Dimensions of HIV Prevention and Treatment for Black Women

Technical Expert Panel Executive Summary

HRSA
Ryan White HIV/AIDS Program

Background

During the course of the HIV epidemic in the United States, Black/African American women have been disproportionately affected. According to the Centers for Disease Control and Prevention (CDC), 57 percent of women who received a diagnosis of HIV in 2018 were Black/African American. In 2018, heterosexual Black women as a population were the fourth highest affected by HIV, behind Black/African American men who have sex with men (MSM), Hispanic/Latino MSM, and white MSM.

Pre-exposure prophylaxis (PrEP) is a proven strategy to reduce HIV transmission. Promotion efforts have focused on MSM, with less awareness and uptake among cisgender Black women. CDC statistics (2017) indicate that only 4.4 percent of Black/African American women who would benefit from PrEP received treatment. Education and outreach efforts related to PrEP that focus on Black/African American women are limited. Panelists related that many clinicians do not discuss PrEP with their sexually active female patients with HIV or how PrEP may be appropriate for their sexual partners.

Viral suppression rates among Ryan White HIV/AIDS Program (RWHAP) clients are higher than among people with HIV who are not receiving services through RWHAP. In 2019, 88.1 percent of RWHAP clients were virally suppressed. Black/African American women have seen similar success: 86.7 percent of Black/African American women served by RWHAP were virally suppressed. Subpopulations have lower rates. These include women aged 20–24 years; women who acquired HIV via vertical transmission (i.e., at birth); and those with unstable housing.

The Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB), which oversees the Ryan White HIV/AIDS Program (RWHAP), convened a three-session Technical Expert Panel (TEP) in October 2020 to examine the research, clinical, and patient landscapes related to HIV prevention and treatment for cisgender Black women. More than 20 panelists representing health departments, community-based health care providers, HIV prevention providers, RWHAP-funded providers, advocates, researchers, and national organizations participated. Also in attendance were representatives from the Centers for Disease Control and Prevention (CDC) and HRSA's Bureau of Primary Health Care (BPHC), Maternal and Child Health Bureau; Office of Women's Health; Office of Planning, Analysis and Evaluation; Office of Global Health; and Federal Office of Rural Health Policy. The discussion focused on the biomedical, behavioral, community-level, and structural dynamics that shape HIV prevention, treatment, and supportive services and community engagement for Black women with HIV across the lifespan.

The discussions were framed by the concept of intersectionality. Intersectionality is a theoretical framework, developed by Kimberlé Crenshaw, that considers the various identities (e.g., race, gender, socioeconomic class, HIV status) and interlocking power dynamics that make up an individual and can result in unique modes of discrimination and privilege. This term—as a political approach, lens of analysis, and research method—has a long history of usage by Black and other women of color who have sought societal change. Black women have advocated for an HIV system of care that truly is intersectional and serves to address the needs stemming from their complex lives. Given the complexities of Black women's lives, it is necessary that RWHAP stakeholders, including clients, understand how the various dynamics affect access to care and health outcomes. The following summary includes considerations for—

- Improving care and supporting Black women with HIV;
- Improving RWHAP services for Black women with HIV;
- Addressing the mental health needs of Black women with HIV; and
- Valuing the lived experience of Black women as clients, peers, and leaders.

Improving Care and Supporting Black Women with HIV

During the course of discussion, several themes and strategies were discussed that relate to engagement of Black women across the HIV care continuum and as leaders in the HIV space and their communities.

> *The Black Women's mantra: "It's A Lot." Most importantly, and most uncomfortably, we are also constantly carrying, not only the work, but the emotional weight of our own struggles and the fragility of our white counterparts, service providers, policymakers—especially white women. Burnout happens most often not because of our work or our passion for the work, but because other folks with more privilege and lower expectations make us more tired than we need to be or should be.*

Acknowledge the Legacy of Oppression. Historical trauma and the burden of current racial inequities and discrimination affect the health and quality of life of Black people in America. Acknowledging this legacy—both in terms of impact on health and access to health care and seeking to address this legacy as a society—is critical to fully meeting the needs of Black women. The premature decline of health in Black women as they age, sometimes referred to as

"weathering," is thought to be associated with stress, dangerous environments, and general social disadvantage. This accelerates negative health effects and increases vulnerability to certain health conditions. In addition, Black women experience mental health stressors across their lifespan, including ongoing discrimination and microaggressions that contribute to chronic stress, which can result in such mental health issues as depression, anxiety, trauma, and substance use disorder. This legacy preserves stereotypes about Black women that can affect their interactions with clinicians and within the larger society. Such stereotypes as the "angry Black woman," "welfare queen," or the "Jezebel" can contribute to the ongoing "shaming and blaming" of Black women for their life circumstances, which often are beyond their control.

Learn to Listen. Women may be inclined to stay in care when they feel that clinicians are listening to their priorities. Panelists described frustration and disappointment with clinicians who fail to connect with them as people. The limited time that clinicians, especially physicians, spend with clients can exacerbate efforts to build patient–clinician rapport. Panelists also emphasized the need to create outreach and educational materials, including social media, that positively depict Black women with HIV who can serve as role models, especially in terms of accessing and remaining in care.

Recognize Diversity among Black Women. To meet the needs of this population, it is important to recognize the diversity of Black women with HIV. Women face unique challenges in terms of accessing care, including language and cultural barriers. Although low income is an indicator of risk for HIV infection and demonstrates a need for RWHAP services, middle- and upper-class Black women with HIV also may benefit from such services as navigation support. Because of their income level, these women do not qualify for RWHAP services and may face greater challenges in coordinating comprehensive care and support services similar to those offered by the RWHAP. It also is important to acknowledge that some Black women may prefer to receive services outside of RWHAP for various reasons (e.g., services are not co-located or convenient to access; services are not tailored to women and families). Similarly, the stigma associated with mental illness may make some women reluctant to access mental health services in a stand-alone clinic and instead choose to access co-located mental health services within their clinics.

Promote Kindness, Cultural Humility, and Creating a Welcoming Environment. Women are more likely to engage and remain in services when they feel welcomed and comfortable and are treated with dignity. Both organizations and clinicians need resources and training to effectively provide services. Panelists identified ways that organizations/clinicians can create a more welcoming environment for Black women and all people with HIV with an emphasis on treating all patients with dignity and compassion. Training all staff in cultural humility and motivational interviewing can serve to strengthen relationships between clinicians and patients. Training patients in health literacy can help them become partners in their own care and more effectively engage with their clinicians.

Strategies for Improving Care and Supporting Black Women with HIV

- Acknowledge layers of oppression; acknowledge the impact of stigma and work to reduce this stigma (e.g., reduce shaming and blaming).
- Train clinicians in compassion, sensitivity, and interpersonal/emotional intelligence skills; talk to patients to learn their life experience, priorities, personal realities, and needs. Clinicians should not make care-related decisions based on bias or assumptions.
- Employ staff who reflect the patient population.
- Clinicians should ask women how they prioritize their needs (e.g., personal needs vs. needs of the family) so that they can address HIV effectively based on patient priorities.
- Acknowledge and respect women's personal agency; treat each woman as an individual.
- Create welcoming spaces.
- Create meaningful ways (e.g., policies, procedures, bylaws) to engage women with lived experience in the design of services and compensate them for their input.
- Include partners when addressing women's sexual health and to support their treatment.
- Facilitate access to services by exploring traditional and nontraditional access points for Black women for HIV prevention and care services, such as minute clinics, pharmacies, places of worship, college campuses, advocacy organizations, and non-HIV community-based health-related organizations.

Improve Care and Coordination to Meet Diverse Needs. Family-centered care, which provides and coordinates care for all family members, is important. Similarly, co-locating services greatly facilitates access to a broad array of services that women and families need and allows access to multiple services within a single appointment. Coordination across primary, HIV, and specialty care providers, with a focus on total wellness, is critical. Offering evening/weekend hours, drop-in appointments, and eliminating "no-show" or late penalties can make services more accessible to people who experience multiple challenges in their daily lives. Providing support for transportation and childcare also is necessary. Additionally, ensuring coordination across care and support services for women older than 50, who make up almost half of the women served by the RWHAP, is critical because the needs of women change as they age.

Facilitate Access to Services. Linking the newly diagnosed to HIV services is critical. Currently, most outreach activities focus on men

who have sex with men while Black women remain inconsistently targeted. One successful model is "test and treat," in which those with a new diagnosis are immediately linked to care and antiretroviral treatment. In some settings, such as emergency departments, staff are onsite to facilitate the linkage. Other models rely on off-site peers to meet a patient with a new diagnosis within a few hours to begin the process of accessing HIV services.

Include All Potential Partners. Discussions around Black women and HIV rarely have focused on all potential partners in their lives, especially cisgender men. Neither has there been an effort to understand how power dynamics in personal relationships affect Black women's access to health care and other necessary services or how they affects health outcomes. Male partners should be educated about sexual health and responsibility and HIV prevention and treatment. Panelists stressed the importance of engaging the male partners of women with HIV to help them better support their female partners. In addition, panelists emphasized the need for more positive portrayals of Black women with HIV and recognizing them as sexual beings with male partners in their lives.

Improving Health Care Services for Black Women with HIV

Panelists discussed various strategies for improving the provision of health care, both within the RWHAP and in the health care system in general.

> *…[A]ll interventions must include childcare, food, transportation, and compensation should be provided, regardless of the type of intervention; trauma-informed and healing-centered interventions; meet them where they're at—low-barrier clinics (open on weekends and nights; no no-show, late, or cancellation penalties; etc.); psychosocial support programs that are created and/or led by Black women.*

Coordinate Comprehensive Health Care and Support Services. Access to a wide range of bundled health care and support services that address the needs of women and their families, including their partners, is necessary. Coordinated, whole-person health services include specialty care, dental, pharmacy, and health care that address the needs of women across her lifespan (e.g., reproductive health services, pregnancy/postpartum care, care for women as they age). Necessary support services include housing, transportation, childcare, employment support, and those that address food insecurity.

Create Co-located, Low-Barrier Services. Facilitating access to services makes it easier for women to stay in care. Having multiple services available in one location allows patients (and their families in some cases) to see multiple clinicians in one visit. Multiple appointments can constitute a significant burden for women (e.g., challenge of coordinating transportation or childcare). Low-barrier services provide patients options, such as evening and weekend hours, telehealth appointments, or drop-in appointments.

Include Peers as Members of the Care Team. Peers—women with lived experience—are important members of the care team. They can serve as the voice of experience and help women navigate unfamiliar systems to access health care and social services. Women also may feel more comfortable speaking to someone who looks like them and shares a similar background, especially about such sensitive topics as sexual history and trauma. In addition, peers may have more time to spend with patients than other members of the care team and can take the time to ensure that a patient "feels heard" and that her priorities are acknowledged and addressed.

Consider Care Transitions Unique to Women. Providing whole-person care must acknowledge the health-related needs of women across their lifetime. These include reproductive health care

Opportunities to Improve Services for Black Women

Panelists identified opportunities to enhance the access to and quality of HIV services for Black women.

- ***Increase Guidance about Services for Black Women.*** Through technical assistance (e.g., webinars, toolkits, and other means), provide guidance to HIV service providers on the needs of Black women and effective models for meeting these needs. Encourage the use of evidence-based models that are effective with Black women.
- ***Encourage Input from Black Women in Program Design.*** Encourage organizations with initiatives targeting women, especially those focusing on Black women, to incorporate the input of Black women into program design and management.
- ***Ensure Meaningful Involvement of Black Women in HIV Services.*** HIV service organizations should examine methods to ensure meaningful involvement of Black women in their activities. For example, include activities to help patients build skills to better participate in their own care (e.g., health literacy). In addition, organizations should explore ways to ensure meaningful involvement of Black women in their programs. For example, many organizations propose to include Black women in the design of services but do not budget to support these activities.
- ***Adopt Outcome Measures/Metrics That Address Intersectionality and Health Equity.*** Identifying measures related to intersectionality could support the provision of services in a truly intersectional way. In addition, "equity" metrics that evaluate the extent to which services increase health equity and reflect what clients care about most could improve services for Black women.
- ***Support Client Leaders.*** Provide funding for mentoring, coaching, and peer-to-peer support for Black women in leadership roles.

(e.g., cervical and breast cancer screening), pregnancy and postpartum care (especially mental health services and screening for depression), and health-related needs related to aging (e.g., menopause).

Explore Nontraditional Approaches. Panelists suggested additional strategies to engage and maintain women in care and improve health outcomes. Leveraging the services of members of the care team, such as a pharmacist, may increase access to care, given that pharmacies often have more accessible hours than clinics. Accessing services from a pharmacist or care team member other than a physician may be less stigmatizing than seeing an HIV doctor. Panelists provided group clinical visits for women as another example. These leverage the social support provided by group members to motivate engagement in care and treatment adherence.

Address Trauma and Intimate Partner Violence (IPV). Adoption of trauma-informed care models for all patients, not just women, is critical to helping patients with a history of trauma access and remain in care. IPV—the physical violence, sexual violence, stalking, and/or psychological aggression by a current or former intimate partner—affects millions of women, men, and children and can have serious physical and psychological health consequences. Greater dissemination of resources and support for implementing programs focused on trauma and IPV would help address these two issues in health care settings.

Addressing the Mental Health Needs of Black Women with HIV

Black women with HIV face multiple mental health challenges, including community/racialized trauma and the trauma related to living with a chronic health condition. Examples of other challenges that affect mental health include adverse childhood experiences, childhood sexual assault, and IPV.

There are **discrete traumatic events** (e.g., rape, accidents, natural disasters) and ongoing traumatic experiences (e.g., adverse childhood experiences, childhood sexual assault, IPV, homelessness, community trauma, racial trauma). Post-traumatic stress disorder can result from trauma, depression, anxiety disorders, and substance use disorder and have significant effects on mental and physical health. Black women experience **mental health stressors** across their lifespan, including microaggressions that contribute to chronic stress. Black women must acknowledge the need to heal by tapping into the resilience that the Black community possesses. Additionally, removing financial barriers to mental health will help address the perception of affordability for mental health services.

> *…[S]pirituality is so important, but often not supported by the medical end either…*

Panelists suggested multiple strategies for addressing the mental health needs of Black women with HIV.

Address Stigma and Perceptions Related to Mental Health Services. Work is necessary to reduce the stigma associated with mental health services and present these services in a more positive light (e.g., as a healing and safe space). It is also necessary to address perceptions related to mental health and mental health services. Targeted educational efforts should focus on terminology around mental health and letting Black women know that when they face mental health challenges, treatment is available and affordable.

Offer Multiple Treatment Modalities. Women may prefer different modalities, such as support groups, individual therapy, and so forth. Medications, which often are prescribed under the care of a psychiatrist, need to be monitored for possible drug interaction with HIV-prescribed medications. Services should address the needs of women across their lifespan, such as the mental health needs of long-term HIV survivors and the needs of postpartum women. Panelists emphasized the necessity of more support groups, especially groups

Definitions

- ***Trauma.*** an external event that overwhelms a person's coping and activates neurobiological stress response.
- ***Stress.*** a threat to an individual's physiological integrity that results in biologic and behavioral responses necessary for survival.

addressing the needs of Black women with HIV and the diversity of women within this population. Along with traditional treatment modalities, panelists stressed the importance of alternative therapies, such as art, music, and dance therapy. Spirituality, meditation/breathing exercises, and exploring other aspects of self-care (e.g., plant-based diets) should also be presented as options.

Educate Women about Their Treatment Options. Women need information about the various treatment options so that they can make informed decisions about their care.

Provide Resources to Clinicians. Clinicians need training and tools to help them address the mental health needs of their patients. Mental health issues, such as trauma and depression, should be addressed regularly during primary care interactions. Patients should be educated about their mental health risks, both in general and related to specific health concerns, such as postpartum depression. Other members of the care team, including peers, can also play a role in patient education and screening.

Valuing Lived Experience: Black Women with HIV as Peers and Leaders

Panelists discussed the many ways that people with lived experiences, in this case Black women with HIV (or "consumer" as referenced by panelists), can play significant roles in their own healing, as well as the healing of their families and communities. These women often are not compensated for their subject-matter expertise. Panelists emphasized the need for training, along with additional guidance about use of RWHAP funds to support peer employees in terms of compensation, training, and other ongoing support. Panelists identified four significant needs related to successfully engaging Black women with lived experiences:

- Training Black women with lived experiences to advocate effectively within the HIV space and gain employment as peers (e.g., patient navigators);
- Fair compensation (including benefits) for the work;
- Opportunities for career advancement (e.g., mentoring, coaching); and
- Support for Black women working in the HIV space.

Considerations discussed that relate to better leveraging and valuing this experience include the following:

Move Consumers to Other Roles. Black women with HIV bring many skills to the HIV space. Harnessing these skills can be mutually beneficial to them and the organizations that serve them. Peer-support positions (e.g., peer navigators) often are the first step on the career ladder in the HIV space for consumers. Panelists emphasized the need to professionalize the roles of peers in organizations, provide them a living wage, and offer opportunities and support (e.g., training and mentoring) for career advancement.

Compensate Women with Lived Experiences for Their Work. Panelists emphasized that the expertise and work provided by women with lived experiences often is undervalued within organizations and the broader community. It also is important to note that as women advance within the HIV space and earn more money, they may no longer qualify for the RWHAP but not earn enough to replace all of the support services available through the RWHAP.

Create Opportunities for Career Advancement. Black women have received training and gained expertise to be leaders in the HIV space, but very few Black women fill leadership roles, especially outside of RWHAP Part D–supported recipients. Assumptions and stereotypes maintained by providers, such as how a person speaks and acts, may result in negative perceptions by potential employers and may limit opportunities for Black women. Employers also may value educational attainment (i.e., degrees) more than lived experience. Coaching and mentoring for women, especially as they advance professionally, are necessary in addition to providing support (and resources) to build a professional network for Black women to share information and strategies, such as how to obtain better compensation and find opportunities for advancement or professional training. Training future leaders is necessary as those who pioneered this work reach retirement age.

Support Women Doing This Work. Black women with lived experience often perform many functions within their organizations, which leads to burnout. Black women in these roles need peer support, such as support groups, and access to mental health services to address burnout and other stressors related to this type of employment.

Conclusion

Black women have been leaders in advocating for necessary HIV services for themselves and all people with HIV since the early years of the HIV epidemic. Supporting the ongoing advocacy and involvement of Black women in the delivery of HIV services in various capacities—as peers, other staff, and leaders—will help ensure that RWHAP services continue to be responsive to the needs of this population.