

The Ryan White HIV/AIDS Program provides comprehensive medical care and support services.

Nearly one-half of clients served are African-American.



## Issues

### African-Americans

African-Americans are the racial and ethnic group most disproportionately affected by the HIV/AIDS epidemic. By providing culturally competent, comprehensive care the Ryan White HIV/AIDS Program is committed to turning this tide.

## Addressing HIV Among African-Americans

If we fail to end AIDS in the Black Community...we fail to end AIDS.

—Phill Wilson, President and CEO of the Black AIDS Institute

The early days of the HIV/AIDS epidemic in the United States imbued the collective consciousness with images of young gay White men in New York and San Francisco dying quick, brutal deaths from a mysterious disease. AIDS appeared to have descended overnight; but as terrifying as it was, media and health officials assured the public that its cause resided in the dangers of gay promiscuity, not pathogens. As James Curran, a medical doctor and spokesperson for the U.S. Centers for Disease Control and Prevention (CDC), explained in a 1981 *New York Times* article, “The best evidence against contagion is that no cases have been reported to date outside the homosexual community.”

It quickly became apparent, however, that the disease originally called gay-related immunodeficiency (GRID) could impact anyone—and quickly did. Communities of color, and most notably African-Americans,<sup>1</sup> were disproportionately impacted from the start. While African-Americans individually may not have believed they were at risk for HIV infection,<sup>2</sup> they understood its threat to their communities. While other communities pointed only to gay White men, William Hawkeswood notes in *Transforming Anthropology* that Harlem residents in New York City understood that the “epidemic thing” had infected “Blacks...who had connection with the white gay scene” and were heterosexual men and women who used injection drugs.<sup>3</sup>

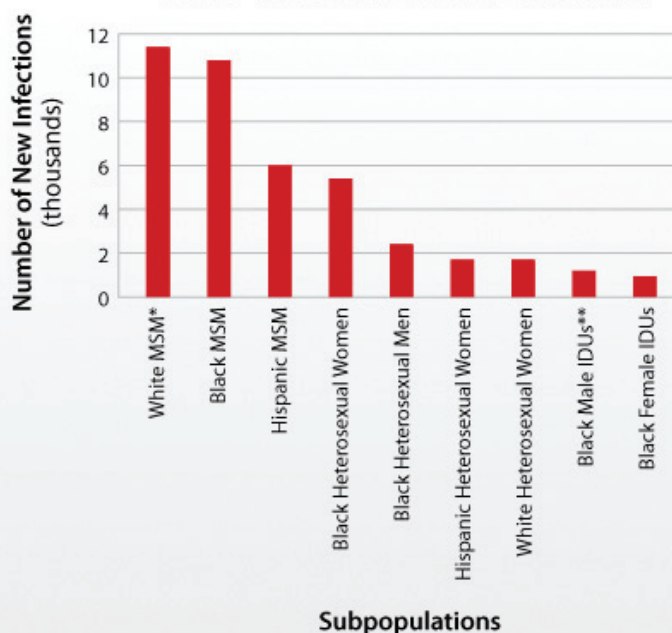
Phill Wilson, president and CEO of the Black AIDS Institute, is a gay African-American man who has lived with AIDS since 1981. He says that “back in the day, as our friends and loved ones got sick, we knew it was serious. Little did we know that it would be the health catastrophe of our generation.”

The devastating impact of HIV on African-Americans cannot be overstated. In 1981, Blacks accounted for approximately one-quarter of all new HIV infections.<sup>4,5</sup> Seven years later, African-Americans surpassed Whites in the number of new HIV infections

for the first time—a trend that continues to this day.<sup>6</sup> Blacks, who account for about 14 percent of the total U.S. population, represent nearly one-half of the estimated 50,000 new HIV cases that occur every year, and about 500,000 of the almost 1.2 million people living with HIV/AIDS (PLWHA) overall.<sup>7,8,9,10,11</sup>

The lifetime risk of HIV is far higher among African-Americans than any other ethnic group. Black women have a 1 in 32 chance of acquiring HIV in their lifetime, compared to White women, who have only a 1 in 588 chance of HIV infection.<sup>12</sup> Black men are at even greater risk, with a 1 in 16 lifetime chance of acquiring HIV, compared to White men, who bear a 1 in 104 risk.<sup>13</sup>

#### ESTIMATED NEW HIV INFECTIONS IN THE U.S. IN 2009, FOR MOST AFFECTED SUBPOPULATIONS



Subpopulation	Number of New Infections
White MSM	11,400
Black MSM	10,800
Hispanic MSM	6,000
Black Heterosexual Women	5,400
Black Heterosexual Men	2,400
Hispanic Heterosexual Women	1,700
White Heterosexual Women	1,700
Black Male IDUs	1,200
Black Female IDUs	940

Source: CDC. *CDC fact sheet: estimates of new HIV infections in the United States, 2006-2009*. Available at [www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf). Accessed December 15, 2011.

\* The term MSM refers to “men who have sex with men.”

\*\* The term IDU refers to “injection drug user.”

## From Community Care to HRSA, HAB Leader

The HIV/AIDS epidemic in the 1980s created a new generation of community organizers. These courageous men and women helped form the earliest networks of HIV care, founding the first AIDS service organizations and leading advocacy efforts on behalf of people living with HIV/AIDS. These efforts would result in the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which established the Ryan White HIV/AIDS Program.

Some of these leaders later brought their experience on the frontlines of the epidemic to the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). This group of invaluable personnel includes Michael Evanson, who began his career in the 1980s delivering care to PLWHA in Washington, DC, at the Whitman-Walker Clinic.

Evanson joined HRSA, HAB as a project officer in 1998, and has played a key role in improving the quality and reach of HIV/AIDS care in underserved communities. Today, he serves as HAB's senior policy analyst, representing the Bureau in the interagency workgroup overseeing the rollout of the National HIV/AIDS Strategy.

He says, "We keep the barriers and stigmas that prevent African-Americans and other marginalized populations from accessing care at the forefront of our conversations about the NHAS. It is only by addressing these issues head-on will we be able to truly end HIV/AIDS in the U.S."

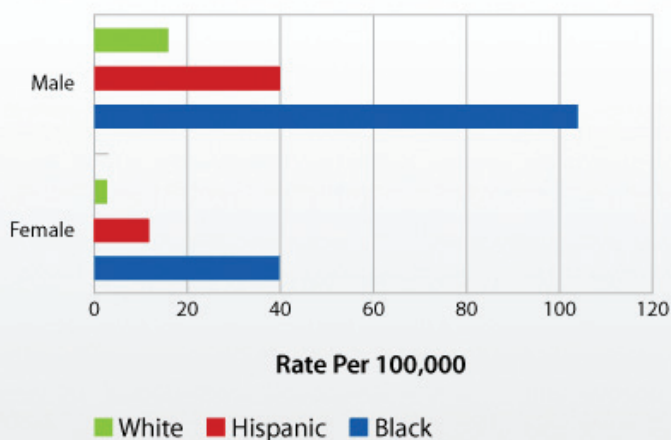
## Roadblocks to HIV Screening, Treatment, and Care in Black Communities

Much of the disproportionate impact of HIV, and subsequent high demand for Ryan White-funded services among African-Americans reflects the socioeconomic drivers found within their communities. David J. Malebranche, an assistant professor of medicine at Emory University's School of Medicine who has a joint appointment with the Rollins School of Public Health in Atlanta, Georgia, says a combination of socioeconomic factors, from lack of insurance to limited health literacy, has helped perpetuate HIV in the Black community. "Take lack of education and employment, displacement, homelessness, powerlessness, trading sex for money—and then throw HIV in the mix—and it's going to be an explosion" of health disparities and HIV infection.

Also added to the "mix" is poverty, with over one-fifth of African-Americans living below the Federal Poverty Level (FPL).<sup>14</sup> This reflects, in part, the economic downturn in 2008 and resulting unemployment experienced nationwide. The recession has devastated African-American communities, which have experienced rates of unemployment nearly twice the national average of 8.8 percent.<sup>15,16</sup> As a result, nearly 21 percent of Blacks report living without health insurance, which has seriously undermined health outcomes and fueled health disparities, such as disproportionate rates of heart disease and diabetes, as well as HIV/AIDS, in Black communities.<sup>17</sup> As one HIV provider in New York City explains, "HIV medications and hospitalizations are expensive. And unfortunately when you are Black and poor, whether you are a man or a woman, it is just one of the things you have to deal with and manage."

African-American women and gay Black men have been particularly hard hit by HIV, though they experience slightly different barriers to care. According to the CDC, most Black women diagnosed with HIV/AIDS live in poverty, which severely undermines their ability to seek HIV services.<sup>18</sup> The story of Delores, an African-American woman

### ESTIMATES OF NEW HIV INFECTIONS IN THE U.S. IN 2009, BY GENDER AND ETHNICITY (RATE PER 1,000)



Gender	White	Hispanic	Black
Male	15.9	39.9	103.9
Female	2.6	11.8	1,189

Source: CDC. CDC fact sheet: *Estimates of new HIV infections in the United States, 2006-2009*. Available at [www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/HIV-Infections-2006-2009.pdf). Accessed December 15, 2011.



HIV was the fourth leading cause of death for African-American men and women ages 25 to 54.<sup>55</sup>

living with HIV, is typical of many African-American women learning their status for the first time:

I was poor, and at that time, I was using drugs and having sex to both feed my habit and keep a roof over my head. I didn't think about the risk of AIDS—I thought about the next fix, and what I had to do to survive. I didn't do anything about it at first, including use condoms, or get into care for two years.

It was not until she got into treatment for her drug addiction, with the help of a Ryan White-funded provider, that she could even accept that she had AIDS. Unfortunately, too many Black women enter HIV care too late. HIV/AIDS has been one of the leading causes of death since 2000 for African-American women ages 10 to 54.<sup>19</sup> In 2011, HIV/AIDS was the number one cause of death among Black women ages 35 to 44.<sup>20,21</sup>

The internalized stigma and stress experienced by many PLWHA are often heightened among African-American women already stressed by the daily responsibilities of caring for children and other family members. It is not uncommon for providers to report that HIV-positive Black mothers often defer medical appointments and purchasing medications to ensure their family's needs are met. Much of this selflessness is driven by cultural norms of “collective responsibility,” in Black communities, which designates African-American women as caretakers of children, their partners, and their extended family and community members.<sup>22</sup>



This role often renders them unable to negotiate safer sex due to pressures to maintain a relationship at any cost, particularly during times of economic scarcity.<sup>23</sup> Asking a partner to use a condom can be construed as both accusatory and an admission of infidelity, possibly resulting in violence and/or abandonment. The latter may be particularly troubling for many Black women due to the ever-shrinking pool of African-American men, who have higher mortality and incarceration rates than men in other ethnic groups, especially in areas of lower socioeconomic status.<sup>24</sup>

Prisons and jails often offer inmates an opportunity to engage in consistent [HIV treatment and care](#), as well as discharge planning to ensure that they can maintain their health after their release. At the same time, [incarceration does place inmates at risk for infectious diseases](#), such as hepatitis, tuberculosis, and sexually transmitted diseases, which can facilitate transmission of HIV during sexual encounters and tattooing.<sup>25</sup> In these instances, heterosexual and gay men<sup>26</sup> often leave jail unaware of their HIV status, or unwilling to disclose their status to partners and





Curtis, diagnosed in 2006, has benefited from the care and services provided by It Takes a Village, a subgrantee of the Denver Part A Transitional Grant Area. To watch his video, visit: <http://hab.hrsa.gov/livinghistory/voices/curtis.htm>.

access treatment and care upon returning home, leaving them at risk to progress to AIDS and/or infect others.

Black MSM have been most heavily impacted by HIV/AIDS in their community. Though only 4 percent of males ages 13 and older in the United States are MSM, they accounted for 61 percent of all new HIV infections in 2009. African-American MSM represented the majority of these cases, with 60 percent of all new HIV infections occurring among young Black MSM ages 13 to 29.<sup>27</sup>

High rates of HIV among African-American gay men stem from a number of factors, including a growing sense of complacency around HIV. This is particularly true among younger generations of African-American gay men, who often consider HIV a disease that happens to other people and can be easily “fixed” with medication. They often point to basketball player Earvin “Magic” Johnson, who announced his HIV status in 1991 and has seemed healthy ever since beginning highly active antiretroviral therapy (HAART).<sup>28</sup> As one advocate notes, “He is doing well and doesn’t ‘look’ like a person you think has AIDS. It doesn’t appear to affect his quality of life. So folks look at that and don’t think that AIDS is that bad—that you can just take a pill.”

As a result, many Black MSM do not know they have HIV until later in their infections. In the CDC’s Young Men’s Survey, conducted from 1994 to 2000, Black MSM were diagnosed with HIV at rates five times those of their White counterparts. Yet of the young men that have sex with men (YMSM) of color who tested positive for HIV in that study, 82 percent said they did not know they were infected, and most did not believe they were at risk for HIV in their lifetime. Only 15 percent were connected to HIV primary care and treatment.<sup>29,30,31</sup>

Homophobia also plays a major role in preventing Black MSM from understanding their risk for HIV, or accessing HIV prevention, testing, treatment, and care services. Rejection by their friends and families often forces them to leave home at an early age, and many end up homeless and engaging in sex work to survive. One nurse at a Ryan White provider site shared how he found a young Black man diagnosed with HIV and syphilis, who had been lost to care and living at a shelter; his mother had died shortly after he learned he had HIV, and his grandparents had turned him away for being “gay with AIDS.”



In 2010, Black women accounted for more than 63 percent of all estimated HIV diagnoses among women in the United States.<sup>56</sup> Most of these cases—88 percent—were attributed to high-risk heterosexual contact.<sup>57</sup>

Black MSM tend to experience earlier sexual debut than their heterosexual counterparts, often with older, more experienced partners.<sup>32</sup> It is not uncommon for young African-American MSM to have relationships with older Black MSM in order to have access to housing, food, and other resources to survive. These relationships, while often caring, have helped perpetuate HIV across multiple generations of Black MSM. Like African-American women, young Black MSM feel they cannot ask their older partners to use condoms, for risk of being cut off or threatened with violence. Many of these older Black men were infected through similar relationships in their youth, and in turn transmit HIV to their younger partners.<sup>33</sup>

### Stigma, Racism, and the 4H Club

Stigma is perhaps the greatest driving force behind HIV infection among African-Americans. Both African-American men and women in many Black communities continue to express a deep reticence to embrace community members living with HIV/AIDS, despite the prevalence of the disease. It is not uncommon for families, fearing reprisals from others, to say that a loved one died of cancer rather than HIV. Michael K. Evanson, senior policy analyst in the Division of Science and Policy at the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), echoes this sentiment:

Unfortunately we are still dealing with stigma particularly in the South where the epidemic is still growing at a more alarming pace than in other areas of the country. You hear stories that people are still very much ashamed to have HIV due to religious beliefs and cultural stigma. People view the disease with a lot of disdain and blame those who are living with it. There are certainly huge barriers that still exist [to testing and care].

Many recount stories of family and friends fearing they might contract HIV through casual contact. Black PLWHA often are forced to eat with disposable cutlery, plates, and cups during social gatherings, and often find their hosts cleaning whatever they touched with disinfectant.

“Admitting that you have HIV is a hard thing. It is hard to even admit it to yourself,” says one gay man from Washington, D.C. “It was difficult for my family to accept my diagnosis and me for a long time. They couldn’t see that I was the same person.”



Distrust of the medical system as well as HIV stigma in the African-American community contribute to testing and engagement in care barriers.



By using culturally competent care to create a safe and accessible medical environment for African-Americans living with HIV/AIDS, particularly women and their families, great strides have been made in diffusing the stigma surrounding HIV/AIDS and its treatment in the African-American community.

Stigma is not only a barrier to screening and diagnosis, it is one of the leading reasons why many African-Americans do not seek out or stay in care. Some Black patients point to bad experiences in the past with providers who did not understand how to address the needs of African-Americans living with HIV. “Before doctors and nurses really got trained, we were turned away. People didn’t want to touch us, or treat us. It is a memory that is hard to forget,” says a Black gay man who has been living with AIDS for the past 25 years. “Who would want to subject themselves to that? And unfortunately many people still anticipate that kind of treatment and stigma when they seek out care in 2012.”

Distrust of the medical system has been a barrier to care for African-Americans long before the AIDS epidemic. Blacks have the highest mortality rates due to heart disease, diabetes, and some cancers, partially because of their distrust of medical providers, and the poor treatment they experience when they get into the system. There is also the lingering legacy of mistreatment by researchers—particularly during the Tuskegee Syphilis Experiment—which left Blacks wary of medical programs and clinical trials.<sup>34,35</sup>



Cultivating a supportive and active community is crucial to improving health outcomes for African-Americans living with HIV/AIDS.

Black **immigrant populations** face additional language and cultural barriers to care. Some may fear arrest due to immigration issues, while others are reticent to seek care due to the ongoing association of HIV with the Caribbean and Africa. Indeed, simply being Haitian was labeled one of the original four risk factors for AIDS in the early 1980s—known as the “4H club”—along with hemophilia, heroin addiction, and homosexuality.<sup>36,37</sup>

The continued stigma and mistrust of health care professionals threatens the well being of African-Americans communities nationwide. Indeed, Blacks tend to test for HIV later in their infection than Whites, and many, like Delores, are diagnosed with both HIV and AIDS, or progress to AIDS within a year of HIV diagnosis. Due to the lapse in time from seroconversion to development of symptoms, African-Americans diagnosed with HIV in their 20s or even 30s may have actually become infected in their teens. During this time, they may have unknowingly transmitted the virus to others. Entering HIV primary care later in their disease progress also could undermine their health outcomes and shorten their lifespan.





HRSA's Bureau of Clinician Recruitment and Service works to create medical education opportunities for health care workers including minority clinicians.

## HRSA Responds to HIV Epidemic Among African-Americans

In the early days of the AIDS epidemic, care was virtually nonexistent. Many patients died in hospital emergency wards. Those who were admitted encountered terrified health care workers and indifferent medical doctors who refused to touch them without wearing HAZMAT “moon suits.” In the midst of this suffering, a loosely connected system of community-based organizations, providers, activists, patients, friends, parents, and partners formed, providing the first real network of health and support services for PLWHA.<sup>38</sup>

HRSA recognized and harnessed the power of this community-based response to HIV/AIDS and funded the first HIV-specific Federal health initiatives, known as the [AIDS Service Demonstration Grants](#), in 1986. Launched in four of the Nation's most heavily impacted cities—New York, San Francisco, Los Angeles, and Miami—the grants provided much needed financial and political capital to those delivering HIV care on the ground. They also legitimized and heralded the community-based response's ability to effectively “provide the spectrum of needed services for people with HIV infection and its complications and provide appropriate alternatives to inpatient care.” For the first time, there was a sense of compassion and support for PLWHA among government officials, the media, and the general public.<sup>39</sup>

The demonstration grants also laid the foundation for the Ryan White HIV/AIDS Program, established with the passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The Program is not an entitlement, but the payer of last resort for PLWHA who otherwise would not be able to afford treatment, care, and support services for themselves or their families.<sup>40</sup> Almost 500,000 PLWHA access Ryan White services annually, most of whom mirror the populations heavily impacted by HIV/AIDS: injection drug users, racial and ethnic minorities, women, and children. Almost one-half of all Ryan White HIV/AIDS Program clients were African-American in 2007 and 2008.<sup>41</sup>

The Ryan White HIV/AIDS Program has responded to the needs of Black PLWHA by providing comprehensive, culturally competent care. Many provider sites are medical homes, which offer patients a continuum of care that includes HIV primary care as well as support and specialty services all under one roof, or within proximity.<sup>42</sup> These multifaceted care structures ensure clients can access the full array of HIV services they need, regardless of the “door” they use to enter care.



Many community-based health centers offer a bright, friendly, and welcoming environment complete with art and other personalized touches to make patients feel at home.





Though Black teenagers account for only 17 percent of the U.S. population ages 13 to 19, they represent 70 percent of all new AIDS diagnoses in their age group.<sup>58</sup>

To ensure that Black PLWHA remain in care, providers often create a welcoming atmosphere complete with comfortable waiting areas that look more like living rooms than hospital hallways. Medical personnel and support workers are trained to understand the unique health concerns, cultural norms, and psychosocial and economic realities of Black PLWHA. In addition, many staff members are African-American themselves and, in the case of clinics serving Black immigrant populations, share their clients' cultural backgrounds. They often speak their clients' language(s), or have access to appropriate translation services.

HRSA and its providers have also taken measures to help allay their clients' fears around confidentiality. In addition, sites often offer same-day appointments, as well as support services, such as transportation, childcare, health education, and housing assistance, to facilitate continued access to care. One provider, who has participated in several HRSA Special Projects of National Significance (SPNS) initiatives concerned with increasing linkages to care for at-risk PLWHA, recalls, "We had an African-American mother who had to bring her four children, all under age 5, with her to the clinic in order to make an appointment. The kids ran everywhere...[but] we were happy to have her there and in care."

The quality of care provided by Ryan White HIV/AIDS Program providers and grantees often rivals, if not exceeds, that delivered by private hospitals and clinics.<sup>43</sup> For many African-American PLWHA, enrolling in the Ryan White HIV/AIDS Program marks their first encounter with systematic, regular care. Much of this is delivered through Part A of the Program, which covers a majority of Ryan White clients.<sup>44</sup> U.S. States and Territories receive Part B funding based on their proportion of living HIV/AIDS cases. These funds have helped States in the rural South and in urban areas, like Washington, D.C., where the epidemic has continued to grow relative to other parts of the country, particularly in Black communities.

Part B also includes the AIDS Drug Assistance Program (ADAP), which evolved from HRSA's [AIDS Drug Reimbursement Program](#), established in 1987, which enabled providers to offer African-Americans and other patients access to zidovudine (AZT), the first drug approved by the U.S. Food and Drug Administration (FDA) to treat HIV. Today, ADAP not only provides PLWHA access to life-saving medications, it supports education programs geared to recruiting African-Americans and other vulnerable PLWHA into highly active antiretroviral therapy—the gold standard of HIV care.

[Pediatric AIDS Service Demonstration Grants](#), first awarded in 1988 and later incorporated into the Ryan White HIV/AIDS Program as Part D, have supported HIV treatment, care, and support services for African-American women and their families. This holistic approach to care has proven to be a lifeline for so many HIV-positive Black women. Part D also helped disseminate guidance developed during the [AIDS Clinical Trial Group Study 076](#) (ACTG-076) in 1994, which demonstrated AZT's efficacy in reducing mother-to-child transmission of HIV during pregnancy and nursing.<sup>45</sup> This approach dramatically reduces perinatal transmission, particularly in Black communities, in which most mother-to-child HIV infections occurred.<sup>46</sup>

HRSA, along with Ryan White HIV/AIDS Program providers and grantees, understands that much remains to be done to end HIV/AIDS and ensure that those living with the disease are engaged in treatment and care. The CDC estimates that 20 percent of PLWHA remain unaware of their status. There are also PLWHA who are aware of their status but not engaged in care, or have fallen out of it. A disproportionate number of PLWHA in all of these groups are African-American, which has serious implications for the health outcomes of Black communities overall. As of 2012, Blacks accounted for approximately one-half of the nearly 600,000 HIV/AIDS deaths that have occurred in the United States since the epidemic began.<sup>47</sup>

Fortunately, Ryan White HIV/AIDS Program providers are well-equipped to address the needs of African-American clients. Those that wish to ramp up their service delivery to Black PLWHA have access to a wide-range of programs and tools that support and foster innovation, and help fill in any gaps in care. For instance, Part C supports a variety of HIV service providers in delivering a tightly woven continuum of Early Intervention Services (EIS) that help identify PLWHA and engage them in care earlier. Newly-diagnosed PLWHA are provided intensive case management as well, which often proves essential to African-American PLWHA in learning how to navigate health care systems and in developing the skills to manage their HIV.<sup>48</sup> Providers targeting African-American PLWHA also benefit from Part C's Planning and Capacity Development Grants Program, which supports providers attempting to engage and retain underserved populations in care.

Most Ryan White capacity-building assistance programs, however, are in Part F. These include the Minority AIDS Initiative (MAI), established in 1998 during a meeting between Federal officials and African-American service providers and community leaders about the continued disproportionate impact of HIV in Black communities. During the meeting, those in attendance declared a “state of emergency” in the Black community, and demanded the government take further action to bolster the response to AIDS among African-Americans, and heavily impacted minorities overall.<sup>49</sup> HRSA and its Federal

partners listened. The MAI supports the expansion of HIV services within minority and minority-serving providers and community-based organizations managing and treating HIV at the grassroots level. Melanie Wieland, who serves as special assistant to the director in HRSA's Division of Service Systems, notes that MAI funding was never meant to be the sole source of programmatic funding, but rather to “close the gap between PLWHA in communities of color” and ultimately reduce HIV incidence and prevalence among ethnic and racial minorities.

MAI funds have played an integral role in expanding HIV service delivery in African-American communities, enabling providers already serving hard-to-reach African-American PLWHA an



opportunity to address issues around infrastructure and HIV/AIDS stigma that have prevented them from addressing HIV disease. Evanson explains, “MAI funds help Ryan White providers already doing good work to provide a greater level of care and treatment than they otherwise would be able to, particularly for African-Americans and other minority groups.”

In addition to the MAI, Part F also includes the Special Projects of National Significance, which supports the development and testing of innovative and cutting-edge models of HIV care that otherwise would not be funded or evaluated. Numerous initiatives have addressed how to engage various vulnerable subpopulations of African-Americans into HIV care, including [Black gay youth](#); PLWHA in jail settings; adolescents; women of color; and Caribbean PLWHA. The best practices generated from these projects are disseminated to Ryan White HIV/AIDS Program providers nationwide to facilitate their replication, which has helped mitigate HIV/AIDS and improve health outcomes within African-American communities.



In 2010, the HIV rate of infection among African-American men was approximately 7.5 times higher than that of White men.<sup>59</sup>

Providers engaging Black PLWHA also have access to technical assistance through Part F's [AIDS Education and Training Centers](#) (AETCs), which provide resources geared to building capacity to deliver comprehensive, culturally and linguistically competent care to patients. Two AETCs in particular address the needs of providers delivering HIV treatment and care services in Black communities with high rates of HIV/AIDS. These are the National Multicultural Center, which addresses the training needs of providers and clinicians delivering care to ethnic and racial minorities, and the AETC National Center for the Expansion of HIV Care in Minority Communities: Building Capacity in Community Health Centers, which enhances the capacity of non-Ryan White-funded CHCs to provide primary medical care and treatment to racial and ethnic minorities living with or affected by HIV/AIDS. Many of these resources include interactive trainings and guidance, factsheets, training manuals, and presentations, including *BE SAFE: A Cultural Competency Model for African Americans*; *The Impact of Stigma on HIV Care Access in the African American Community*; and *Developing a Peer-Based Early Intervention Services Program*. Like SPNS, they also address the unique needs of different African-American groups, such as Black PLWHA not in care and women over 50.<sup>50,51,52</sup>

### **The Future of the Ryan White Response to HIV in Black Communities**

In the 30 years since the HIV/AIDS epidemic began, there have been many lessons learned. Activists, PLWHA, families, health care workers, and others have demonstrated the power of the community-based response in creating innovative and powerful continuums of care that successfully engage HIV-positive African-Americans.

With support from the Ryan White HIV/AIDS Program, providers have extended the lives of countless African-American PLWHA, preventing new infections and ultimately reducing HIV prevalence and mortality. Access to lifesaving drugs has improved the health outcomes of Black communities overall, including that of HIV-positive African-American mothers, who no longer have to worry about transmitting the virus to their unborn children. This tightly woven network of care will be further enhanced with the full implementation of the Patient Protection and Affordable Care Act (Pub.L. 111–148) in 2014, which will ensure greater access to health care among African-Americans living with and affected by HIV/AIDS. It will also bolster the reach of the providers who serve them.

Perhaps most essential to the success of the Ryan White HIV/AIDS Program in serving Black PLWHA is the continued high quality of care delivered by providers and renewed emphasis on outreach and linkage to care and retention efforts. These have only improved since the rollout of the National HIV/AIDS Strategy (NHAS), begun in 2010. Providers will benefit from the collaboration at the Federal, State, and local levels strengthened by the launch of the NHAS but built upon the groundwork already set forth by the Ryan White HIV/AIDS Program. Ultimately, it will result in more integrated approaches to supporting providers delivering care to vulnerable communities, and will benefit medical personnel delivering services to Black PLWHA. Evanson, who represents HRSA in its interagency activities to advance the NHAS, says, “The Strategy has contributed to a greater sense of vision and purpose that we have welcomed. It adds an additional mantle of responsibility within the work of the Ryan White HIV/AIDS Program.”

Within the African-American community itself, there is a sense that stigma may one day be a thing of the past. Wilson says, “Several Black churches are creating AIDS ministries, and organizations, like the National Association for the Advancement of Colored People (NAACP) and the Urban League, have gotten AIDS coordinators.” He says that the community realized it was up to them to solve the problem of AIDS—to be a voice in the process and in supporting the Ryan White HIV/AIDS Program. “Nobody can come in and fix that for us.”





Because of people like Janet Nunn, clinical social worker at the Detroit Medical Center/Wayne State University HIV/AIDS Program, patients are staying in care, accessing the services they need, and leading healthier lives.

### Providing Care for Youth in Detroit

Almost 7,500 PLWHA reside in Detroit, most of them Black MSM. Rates of HIV within this population have risen dramatically in recent years, according to the Michigan Department of Public Health. HIV has spiked most dramatically among Black gay youth, ages 13 to 19, despite aggressive awareness and outreach.

Though traditionally associated with care for HIV-positive women and their families, Part D of the Ryan White HIV/AIDS Program supports 17 grant programs focused on engaging HIV-positive youth, ages 13 to 24, in outreach and care.<sup>53</sup> One of these is the Horizon Project, a program of Wayne State University School of Medicine, which provides young MSM, many of whom are African-American, with specifically targeted outreach, support, and care.

This is where “Jose Green” receives his care.<sup>54</sup> He was 18 years old and newly graduated from high school when he learned of his status. Though not open about his sexuality, his mother, Rosa, says she knew he was gay. Together, they found Horizons and “got him into treatment right away,” she says. At a time when people still struggle with shame and stigma around HIV/AIDS, Rosa says she never missed a beat. “He is my son.”

It was at Horizons that Green found his voice as an advocate, and eventually joined the staff. Now in his early 30s, he lives in Washington, D.C., where he continues to tell his story for organizations like Henry J. Kaiser Family Foundation and the CDC. He is a Horizons Project success story.

Angelique Outlaw, an assistant professor at Wayne State University School of Medicine and the director of prevention/outreach services at Horizons, says their goal has always been to get young people like Green in care and keep them healthy. “It isn’t easy,” she says. “Many of the youth that come through the doors at Horizon don’t have a support system like Rosa Green in their corner.”

Instead, they are working through challenging living and family situations. “Often we have to help them tell their parents that they are HIV-positive,” Outlaw says. Her colleague, Dr. Salome Cokern, who serves as the Clinical Care Manager and Psychologist at the Horizons Project, says they work with youth in a very holistic way, and often connect them with a multidisciplinary team of doctors, social workers, and advocates.

## Credits and Sources

### Sources

1. In this essay, the terms African-American and Black are used interchangeably to refer to all people of African descent in the United States, its territories and possessions.
2. U.S. Centers for Disease Control and Prevention (CDC). HIV/AIDS Among Racial/Ethnic Minority Men Who Have Sex with Men—United States, 1989–1998. *MMWR*. 2000;49:4–11. Available at [www.cdc.gov/mmwr/preview/mmwrhtml/mm4901a2.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4901a2.htm). Accessed June 19, 2011.
3. Hawkeswood W. AIDS ain't a gay thing: the impact of AIDS on gay Black men. *Transforming Anthropology*. 1993;4.1&2:2736.
4. Holmberg SD. The estimated prevalence and incidence of HIV in 96 large US metropolitan areas. *Am J Public Health*. 1996 May;86(5):642–54.
5. Hoff R, et al. Seroprevalence of human immunodeficiency virus among childbearing women. March 1988;318:525–530.
6. Hall HI, Song R, Rhodes P, et al. Estimation of HIV incidence in the United States. *JAMA*. 2008;200(5):520–529.
7. Whitmore S, Satcher A, Hu S. Epidemiology of HIV/AIDS among non-Hispanic Black women in the United States. *Journal of the National Medical Association*. July 2005. Vol. 97, No. 7.
8. CDC. HIV/AIDS surveillance report. *Morbidity and Mortality Weekly Report (MMWR)*. 2002; 21. Available at [www.cdc.gov/hiv/surveillance/resources/reports/2009report/](http://www.cdc.gov/hiv/surveillance/resources/reports/2009report/). Accessed November 10, 2011.
9. CDC. *CDC fact sheet: HIV among women*. 2011. Available at [www.cdc.gov/hiv/topics/women/pdf/women.pdf](http://www.cdc.gov/hiv/topics/women/pdf/women.pdf). Accessed December 15, 2011.
10. CDC. *CDC fact sheet: HIV/AIDS among African Americans*. October 2011. Available at [www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf).
11. Henry J. Kaiser Family Foundation. *Black Americans and HIV/AIDS*. February 2012. Available at [www.kff.org/hiv/aids/upload/6089-09.pdf](http://www.kff.org/hiv/aids/upload/6089-09.pdf). Accessed February 5, 2012.
12. Hall H Irene et al. Estimating the lifetime risk of a diagnosis of the HIV infection in 33 states, 2004–2005. *JAIDS*;49:3.
13. CDC. *CDC fact sheet: HIV and AIDS among African Americans*. October 2011. Available at [www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf).
14. CDC. CDC Health disparities and inequalities report—United States, 2011. *Morbidity and Mortality Weekly Report*. January 14, 2011;Supplement, Volume 60. Available at [www.cdc.gov/mmwr/pdf/other/su6001.pdf](http://www.cdc.gov/mmwr/pdf/other/su6001.pdf). Accessed January 15, 2012.
15. U.S. Department of Education. National Center for Education Statistics. Institute of Education Sciences. *Trends in high school dropout and completion rates in the United States: 1972–2009: compendium report*. October 2011. Available at [nces.ed.gov/pubs2012/2012006.pdf](http://nces.ed.gov/pubs2012/2012006.pdf). Accessed December 20, 2011.
16. Bureau of Labor Statistics. Economic News Release. Employment Situation. Available at [www.bls.gov/news.release/empst.t02.htm](http://www.bls.gov/news.release/empst.t02.htm). Accessed February 1, 2012.
17. Mendes E. More Americans Uninsured in 2011. *Gallup Wellbeing*. Available at [www.gallup.com/poll/152162/Americans-Uninsured-2011.aspx](http://www.gallup.com/poll/152162/Americans-Uninsured-2011.aspx). Accessed February 1, 2012.
18. CDC. *CDC fact sheet: HIV among women*. 2011. Available at [www.cdc.gov/hiv/topics/women/pdf/women.pdf](http://www.cdc.gov/hiv/topics/women/pdf/women.pdf). Accessed December 15, 2011.
19. CDC. *CDC fact sheet: HIV and AIDS among African Americans*. November 2011. Available at [www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf).
20. CDC. *CDC fact sheet: HIV and AIDS among African Americans*. November 2011. Available at [www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/FastFacts-AA-FINAL508COMP.pdf).
21. National Alliance of State & Territorial AIDS Directors (NASTAD). Black women and HIV/AIDS: findings from the Southeast regional consumer and provider focus group interviews. *Black women*. March 2010. Issue brief no 2.
22. Beard H. Getting real: *Black women taking charge in the fight against AIDS*. Black AIDS Institute. 2005. Available at [www.black-aids.org/docs/12\\_05\\_women.pdf](http://www.black-aids.org/docs/12_05_women.pdf). Accessed August 19, 2011.
23. Amaro H. Love, sex, and power: Considering women's realities in HIV prevention. *American Psychologist*. June 1995;Vol 50(6):437–447. doi: 10.1037/0003-066X.50.6.437.
24. Geronimus AT, Bound J, Colen CG. Excess black mortality in the United States and in selected black and white high-poverty areas, 1980–2000. 2011. *Am J Public Health*;101(4).
25. The Pew Center on the States. *One in 100: behind bars in America 2008*. 2008. Available at [www.pewcenteronthestates.org/uploaded-Files/One%20in%20100.pdf](http://www.pewcenteronthestates.org/uploaded-Files/One%20in%20100.pdf). Accessed January 15, 2011.
26. HIV/AIDS surveillance generally employs the term “men who have sex with men” (MSM) to describe all sexual activity between men, regardless of how they describe their individual sexual orientation. For the purposes of this essay, however, we use the term gay men.
27. Prejean J, Song R, Hernandez A, et al. 2011. Estimated HIV Incidence in the United States, 2006–2009. *PLoS ONE*. 6(8):e17502. doi:10.1371/journal.pone.0017502 Available at [www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502](http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0017502). Accessed August 4, 2011.
28. MacKellar D, Valleroy LA, Secura GM, et al. Unrecognized HIV infection, risk behaviors, and perceptions or risk among young men who have sex with men: opportunities for advancing HIV prevention in the third decade of HIV/AIDS. *J Acquir Immune Defic Syndr*. 2005;38:603–614.
29. Centers for Disease Control and Prevention (CDC). HIV/AIDS Among Racial/Ethnic Minority Men Who Have Sex with Men—United States, 1989–1998. *MMWR*. 2000;49:4–11. Available at: [www.cdc.gov/mmwr/preview/mmwrhtml/mm4901a2.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm4901a2.htm). Accessed June 19, 2011.
30. Valleroy LA, MacKellar DA, Karon JM, et al. HIV prevalence and associated risks in young men who have sex with men: Young Men Study.*JAMA*. 2000;284:198–204.
31. CDC. Youth risk behavior surveillance—United States, 2009. *MMWR*. 2010;59(SS-5). Available at: [www.cdc.gov/mmwr/pdf/ss/ss5905.pdf](http://www.cdc.gov/mmwr/pdf/ss/ss5905.pdf). Accessed May 30, 2011.
32. CDC. Health risks among sexual minority youth. November 2011. Available at [www.cdc.gov/healthyyouth/disparities/smy.htm](http://www.cdc.gov/healthyyouth/disparities/smy.htm). Accessed January 6, 2012.

33. Power R, Koopman C, Volk, J, et al. Social support, substance use, and denial in relationship to antiretroviral treatment adherence among HIV-infected persons. *AIDS Patient Care and STDs*. May 2003, 17(5): 245–252. doi:10.1089/108729103321655890.
34. Final Report of the Tuskegee Syphilis Study Legacy Committee. May 20, 1996. Available at [www.hsl.virginia.edu/historical/medical\\_history/bad\\_blood/report.cfm](http://www.hsl.virginia.edu/historical/medical_history/bad_blood/report.cfm). Accessed August 14, 2012.
35. Lawrence J. The Indian Health Service and the sterilization of Native American women. *The American Indian Quarterly*. Summer 2000. 24;3: 400–419.
36. Opportunistic infections and Kaposi's Sarcoma among Haitians in the United States. *MMWR*. July 9, 1982;31(26):353–4 and 360–1.
37. Gilman S. AIDS and syphilis: the iconography of disease. *AIDS: Cultural Analysis/Cultural Activism*. MIT Press. 1987. Vol. 43.
38. Altman K. Government plans random AIDS tests for 45,000 in U.S. *New York Times*. June 6, 1987. Available at [www.nytimes.com/1987/06/06/us/government-plans-random-aids-tests-for-45000-in-us.html](http://www.nytimes.com/1987/06/06/us/government-plans-random-aids-tests-for-45000-in-us.html). Accessed May 20, 2011.
39. Howell E. The role of community-based organizations in responding to the AIDS epidemic: examples from the HRSA service demonstrations. *Journal of Public Health Policy*. Summer 1991;Vol. 12, No 2: 165–174.
40. Health Resources and Services Administration, HIV/AIDS Bureau (HRSA, HAB). *Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care*. August 2010. Available at [hab.hrsa.gov/data/biennialprogressrpts.html](http://hab.hrsa.gov/data/biennialprogressrpts.html). Accessed October 10, 2011.
41. HRSA, HAB. *Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care*. August 2010. Available at [hab.hrsa.gov/data/biennialprogressrpts.html](http://hab.hrsa.gov/data/biennialprogressrpts.html). Accessed October 10, 2011.
42. Bhatt V, Giri S, Koirala S. Health workforce shortage: a global crisis. *The Internet Journal of World Health Science and Societal Politics*. 2010;Volume 7, Number 1. Available at [www.ispub.com/journal/the-internet-journal-of-world-health-and-societal-politics/volume-7-number-1/health-workforce-shortage-a-global-crisis.html](http://www.ispub.com/journal/the-internet-journal-of-world-health-and-societal-politics/volume-7-number-1/health-workforce-shortage-a-global-crisis.html). Accessed January 25, 2012.
43. Hirschhorn LR, Landers S, McInnes DK, et al. Reported care quality in federal Ryan White HIV/AIDS Program supported networks of HIV/AIDS care. *AIDS Care*. 2009 Jun;21(6):799–807.
44. HRSA, HAB. *Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care*. August 2010. Available at [hab.hrsa.gov/data/biennialprogressrpts.html](http://hab.hrsa.gov/data/biennialprogressrpts.html). Accessed October 10, 2011.
45. CDC. *HIV Surveillance Report, 2008*. 2010. Table 7.
46. Lindegren M, Byers R, Thomas P, et al. Trends in perinatal transmission of HIV/AIDS in the United States. *JAMA*. 1999;282(6):531–538. doi: 10.1001/jama.282.6.53
47. CDC. *CDC fact sheet: HIV in the United States*. November 2011. Available at [www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf](http://www.cdc.gov/hiv/resources/factsheets/PDF/us.pdf). Accessed January 1, 2012.
48. National Policy Forum. The basics: the Ryan White HIV/AIDS Program. March 10, 2010. Available at [www.nhpf.org/library/the-basics/Basics\\_RyanWhite\\_03-10-10.pdf](http://www.nhpf.org/library/the-basics/Basics_RyanWhite_03-10-10.pdf). Accessed May 22, 2011.
49. Aragón R, Kates J. *The Minority AIDS Initiative*. June 2004. Henry J. Kaiser Family Foundation. Available at [www.kff.org/hiv/aids/upload/Minority-AIDS-Initiative-Policy-Brief.pdf](http://www.kff.org/hiv/aids/upload/Minority-AIDS-Initiative-Policy-Brief.pdf). Accessed on January 10, 2012.
50. McNeil J, Campinha-Bacote J, Tapscott E, Vample G [Eds]. *BE SAFE: A Cultural Competency Model for African-Americans*. 2002. Available at [www.aids-ed.org/aidsetc?page=etres-display&resource=etres-95](http://www.aids-ed.org/aidsetc?page=etres-display&resource=etres-95). Accessed May 21, 2011.
51. Lee D. *Impact of Stigma on HIV Care Access in the African-American Community*. Northwest AETC and African Americans Reach and Teach Health. October 2008. Available at [www.aidsetc.org/aidsetc?page=etres-display&resource=etres-403](http://www.aidsetc.org/aidsetc?page=etres-display&resource=etres-403).
52. McKay E, Phillips H, Berl H. *Developing a Peer-Based Early Intervention Services Program*. December 6, 2011. Available at: [www.careacttarget.org/library/Peer\\_EIS\\_Program\\_Call\\_Slides\\_2011.ppt](http://www.careacttarget.org/library/Peer_EIS_Program_Call_Slides_2011.ppt).
53. HRSA, HAB. *Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care*. August 2010. Available at [hab.hrsa.gov/data/biennialprogressrpts.html](http://hab.hrsa.gov/data/biennialprogressrpts.html). Accessed October 10, 2011.
54. The names of Jose Green and his mother have been changed for confidentiality.
55. CDC, National Center for Injury Prevention and Control. *WISQARS leading causes of death reports: 10 leading causes of death, United States, Black*. 2007.
56. CDC. HIV/AIDS surveillance report. *Morbidity and Mortality Weekly Report (MMWR)*. 2012; 22, Table 1b. Available at: [www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm](http://www.cdc.gov/hiv/surveillance/resources/reports/2010report/index.htm). Accessed March 15, 2012.
57. Prejean J, Song R, Hernandez A, et al. Estimated HIV incidence in the United States, 2006–2009. *PLoS ONE*. August 2011;6(8):e17502. doi:10.1371/journal.pone.0017502. Accessed March 20, 2012.
58. Henry J. Kaiser Family Foundation. *Black Americans and HIV/AIDS*. March 2012. Available at: [www.kff.org/hiv/aids/upload/6089-10.pdf](http://www.kff.org/hiv/aids/upload/6089-10.pdf). Accessed March 20, 2012.
59. CDC. *HIV in the United States: at a glance*. March 2012. Available at: [www.cdc.gov/hiv/resources/factsheets/PDF/HIV\\_at\\_a\\_glance.pdf](http://www.cdc.gov/hiv/resources/factsheets/PDF/HIV_at_a_glance.pdf). Accessed March 15, 2012.

## Photography

Photographs © See Change