FINDING A SAFE PLACE FOR CARE
It’s easy to miss The Women’s Collective (TWC), with its discreet storefront set in a shopping plaza in Washington, DC. Walking through the front doors, however, visitors will find a large, brightly lit space framed by purple walls that easily accommodates clients and their families. Staff members greet visitors at the door, answering questions and leading them to the waiting area. Inviting couches line the walls, facing a coffee table holding HIV educational materials and a television tuned to a TWC informational video. In it, women of color discuss their experiences living with HIV/AIDS and the services they have received from the agency. In the adjacent room, case managers meet with clients in their cubicles, which line the middle of the space. Doors around the room lead to training areas, where the agency conducts HIV testing, educational seminars, and more.

“We have 20 staff members taking care of 300 HIV-positive women and girls,” says Patricia Nalls, executive director and founder of TWC. “They conduct HIV testing and linkage to care for thousands of women, men, and girls [annually] and teach hundreds of women living with HIV/AIDS about behavior change and modification, and how to live healthy with HIV.”

The agency, which serves primarily African-American women,* is essentially a one-stop shop for its clients. It receives funding through Parts A and B of the Ryan White HIV/AIDS Program, which is administered by the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB).

“We provide every service imaginable at TWC, with the exception of primary medical care,” continues Nalls. “It is possible for women and their families to spend all day here, conferring with case managers to set up

*The terms “African-American” and “Black” are used interchangeably in this report to refer to all women of African descent in the United States, including those born in Africa and the Caribbean.
I am pleased to introduce this edition of HRSA CARE Action, which provides an overview of the successful strategies implemented by Ryan White HIV/AIDS Program grantees and providers to engage African-American women living with HIV/AIDS in treatment and care.

Black women living with HIV/AIDS face many barriers to care. They tend to be the primary caregivers in their communities, often placing the needs of their partners, family members, and children ahead of their own. Many Black women are unaware that they are at risk for HIV/AIDS until after they have sought medical assistance for HIV symptoms. It is not uncommon for African-American women to be diagnosed with both HIV and AIDS or to progress to AIDS shortly after diagnosis. Accessing HIV care often marks their first experience with regular health care of any kind, a process that can be intimidating and overwhelming.

To overcome these obstacles, HRSA grantees and providers have created welcoming clinics featuring flexible schedules and culturally competent staff. These sites increasingly offer services under one roof—from child care to medical care—to help Black women access the services they need without worrying about long commutes or time constraints.

HRSA also supports the development of new models of care that successfully engage and retain Black women in care. This work includes the Special Projects of National Significance’s Enhancing Access for Women of Color Initiative as well as the forthcoming Integrating HIV Innovative Practices (IHIP) training manuals, curricula, and webinars addressing the recruitment and retention of hard-to-reach populations into care.

We hope this newsletter will inspire you and your colleagues to incorporate some of the best practices discussed here as well as to establish some of your own. It is through these collective efforts and dynamic partners that we will eventually engage all Black women living with HIV/AIDS into care.

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**Photographs**
Cover: A patient and provider at the Grady Health Services in Atlanta, Georgia.

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medical appointments and wraparound services, using a computer to work on a resume, as well as attending various trainings.”

Indeed, TWC’s impressive roster of services includes a mobile health unit offering HIV/STD screening, a food bank, substance use counseling, mental health support, child care, Prevention with Positives training, and youth leadership development. The agency even holds holiday parties for clients and their children to foster community among and disseminate health information to families living with and affected by HIV. The agency’s outreach workers regularly distribute HIV educational materials and condoms to local sex workers throughout DC. On Capitol Hill, TWC staff champion local and national HIV/AIDS policy that is responsive to the unique needs of women living with HIV. Staff and clients serve as voting members on the Washington, DC, Part A Ryan White Planning Council, bringing attention to the needs of women, children, and youth infected and affected by HIV.

**BARRIERS TO CARE**

TWC exemplifies the culturally competent services delivered by Ryan White HIV/AIDS Program grantees and providers that are targeting African-American women living with HIV. The importance of these services in breaking down the barriers that keep Black women out of care cannot be overstated. In 2009, Black women accounted for nearly one-third of new HIV infections and almost 60 percent of new infections among all women.3,4 Approximately two-thirds of the 300,000 women estimated to be living with HIV/AIDS in the United States are Black.5,6

**Children and Relationships**

Though researchers have not definitively explained the continued disproportionate impact of HIV among African-American women,7,8 they do agree that it stems from a complex interplay of social, economic, psychological, and cultural issues.9,10 Some studies show African-American women may prioritize their children’s needs at the expense of their own HIV care.11,12

Nalls supports this notion, recalling that in the early days of the AIDS epidemic, “most services were set up for single men living with HIV. Meal deliveries meant one meal, which we divided up for our kids. We often missed doctor’s appointments, because who else would meet our kids after school?”

Representatives of participating sites at the May 2012 meeting of HRSA’s Special Projects of National Significance (SPNS) Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color Initiative support this idea. They noted that the women participating in the SPNS initiative were older than originally
The desire to take care of family also may play a role in some Black women’s decision to seek or maintain unhealthy relationships, especially with men who provide access to resources, such as money, food, housing, and transportation, as well as social standing within their community. In these situations, women may avoid negotiating safer-sex due to fears of abandonment or intimate partner violence. As a recent study produced by the National Alliance of State and Territorial AIDS Directors (NASTAD), observed, “Black girls do not receive communication [from their families or other influential adults] about their bodies, sex or love, leading to diminished communication with sexual partners. Many do not know how to seek, acquire or maintain [relationships] without putting themselves at risk.”

These women also may not realize they are at risk for HIV, even if they know in general about the impact of AIDS in their community. It is not uncommon to find women who believe HIV is a “gay man’s disease,” or be in denial about, or unaware of, their partners’ past and current risk behaviors and life experiences—until they test positive for HIV. Black women at particular risk are those with male partners who have (or have had) unprotected sexual encounters with women and/or men; substance use disorders; and a history of incarceration.

Young Women
The economic realities some African-American women face may contribute to HIV transmission. This may be particularly true for younger Black women, who are more likely to become single heads of households before age 18. Nearly one-half of these households live at or below the Federal Poverty Level (FPL). Also possibly undermining Black women’s health are the recent spikes in joblessness nationwide, which has intensified poverty in African-American communities. Many single Black women and their families now live in “extreme poverty,” a term defined as subsisting on income of less than one-half the FPL.

Some studies have suggested that early sexual debut (i.e., before age 13) may put young people, including African-American girls, at greater risk for HIV. While African-American women ages 20 and under are more likely to have an unplanned pregnancy, drop out of high school, and/or experience intimate partner violence than women from other racial and ethnic groups, the research does not indicate that they have more unprotected sex or a greater number of sexual partners.

Immigrant Black Women
Immigrant Black women have faced additional barriers to treatment and care, often because of concerns about and experiences with clinic staff unable to provide culturally competent care. Medical personal may be unfamiliar with different cultural ideas about reproductive health, or not possess the linguistic skills or translation services necessary to communicate with immigrant Black women seeking care. These situations could result in immigrant women feeling unable to communicate their health concerns, and leave them confused about their treatment regimen. Fears of deportation may make undocumented women reluctant to access HIV care, particularly from clinics that resemble government buildings or have staff that wear uniforms.

Even when not needed for economic support, women may consider their partners essential to their social standing within their community, an attitude that leads many women to “keep their man” at any cost.

In addition, many immigrant Black women, particularly from the Caribbean and Africa, avoid care as a result of stigma around HIV/AIDS and fears about what their status may say about them. Some may have experienced or internalized attitudes of blame around their home country’s high rate of HIV/AIDS and its long history in the global pandemic. Indeed, in the early 1980s, the U.S. government declared Haitian nationality one of the four major risk factors for AIDS—known as the “4H club”—along with hemophilia, heroin addiction, and homosexuality.

Stigma
For some Black women, accessing health care can be challenging. HIV prevention, testing, treatment, and care can be particularly difficult to negotiate. HIV/AIDS is associated with injection drug use and homosexuality, both of which are heavily stigmatized in some African-American communities, particularly among older generations, churches, and public institutions, which wield considerable influence over younger people, especially around issues of health and well-being.

Unfortunately, we are still dealing with stigma, particularly in the South and Washington, DC, where the epidemic continues to grow at a more alarming pace, particularly among African-Americans, than in other areas of the country. In those areas, HIV-positive people are still very much ashamed, due to religious beliefs and cultural stigma. Their families and communities view the disease with a lot of disdain and blame.

Poor Health Outcomes and Trauma
Compared with their counterparts in other racial and ethnic groups, HIV-positive Black women often do not get tested for HIV until they experience symptoms.
women also are commonly diagnosed with coinfections, such as hepatitis C, which share many of the same risk factors and modes of transmission with HIV. Since many of these women delay getting tested, their HIV disease and coinfections are often identified in their later stages. Black women are often diagnosed with both HIV and AIDS concurrently or develop AIDS within a year of being tested. Late testing often reflects ongoing distrust of the medical system by African-Americans overall, whose community members have the highest mortality rates from heart disease, diabetes, and some cancers. They also are more likely to experience mistreatment and/or feel disrespected by their care providers.42,43,44

For women traumatized by past abuse, an HIV diagnosis may undermine their mental health ability to engage in HIV prevention, treatment, and care. Internalized HIV stigma plays a large role in reluctance to access care, explains Linda Scruggs, director of programs at AIDS Alliance for Children, Youth, and Families:

Newly-diagnosed women may have a difficult time getting into care and disclosing their status to their families and friends. Until they got their own diagnosis, they may have been part of the community conversation stigmatizing HIV, or supported throwing HIV-positive family members out of the house, having them eat off disposable dishes, or following them through the house with disinfectant. We’ve come so far with treatment of HIV, but attitudes are still lagging behind.

Even among women who know the risks, negotiating condom use can be difficult and considered a reflection of distrust of one’s partner. Jean Porter, who is the primary investigator for AID Atlanta, says she commonly sees this pattern of behavior among Black women who access her agency’s services. As Porter explains, “Women will do what it takes to avoid confrontation and keep their partner. If he doesn’t want to wear a condom, he doesn’t have to wear a condom.”

**THE PATH FROM DIAGNOSIS TO CARE**

African-American women diagnosed with HIV/AIDS often report feeling “isolated, alone and not knowing what to do.” The idea of managing their disease in the face of so much stigma and the daily responsibilities of caring for their family can seem overwhelming. Ryan White HIV/AIDS Program medical doctors, health care personnel, case managers, peer counselors, and others often help these women initiate and remain engaged in care.

Many providers take great pains to create culturally competent care systems for Black women living with HIV and their families. Like TWC, many of these clinics seem less like a medical center than a safe “medical home away from home.” Administration and medical staff mirror or understand their patients’ cultural and linguistic backgrounds. Patients, in turn, learn how to take control of their care, particularly around issues of sexual and reproductive health. All primary and specialty care provider services are offered in one location or in close proximity in order to expedite access by clients.45

The Family Circle Network, in Atlanta, Georgia, unites the efforts of several Ryan White Part D–funded medical homes. Together, these clinics represent a tightly woven safety net of care and support services geared to Black women living with HIV/AIDS and their families. One of these partners, AID Atlanta, recently completed a 5-year demonstration project targeting Black women living with HIV/AIDS in local jails.

Funded through the SPNS Enhancing Linkages to HIV Primary Care and Services in Jail Settings Initiative, the project offered recently released HIV-positive inmates a 30-day triage that focused on providing intensive medical services and support including HIV primary care, clothing, substance use treatment, and housing. Life skills training was also provided, engaging women in literacy and job skills building. Mental health services proved essential to keeping the women linked to care. As Porter explains, “For these women, self-esteem plays a huge part. If you have HIV, you may feel like damaged goods and think, ‘What difference does it make if I get clean or not? What does it matter if I stay treatment adherent?’”

For African-American women living with HIV, the Ryan White HIV/AIDS Program will continue to offer a pathway not just to care but to a healthier life—for themselves and their families.

She recalls one African-American woman new to care at the clinic who said, “When I finally got sober, it was like being newly diagnosed.” Porter adds, “All of the impact, guilt, and shame come to fruition for these women at once when they enter care, which makes comprehensive services that include mental health support essential. . . . You cannot compartmentalize HIV care.”

Indeed, AID Atlanta offers most, if not all, primary, specialty, and wraparound services under one roof or in close proximity. Moreover, services are provided in a woman-responsive environment that focuses on providing care in a respectful, culturally competent, and flexible atmosphere, regardless of the patients’ stage of engagement, whether it is entering, falling out of, or securely in care. This approach, coupled with the use of electronic health care records, has helped countless African-American women take better care of their health.

Another Family Circle Network provider, SisterLove, run by founder and president Dázon Dixon Diallo, exemplifies the Ryan White HIV/AIDS Program’s dedication to reengaging patients lost to care through systematic outreach. One SisterLove client, Martha, recalls her ongoing relationship with
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—Jean Porter, primary investigator for AID Atlanta

the clinic since her diagnosis in 1996: “I went to jail and was in prison. When I was released, SisterLove gave me transitional housing and later helped me find a house.”

Martha later stopped taking her medication during a difficult period of her life; but, as soon as she was able, returned to SisterLove to get back on track with her care. Ryan White HIV/AIDS Program providers serving African-American women living with HIV continually seek ways to bolster their ability to engage this vulnerable population in care. Many participate in capacity-building efforts supported by the HRSA/HAB Minority AIDS Initiative, which provides funding to help bridge gaps in service delivery to racial and ethnic minorities. Melanie Wieland, special assistant to the director of the Division of Service Systems within HRSA/HAB, says providers like SisterLove and AID Atlanta exemplify the Ryan White HIV/AIDS Program’s efforts to “meet people living with HIV where they are. This can mean providing health education training within the clinic, sending out a mobile unit, or even conducting home visits . . . whatever it takes to make patients less fearful and more receptive to receiving treatment.”

African-American women living with HIV often disengage from care due to demands from family, work and, sometimes, substance use or other unaddressed health issues. The most successful of Ryan White providers have established easy-to-navigate protocols for patients accessing services as well as multiple entry points into care. For instance, Community of Hope Health Services, another Washington, DC, clinic and former Ryan White HIV/AIDS Program provider, opened several clinics throughout the city to facilitate client access to its full spectrum of services. Like TWC, the agency has adopted a generic, non-HIV-related name and offers discreet yet easily accessible locations throughout the city. Sites feature same-day appointments, extended hours of operation, transportation, and welcoming waiting areas that look and feel like living rooms.

The clinic’s medical director, Rachelle Toman, says that Community of Hope’s medical home approach helps ensure that Black women and their families connect to their full spectrum of care, regardless of the reason they entered the clinic. “The Black women living with HIV we treat often are dealing with chaotic lives. Once they enter the door, we work hard to not only get their bloodwork done, we get them in to see the dentist, set up an appointment with a behavioral therapist, and so on,” Toman explains. “We are able to connect them with a wealth of services throughout that one contact, rather than refer them out to 4 or 5 locations, strengthening their treatment and care adherence.”

Ryan White HIV/AIDS Program providers also understand the lives of HIV-positive Black women. Many clinics offer onsite day care to help mothers keep their appointments and stay engaged with their treatment regimens. As one Part B provider in Pennsylvania shared, “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.”

Health education is key to retaining African-American women living with HIV/AIDS in care. For some Black women, entering HIV care may mark their first experience with regular medical care. They may also delay care until emergency assistance is required. Toman says, “We helped women take charge of their care by encouraging them to put themselves at the head of the list occasionally.”

This approach to fostering engagement and retention in care involves communication and coordination of care among providers serving the same patient, enabling them to act as a team and reduce duplication of services. Moreover, it alleviates the stress many African-American women have experienced in attempting to navigate intricate appointment schedules that take them to different locations while juggling work (often at multiple jobs), school, and family responsibilities.

Ryan White HIV/AIDS Program providers and grantees have sought to further develop the capacity of women living with HIV to access treatment and care. The AIDS Alliance for Children, Youth, and Families, for example, facilitated the Consumer Leadership Corps Training Program (CLCTP) through a cooperative agreement with HRSA/HAB from 2001 to 2011. The cutting-edge program trained African-American women living with HIV to be HIV educators. Many of the participants had already demonstrated leadership in their community as self-taught community organizers or in the workplace, before attending CLCTP.

“Black women living with HIV from every kind of background participated, from recovering addicts to doctoral candidates. But all of them benefited from the training,” says Scruggs, who ran CLCTP. “They acquired skills to discuss a range of topics, from how to describe a T-cell to the importance of taking one’s medications. Understanding how to share this information not only helped them assist their trainees but themselves. All of our trainees graduated better equipped to manage their HIV disease, treatment adherence, and health outcomes.”

Many of the trainees used their diverse skills, which ranged from HIV education to grant writing, to become
professional consultants to other HIV organizations within their communities, bolstering their economic and health outcomes. They also helped represent all women living with HIV disease by speaking at public AIDS awareness events and serving on Ryan White Planning Councils. Ultimately, AIDS Alliance trained more than 300 HIV educators, who in turn reached more than 10,000 people. Through the years, Scruggs says that the training revealed the depth of the “internalized trauma and stigma that so many African-American women carry within them related to their HIV status.” Mental health professionals were brought in to several sessions to help participants work through their issues. “Only then,” Scruggs explains, “could they get to a place where they could help themselves and others.”

**ENGAGING IN CARE, ENGAGING THE FUTURE**

HRSA/HAB providers continue to lead the way in creating successful linkages to care for African-American women living with HIV/AIDS and their families. In the future, these women will enjoy even greater flexibility in accessing HIV care. Much of this flexibility reflects the initial impact of the National HIV/AIDS Strategy, which rolled out in 2010 and has already created greater synergy and coordination of HIV treatment and care services at the Federal, State, and local levels.46,47 Moreover, the full implementation of the Patient Protection and Affordable Care Act (P.L. 111–148) will ensure that even greater numbers of African-American women living with HIV/AIDS have insurance coverage.48

For African-American women living with HIV, the Ryan White HIV/AIDS Program will continue to offer a pathway not just to care but to a healthier life for themselves and their families. Sandra Malloy, a 2007 CLCTP graduate, says learning how to become an HIV educator through Ryan White training made her a better representative of the South Carolina HIV/AIDS Council’s Positive Voices program and a more educated HIV patient herself.

“I learned how to disclose my status in a way that empowered me to get care, and I help other Black women living with HIV/AIDS to do the same,” she says. “And I am happy to say that my work rubbed off on my daughter. She learned from me how to facilitate HIV awareness trainings at her high school.”

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**ONLINE RESOURCES**


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**REFERENCES**

3 U.S. Department of Health and Human Services, **Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB). Going the distance: the Ryan White HIV/AIDS Program—20 years of leadership, a legacy of care.** 2010. Available at: [hab.hrsa.gov/data/biennialprogressrpts.html](hab.hrsa.gov/data/biennialprogressrpts.html).