in ending the epidemic at the local, state, or national level should support coverage expansion in all states. While Medicaid expansion in the remaining 14 states that have not expanded could help in increasing access to comprehensive health coverage for people living with HIV and at-risk for HIV, state-specific approaches short of a full expansion may be beneficial if they ensure robust, affordable, and stable coverage for people living with HIV and other enrollees.
- 3. Improve access to care in rural areas.** People living with HIV in rural communities continue to experience significant barriers to care, including transportation and stigma. Federal and state governments should aggressively invest in innovative approaches to increasing access to preventive and care services, including through telehealth, which has been shown to improve access for a variety of health conditions and to reduce costs for rural patients.<sup>232,233</sup> HIV stakeholders should support efforts to shore up rural health infrastructure, including advocacy for innovative payment models that reflect the realities of rural health care provision more broadly.<sup>234</sup>

## FACILITATORS AND BARRIERS TO THE HIV RESPONSE

- 4. Invest in public health infrastructure, workforce and surveillance.** The federal government and states should invest in the public health infrastructure and human resources necessary to maintain robust and interoperable HIV surveillance systems, while strengthening the overall public health system. Congress should direct increased funds to efforts that integrate HIV service providers into surveillance systems, allowing data to inform their linkage and retention efforts as well as other provider activities.
- 5. Address unmet social needs.** Poverty and unmet social needs remain major barriers to HIV prevention, care, and treatment throughout the country. As extensive evidence indicates, stable housing is one of the strongest predictors of whether a person can maintain HIV primary care, and housing significantly reduces engagement in transmission risk behaviors.<sup>235,236,237</sup> Congress should continue to support the Housing Opportunities for People With AIDS program and consider increases in future years. In addition, policymakers at the federal and state levels should consider making some or all of the new funds under the recent federal HIV strategy as flexible as possible to permit innovative local solutions to address social determinants of health.
- 6. Reduce stigma.** Addressing HIV requires a policy environment that supports people living with or at risk of HIV. The federal government should consider the impact of policies that harm LGBTQ people, immigrants, women, and other populations—policies like the proposed weakening of section 1557 nondiscrimination regulations under the ACA. States could take measures to modify or rescind policies that reflect and reinforce stigma related to HIV, including but not limited to HIV criminalization statutes.



## TARGETED PROGRAMMING

7. **Target programs and resources for youth.** Young MSM and other LGBTQ youth of color continue to bear an enormous share of the HIV burden. Federal and state policymakers should assess whether funds in the RWCA program and CDC prevention grants adequately support this population with a range of social services and peer support, as well as through scaling up universal HIV-prevention and education programs grounded in evidence-based, non-stigmatizing information about HIV. People who reflect the population served should staff the programs serving young MSM of color and other youth. States and payers should also review their respective laws and policies to ensure that minors and youth can access needed services, including PrEP, safely and privately. States should review their consent and confidentiality laws to ensure that minors and youth can access needed services safely and privately. In addition, state Medicaid programs and other payers could develop policies allowing suppression of mailed explanations of benefits or denial notices, to preserve the privacy of minors and other sexual and reproductive health services.
8. **Maintain focus on maternal health, vertical transmission, and pediatric care.** Federal policies and frameworks have been critical to the gains made in reducing new infant infections over the last two decades and caring for children living with HIV. The intensity of efforts needed to maintain this progress should continue to increase, and these efforts should ensure that specialty obstetrical, maternal, and pediatric HIV care remain widely available. In order to ensure adequate resources are available to respond to emerging trends, the Centers for Disease Control and Surveillance could consider how to strengthen national, state, and local surveillance to improve outcomes among women living with HIV and their infants. In addition, dedicated efforts should focus on reducing ethnic and racial disparities in new pediatric HIV infections and serving adolescents, who represent the largest group of children living with HIV and are at particular risk of poor outcomes.
9. **Prioritize equitable access to PrEP.** Although PrEP use is increasing, those most at risk for HIV infection are lagging in terms of uptake. PrEP should be prioritized as a part of comprehensive primary care and prevention/wellness programs and federal funding streams, with a focus on MSM of color and women of color. All efforts should be made to reduce barriers to PrEP access, including increasing patient and provider awareness, combating PrEP-related stigma, supporting PrEP navigation, and addressing patient or systemic financial barriers related to the cost of PrEP drugs and related clinical services. Public and private payors should remove any barriers to PrEP access, such as burdensome prior authorization requirements, for all populations at risk, including dependent minors. Provider organizations should leverage the new USPSTF recommendations to promote knowledge of PrEP and practice support among providers, particularly in the primary care setting.
10. **Increase programs to address HIV and substance use disorders.** SSPs are increasingly accepted on both sides of the aisle as an effective harm-reduction intervention that does not increase drug use; however, they are still greatly underused as HIV-prevention resources. At the federal level, any remaining barriers to using federal funds for SSPs should be eliminated, and Congress should develop funding streams devoted to supporting SSPs so that they do not compete for funds with other evidence-based prevention programs. States and localities could eliminate existing barriers to SSPs and request federal funds for SSPs.

# Conclusion

As the United States nears the end of the fourth decade of the HIV epidemic, public health agencies and providers at the local level continue to lead the charge. Meeting the new national targets of a 75 percent reduction in new HIV infections in five years, with at least 90 percent reduction in 10 years, will require significant resources and supportive policies to bolster on-the-ground work in communities across the country. Though the jurisdictions profiled in this report vary significantly by geography, politics, resources, and epidemiology, they share many common challenges and hopes. Federal, state, and local policymakers should work to support their efforts with resources and supportive policies to help support people at risk of HIV and living with HIV—and to end the epidemic in America.



# Appendix: Project Interviewees

Jurisdiction	Health Department Interviewees	Provider Interviewees
Seattle, WA	<p>Julie Dombrowski, M.D., MPH Associate Professor of Medicine, University of Washington Deputy Director, Public Health - Seattle &amp; King County HIV/STD Program</p>	<p>Shireesha Dhanireddy, M.D. Director, Infectious Diseases and Travel Clinic Director, Madison Clinic Harborview Medical Center Professor of Medicine, Division of Infectious Diseases University of Washington</p> <p>Gwendolyn Barker, MPH Clinic Manager, Madison Clinic Harborview Medical Center</p>
The Bronx, NY	<p>Oni Blackstock, M.D., MHS, Assistant Commissioner, NYC Department of Health; Clinical Assistant Professor, Albert Einstein College of Medicine</p>	<p>Barry S. Zingman, M.D. Medical Director, AIDS Center Clinical Director, Infectious Diseases, Moses Division Professor of Medicine, Albert Einstein College of Medicine Montefiore Medical Center The University Hospital for Albert Einstein College of Medicine</p>
Kansas City, MO	<p>Samantha Hughes, M.P.A. Interim HIV Service Manager City of Kansas City, MO - Health Department</p>	<p>Dennis Dunmyer Chief Operating Officer KC CARE Health Center</p>
Jacksonville (Duval County, FL)	<p>Joseph E. Mims Area 4 HIV/AIDS Program Administrator Florida Department of Health in Duval County</p>	<p>Daniel Merkan Director of Policy Jacksonville Area Sexual Minority Youth Network (JASMYN)</p>
Clark County, NV (Las Vegas)	<p>Joseph P. Iser, M.D., DrPH, MSc Chief Health Officer Southern Nevada Health District</p>	<p>Antioco Carrillo, MSW Executive Director Aid for AIDS of Nevada</p>
Scott County, IN	<p>Michelle Matern, MHA Scott County Health Department Administrator</p>	<p>William Cooke, M.D., FAAFP, AAHIVS Foundations Family Medicine</p>
Richmond, VA	<p>Melissa Viray, M.D. Deputy Director Richmond City and Henrico Health Districts</p> <p>Justin Wallace, MPH HIV Prevention Supervisor Richmond City Health District</p>	<p>Phyllis Mann, MED., MS, CSAC, MAC Wellness Supervisor Medical Case Manager Vernon J Harris Medical Center Capital Area Health Network</p>
Montgomery, AL	<p>Alabama Department of Public Health:</p> <p>Allison R. Hatchett, MPH Director Direct Care Ryan White HIV/AIDS Program Part B Division of HIV Prevention and Care</p> <p>Sharon Jordan, MPH Director, Division of HIV Prevention and Care</p> <p>Jora T. White, MA Director, Prevention Program Branch Bureau of Communicable Disease</p>	<p>Medical Advocacy and Outreach, Alabama:</p> <p>Laurie Dill, M.D. Medical Director</p> <p>Michael Murphree, L.C.S.W., Chief Executive Officer</p> <p>Ashley M. Tarrant, MPH Chief Operations Officer</p>

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# Notes







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