

Optimizing the Behavioral Health of Women Living with and Vulnerable to HIV

HIGHLIGHTS

- ▶ **The Women's Research Initiative on HIV/AIDS (WRI)**, a program established by The Well Project in 2003, is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy. In April 2023, the WRI convened a meeting to address ways to optimize the behavioral health of women living with and vulnerable to HIV.
 - The Well Project and the WRI use the term "women" to describe anyone who identifies as such across the gender spectrum.
 - This issue brief is based on presentations and discussions from the WRI 2023 meeting and is supplemented by additional research and information.
- ▶ **The relationship between HIV and behavioral health**, specifically mental health and substance use, is interactive and multi-layered. Holistic care for women living with and vulnerable to HIV must meaningfully respond to and center their behavioral health needs.
 - A behavioral health toolbox that is accessible across socioeconomic status could arm women living with and vulnerable to HIV with an array of approaches to address their behavioral health needs, including self-care, social support, substance use treatment, and mental healthcare.
- ▶ **Substance use**, which is affected by individual, social, and structural factors, can have a profound impact on HIV acquisition and care among women.
- ▶ **Among women living with HIV, Black women, other women of color, and women of trans experience (trans women)**, are disproportionately affected by behavioral health issues,^{1,2} and require specialized attention and interventions.
- ▶ **Lived experience must be valued across the HIV field** as an aspect of HIV "expertise," on par with competencies such as clinical acumen and policy proficiency, in order to meaningfully engage women living with HIV in research, policy, and treatment and to optimize those efforts.

Why is behavioral health important?

Behavioral health describes the connections between actions one takes and the health of the body and mind. While it is often used interchangeably with mental health, it is a more expansive term that refers to the diagnosis, treatment, and prevention of mental health issues, substance use, life stressors and crises, and related physical symptoms.³ This crucial space is where many health concerns lie and has a tremendous impact on quality of life.

Issues related to behavioral health are prevalent and coexist with HIV (and occur more frequently among women than men), affecting women across the HIV continuum of care and beyond.⁴

MENTAL HEALTH ISSUES AND HIV AMONG WOMEN

Research has demonstrated that women living with HIV are more likely to experience mental health issues including depression, anxiety, and post-traumatic stress symptoms than either men living with HIV or women not living with HIV.^{5,6} One survey found that women experience more than three times as many mental health issues after they receive their HIV diagnosis compared to before,⁷ suggesting that HIV may exacerbate established gender disparities in depression, anxiety, and post-traumatic stress disorder.

These disparities can be caused by a variety of factors, including the burden of being the primary caregiver, lower household income, less education, and insufficient social support. In addition, intimate partner violence is linked to depression, post-traumatic stress, and suicide attempts.⁸

Stigma and stress can also negatively affect the mental health of women living with HIV, resulting in feelings of social isolation, anxiety, and loneliness, which are key elements of depression.⁹ A meta-analysis of studies that looked at stress among women living with HIV found that their perceptions of their health and resulting limitations were major sources of stress, even when effective treatment was available.¹⁰ Another study found that after being diagnosed with HIV, women reported experiencing stress about their relationships and disclosing their HIV status.¹¹

These mental health issues can affect all aspects of HIV prevention, treatment, and care. For example, untreated depression is associated with increased sexual expression and decreased inhibitions that may increase the likelihood of HIV acquisition. Untreated depression may also lead to more rapid HIV disease progression, an increased likelihood of vertical HIV transmission, lower rates of medical appointment attendance and HIV treatment adherence, and increased mortality.¹²

Mental health issues often are interrelated for women living with HIV: research has demonstrated a strong association between depression, childhood trauma, and partner violence among them.¹³ For Black, Latina, and other women of color, additional stressors related to racial and ethnic stigma (along with stigma associated with HIV status and gender) may exacerbate other mental health issues, such as depression.¹⁴

Limited research around Lifetime Survivors of HIV

There are limited data about behavioral health among women and girls who acquired HIV perinatally, known as "Lifetime Survivors" and "Dandelions."

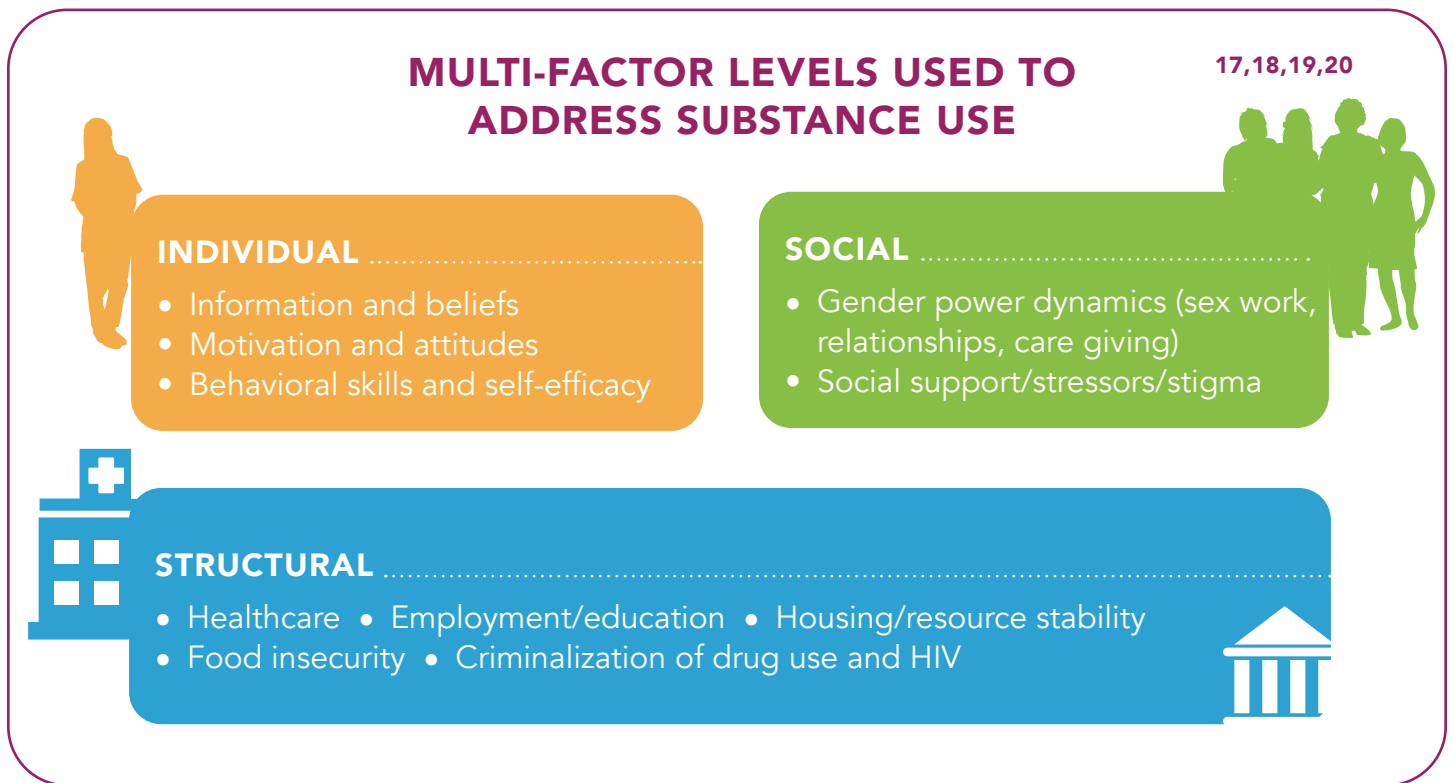
While existing research indicates higher rates of behavioral health concerns among Lifetime Survivors*, the root causes of these conditions require further exploration. This often-neglected population (most of whom are now adults) have unique experiences and challenges that need to be better understood and addressed.

SUBSTANCE USE AND HIV AMONG WOMEN

Substance use – including alcohol and drugs – intersects with HIV in many ways. While it directly links to HIV acquisition (16 percent of new HIV diagnoses among women in 2019 were the result of injection drug use¹⁵), there are also other, indirect pathways through which substance use facilitates HIV transmission for women and others. Substance use can:

- Lower inhibitions, affecting perceived potential to acquire HIV and recall (cognitive)
- Increase sexual and drug-use behaviors that increase vulnerability to HIV and reduce behavioral control in, for example, the use of condoms or treatment adherence (behavioral)
- Increase vulnerability to HIV through the "risk environment," which includes the social and physical space in which people live and exist and related external factors (such as insufficient access to healthcare) that influence health behaviors and outcomes (sociostructural)¹⁶

While efforts to address substance use have traditionally focused on the psycho-social properties of an individual, there are also social and structural factors that must be addressed in order to effect change. Cutting across these layers are social statuses (race/ethnicity, gender identity, class) and health statuses (mental health disorder, substance use disorder, living with HIV).



Effective efforts to address substance use among women living with HIV integrate two different approaches:

- **Syndemic approaches** acknowledge that co-occurring epidemics (such as HIV and substance use) are more concentrated in specific populations and interact with each other to produce poorer health outcomes than either epidemic would in isolation.
- **Intersectional approaches** recognize that interlocking status-based systems of power and privilege (including heteronormativity, racism, and sexism) produce environments that sustain these syndemic, intersecting epidemics.

Among women living with HIV, intersectional and syndemic forces intertwine to produce increased disease burden (HIV, substance use, mental health), restrict access to effective interventions (HIV treatment, pre-exposure prophylaxis or PrEP, methadone, syringe services), and attenuate the efficacy of available treatments (withholding and/or denying treatment).^{21,22,23}

Future research and programming efforts should address key issues in the current policy landscape (e.g., drug use criminalization, HIV criminalization, assaults on reproductive justice and transgender personhood) that have a potential impact on the behavioral health of women living with and vulnerable to HIV; enhance implementation science to scale up and sustain what works; and leverage meaningful partnerships between community and researchers to translate science.

BEHAVIORAL HEALTH AMONG BLACK WOMEN AND OTHER WOMEN OF COLOR LIVING WITH AND VULNERABLE TO HIV

Behavioral health issues among women living with HIV are exacerbated among women of color.²⁴ This is particularly true among Black women and Latinas (the populations with the highest HIV burden among women of color) and require specialized attention.

BLACK WOMEN

In 2021, while representing 14 percent of the US female population, Black women accounted for more than half (54 percent)²⁵ of new HIV diagnoses among women. Black women are 11 times more likely to be diagnosed with HIV than are white women.²⁶ A recent survey found that one-third of Black women in the US would have a diagnosis of a mental disorder in their lifetime.²⁷ Effects of systemic racism and discrimination create or compound a variety of stressors experienced by Black women that contribute to this statistic:

- “Living while Black” and feeling particularly concerned about the safety of Black children²⁸
- Being a provider and caretaker/making and saving money²⁹ (one quarter of Black women in the US live in poverty compared to 11 percent of white women³⁰)
- Single motherhood (64 percent of Black children live with a single mother compared to 24 percent of white children)³¹
- Financial responsibility (84 percent of Black mothers are the sole earner or earn more than 40 percent of their household income)³²
- Pressure not to disappoint others³³

“I grew up in a powerful household that was very Black and Christian – therapy was seen as weak, instead we were encouraged to pray about our issues,” said Kim Canady, a woman living with HIV. “It took time for me see the benefits and to figure out how therapy could work for me.”

Black women living with HIV face additional stressors due to HIV stigma, marginalization of their racial identity and their mental health and are more likely to have co-existing mental health conditions and worse overall mental health.³⁴

LATINAS

In 2019, Latinas accounted for 18 percent of new HIV diagnoses among women, while representing 19 percent of all women in the United States.³⁵ Latinas are nearly three times more likely to be diagnosed with HIV than are white women.^{36,37} Latinas experience depression at about twice the rate of Latino men and are at a higher risk for depression than Black and white women, due to a variety of social determinants.³⁸ Compared to Latino men, they are:

- More likely to live in poverty (78 percent vs. 54 percent)
- Less likely to be employed (29 percent vs. 48 percent)
- Less likely to have more than a high school education (28 percent vs. 47 percent)

Latinas face additional challenges, including language barriers (which can lead to difficulties navigating healthcare and ultimately worse health outcomes³⁹), lack of transportation, low rates of private health insurance, prioritization of family over personal health,⁴⁰ concerns regarding immigration status, and religious beliefs and practices (which can impact the degree to which they use condoms or engage with information about sex).⁴¹

The influences of structural determinants of health on trans women living with HIV:

One woman's behavioral health journey

by ARYAH LESTER

As a Black woman of trans experience, my life and existence are spread across many intersections our systems are not built for. When I have a negative experience, I'm not always sure if it's because of my Blackness, my womanhood, or my transness. Regardless, I learned early that behavioral evidence-based interventions are not built for me. They are designed to help us live in a dysfunctional world rather than addressing the dysfunction created by that world.

The following narrative captures but a glimpse of the structures I've endured and that have affected my behavioral health, including society and family, education, economic stability, and housing and healthcare access.

I was called "The Wiz" when I was younger and I always excelled academically. During that time, I was abused by a family member and friends of my family, which was never really addressed. When I graduated from high school, despite acceptance letters to Yale and Harvard, I had to settle with a private Christian college that offered a full ride, which would make me independent from my parents. I started figuring out my truth at that time, and realized it was not the right place for me. My college put me in conversion therapy, which led to a suicide attempt. I was placed in a psychiatric hospital for weeks and told: "This is your life now." This was one of my first experiences with behavioral healthcare and it was based upon erasure of intrinsic parts of my humanity.

After college, I moved to New York and worked for corporate America after a stint of homelessness, staying in shelters, and engaging in sex work after fully transitioning. When my grandfather died, I was distraught – my parents had disowned me, but he and my aunts and uncles always supported me, even after transition. In requesting time off work, I mentioned my transness because I had a few years under my belt, as well as three promotions. After attending the funeral and returning to work, I received a letter saying my presence made the workplace unsafe and that I would need to seek psychiatric treatment before returning to work. While attempting to do so with employer-provided insurance (which didn't cover psychiatric treatment), I was fired via a letter for missing work.

Loss of opportunity forced me to move to Florida, where I was forced once again to engage in sex work. I struggled to receive emergency housing because Miami-Dade County then had no provisions for trans people. Even when I found a job at an LGBTQ organization (where I was again promoted thrice), my transness was an issue and I was underemployed. There was no therapy available for me, and the only support I could access was the support group I coordinated for transgender and gender non-conforming individuals.

I have since become a high-profile individual in the HIV, public health, and equitable communities fields, recognized for my skill set and lived expertise. I have a deep appreciation and understanding for the role that behavioral health plays in all of our lives, both positively and negatively. I currently have a therapist who is also a Black woman of trans experience and access to a slew of resources and opportunity. Despite that, there are spaces in which people like me with less access and resources remain unsafe.

My experiences with behavioral health issues and care have ranged from helpful to truly traumatic. Ultimately, those experiences have taught me that we will not make significant inroads in addressing behavioral health for trans women living with HIV until we recognize that fixing systemic issues is impossible at the individual level. We must look at the actual human condition and societal structures and determine how we can collectively make changes.

ADDRESSING BEHAVIORAL HEALTH

Behavioral health treatment and support can improve quality of life across a variety of measures (e.g., substance use, mental health disorders, sense of well-being) among women living with HIV. It can also improve HIV treatment adherence and decrease mortality. However, significant challenges prevent the benefits of behavioral treatment and support from being experienced equitably. The systemic racism embedded in the foundation of the US healthcare system has resulted in provider bias, disparate medical outcomes, inadequate insurance, distrust of the medical system, and other fundamental challenges that affect the ability of Black women and other women of color to seek and access behavioral health services. Furthermore, behavioral health professionals, particularly Black and Latino/a providers, are in short supply in many areas of the US, even as an increasing number of individuals are seeking therapy.⁴² These myriad challenges are amplified among women living with HIV, who may also face provider stigma, logistical barriers (lack of childcare and/or transportation, etc.), and other obstacles to identifying and accessing suitable support and treatment. Diminished acceptance of and stigma around therapy within some racial and ethnic communities render care more challenging still for Black women and other women of color living with HIV.

Women are best served by a holistic approach to well-being that is informed by an understanding of the ways that multiple forms of inequality or disadvantage are intersectional and multiplicative, compounding mental and physical health challenges and outcomes, particularly for Black women, other women of color, and trans women. A well-informed holistic approach should provide interpersonal support; interventions in settings that feel safe, without stigma associated with mental health and substance use treatment or HIV status; and clinicians who feel trustworthy and relatable.

“It is important to recognize that there is both ‘big P policy’ and ‘little p policy’ – smaller changes that generate less attention can make a huge difference.

Our voices matter.”

B. Kaye Hayes, MPA, Deputy Assistant Secretary for Infectious Disease; Director, Office of Infectious Disease and HIV/AIDS Policy (OIDP); Executive Director, Presidential Advisory Council on HIV/AIDS (PACHA).

WHAT IS THE ROLE OF POLICY IN BEHAVIORAL HEALTH AND HIV?

Policy is a crucial partner to HIV research, as it facilitates (and in many cases funds) these efforts and informs how research findings are translated into practice. Broadly, policy is important to everything that occurs in US society, structuring lives in ways both beneficial and harmful. More specifically, policy structures endeavors around behavioral health and HIV through laws, guidance, grants language, and funding and can act as a lever to make change.

The Department of Health and Human Services (HHS) is responsible for this work at the federal level, with several of its agencies particularly focused on the issue: the National Institutes of Health (NIH) and its constituent entities, especially [the National Institute on Drug Abuse \(NIDA\)](#), [the National Institute of Mental Health \(NIMH\)](#), and the [NIH Office of AIDS Research \(OAR\)](#); the [Health Resources and Services Administration \(HRSA\)](#); the [Centers for Disease Control and Prevention \(CDC\)](#); and the [Substance Abuse and Mental Health Services Administration \(SAMHSA\)](#). These agencies conduct a broad range of research and programmatic activities to address and support the behavioral health of women living with and vulnerable to HIV.

Applying successful approaches to HIV-related behavioral health research and practice employed in international programs supported by US government agencies, notably [PEPFAR](#) (President’s Emergency Fund for AIDS Relief), may prove valuable to domestic efforts.

GAPS, NEEDS, AND OPPORTUNITIES

As described above, the landscape surrounding behavioral health, HIV, and women is complex, but there are best practices and successful interventions that can and should inform future efforts. Beyond the obvious need to explore, develop, and fund interventions that address the systemic conditions that undermine the behavioral health of women living with and vulnerable to HIV, WRI 2023 participants identified a series of recommendations related to research, education, advocacy, and policy for consideration and potential implementation by the broader HIV community.

For funding agencies and researchers:

Engage in efforts to ensure that behavioral health research reflects and addresses the needs of women living with and vulnerable to HIV

- Identify and disseminate a series of resources that include best practices in integrating women with lived experiences into the conception, leadership, and execution of research focused on behavioral health and HIV; address the need for appropriate compensation and recognition of women participants
 - Acknowledge the potential harms of research and the importance of being trained on the behavioral health needs of women by developing an informed consent instrument for researchers
- Develop novel mechanisms to sufficiently fund researchers who include and address women in behavioral health research
- Work with funders, conferences, and journals to require analysis by gender, in addition to sex, in behavioral health studies and other HIV research
- Support research to assess the impact of anti-transgender legislation on behavioral health outcomes among trans women living with and vulnerable to HIV and develop strategies to mitigate it
- Further employ existing quality-of-life indicators and incorporate into behavioral health research protocols
- Incorporate plans for post-trial access to interventions into behavioral health research proposals; communicate that information to participants and other community members
- Identify mechanisms to fund storytelling as a methodology to ensure that lived experiences related to behavioral health are understood and addressed in research and programming

For policymakers, advocates and funders:

Undertake policy efforts that drive awareness of and increase funding for behavioral health among women living with and vulnerable to HIV

- Provide counsel to federal leadership on how to improve and optimize efforts to respond to behavioral health needs of women living with and vulnerable to HIV
 - Work with federal leadership to better integrate behavioral health into the National HIV/AIDS Strategy
 - Conduct educational sessions for state and federal legislators; address current policy landscape and the impact of disparate policy efforts on the HIV landscape (including immigration, reproductive justice, war on drugs, etc.)

Core principles to guide future endeavors must:

- Integrate HIV and behavioral health treatment
- Be community led and focused
- Adapt to the reality that deeper needs require more time and care
- Tailor interventions to vulnerable populations

- Develop policy recommendations to create new and amplify existing efforts to meaningfully address challenges in behavioral health workforce development, with a focus on Black women and other women of color
- Work with funders to adapt review process around research grants for behavioral health
 - Educate grant reviewers on issues related to women and behavioral health to ensure understanding of relevant issues
 - Develop mechanisms that ensure meaningful community involvement in grant review process
 - Work with NIH and others to ensure that the HIV community has the tools they need to participate effectively in the RFP (request for proposals) process
- Increase funding for peer education and peer support groups to support behavioral health needs of women living with HIV
- Convene quarterly policy calls for multisectoral, multidisciplinary group (including researchers, advocates, policymakers, women living with HIV, etc.) focused on the behavioral health needs of women living with and vulnerable to HIV to discuss opportunities for collaboration

For relevant public agencies and community and advocacy organizations:

Conduct education and advocacy efforts to expand understanding among a broad audience of behavioral health issues that affect women living with and vulnerable to HIV

- Develop and disseminate a series of materials describing the intersection of behavioral health and HIV (with an emphasis on Black women and other women of color) in a graphically interesting, user-friendly format for community and provider audiences
 - Encourage dialogue and expand the conversation around substance use
 - Reframe the narrative around race to emphasize that race is not the problem, racism is
 - Analyze and combat the impact of anti-transgender legislation on the behavioral health of trans women living with and vulnerable to HIV
- Create and compensate a corps of storytellers who are willing to share their lived experiences with policymakers and researchers; identify speaking opportunities; provide safety planning to account for and mitigate impact of recounting traumatic experiences
- Promote understanding of the needs of caregivers (e.g., women who care for family members and others) and the way that role impacts the experience of living with HIV; develop supportive tools

Interrogating “resilience”

It is important to interrogate the notion of and language around “resilience.” While the term is generally intended to connote strength and positivity, it may imply a responsibility to react in a prescribed manner to destabilizing circumstances, thus layering yet another burden upon women living with HIV. *“I am sick and tired of having to be resilient,”* said Bridgette Picou, LVN, a woman living with HIV. *“I just want to thrive and be happy, without having to always be resilient or look for the best in situations.”* In addition to “thrive,” potential language replacements suggested by women living with HIV include “prevail,” “flourish,” and “steadfast.”

CONCLUSION

The behavioral health needs of women living with and vulnerable to HIV are significant and must be integrated into and addressed through HIV prevention and care. Challenges related to mental health and substance use can affect women's quality of life, vulnerability to HIV acquisition, treatment success, and mortality. Marginalized populations, including Black women, Latinas, and trans women, experience additional behavioral health challenges, and their unique needs must be considered in the development of behavioral health research, services, and policy. These efforts must also address the challenges posed by the systemic racism embedded in the US healthcare system. While some progress has been made, ensuring broader success requires thoughtful, coordinated efforts that center the needs of women living with and vulnerable to HIV.

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* *Lifetime survivors* is a term brought into the WRI 2023 convening by Kimberly Canady that is supported by the Dandelions Movement (by and for people who acquired HIV at birth)

To access current and past WRI meeting information and reports, [please click here](#).

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ABOUT THE WELL PROJECT AND THE WRI

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls across the gender spectrum. Its program, the Women's Research Initiative on HIV/AIDS (WRI), is a multidisciplinary and multisectoral effort dedicated to identifying gaps for women in HIV prevention, treatment, and cure research and policy. For more information, please visit www.thewellproject.org.

