What Is Meaningful Involvement of Black Women in HIV Work?

For advocate LaTrischa Miles, it means Black women with HIV can take substantive leadership roles—and much more.

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For LaTrischa Miles, it is the people and community that she serves that keep her grounded in her work.

She serves as a treatment adherence manager at Kansas City CARE Health Center, an organization that is "dedicated to providing quality care, access, research and education to the underserved and all people in the Kansas City community."

Her advice for other women and girls impacted by HIV is simple: "Be educated. Be empowered. Be an advocate in your own health care. You're worth it, and you are enough."

Around National Women and Girls HIV/AIDS Awareness Day, which is marked each March 10, we caught up with Miles to learn more about her work and how we can center Black women and girls in our work to stop HIV together.

How did you get involved in this work?

I got involved in this work after I was diagnosed with HIV. I was separated from my husband, a mother of three and I was scared. I felt like death was imminent. I knew nothing about HIV. I did not know anyone with HIV and I felt very alone. To be transparent, I did not know what to do about my health.

The average person is not educating themselves about HIV because they don't think they are at risk. I didn't, I was married so I didn't think HIV would affect me…but it did. If I contracted HIV being married, anyone is at risk.

I didn't want another woman to go through the same thing that I went through — scared, alone, confused and uneducated about HIV.

National Women and Girls HIV/AIDS Awareness Day is a day to raise awareness about the impact of HIV on women and show support for women living with HIV. What does that mean to you?

National Women and Girls HIV/AIDS Awareness Day means a number of things to me. The two words that come to mind are “opportunity” and “support.”

This day is an opportunity to educate women and girls about how to prevent HIV and to spark conversations about sexual health, giving them the knowledge about how to protect themselves. We want to encourage testing so women and girls know their status — and give information in a nonjudgmental manner.

This day is one of support and recognition for women with HIV. We need support in every area of HIV care and treatment. This includes more women in clinical research and expanding essential supportive services to keep women in care, such as housing, childcare and transportation.

Why is it important for women and girls to talk about HIV? What are some ways to start the conversation?

It’s important to talk to women and girls about HIV to get prevention messages out to the public to our families and in our communities. There are many factors that affect women’s lives and put them at risk for HIV. Women who do not have stable housing may also have less power to negotiate safer sex in relationships, putting them at increased risk for intimate partner violence and for acquiring HIV. Our young women may be particularly vulnerable to HIV due to the power dynamics in relationships, especially if they are dating an older partner. We must empower women through education and mentoring.

What are some ways to start the conversation? It starts by building relationships. When you build relationships you gain trust and when you gain trust, you earn the right to share more intimate conversations with family and friends.

Be transparent; tell your story if you’re living with HIV. If not, educate yourself about HIV and healthy sex practices, encourage testing and knowing your status. So often we think HIV is all about someone else when HIV is about US.

What does it mean to meaningfully involve Black women with HIV in this work? How can we operationalize MIPA [Meaningful Involvement of People Living with HIV/AIDS] principles in our work?

Meaningful Involvement of Black women with HIV in this work means so much.

It means Black women are engaged in their own health care by demanding a place at decision making tables. “Nothing about us without us.”

It means Black women with HIV can take substantive leadership roles in organizations.

It means Black women are involved in implementation of programs from creation to implementation.

It means Black women are involved in the policy-making process, including the development and monitoring at all levels.

It means Black women are afforded the opportunity to succeed by providing adequate training (i.e., professional orientation and job mentoring) that any other professional would receive to be successful.

It means Black women are supported in HIV advocacy work and inclusion of law reform such as HIV criminalization.

How can we operationalize Meaningful Involvement of People with HIV/AIDS principles in our work?

Organizations have to take MIPA seriously. One aspect is to ensure PLWH are not volunteers but are working in paid positions. If paid positions are not available, stipends or honorariums should be considered for their time and efforts in HIV work.

Other suggestions to address challenges to implement MIPA are to:

- Provide administrative and/or clinical supervision to support PLWH.

- Develop an orientation training program to the organization's policies and procedures and to the position.

- Ideally, a mentor would be beneficial.

- If available, offer higher learning (junior college) as an option for professional development and leadership.

Black women are disproportionately affected by HIV, in terms of new diagnoses and HIV health outcomes, compared to women of other races/ethnicities. How can we address this disparity? How can we address the social and structural issues that impact Black women's health?

How can we address this disparity? The realities that many Black women face are racism, discrimination, poverty and economic inequalities that lead to poor health. All too often intimate partner violence, incarceration, substance use and trauma are contributors to new HIV diagnoses as well. We have to address inadequate trauma-informed care and training in our institutions. While things are better today than a few years ago, Black women still have an uphill battle when it comes to improving our lives and upholding our rights.

How can we address the social and structural issues that impact Black women's health? We can address the social and structural issues that impact Black women's health by addressing the social determinants of health that exist — the actual conditions that some of them live and work in, the risk they take to survive. We cannot discount the inequities that have been prevalent for generations. Black women are caretakers within the family and have the responsibility of caring for the whole family.

We must implement targeted prevention and care campaigns for Black women with community partners, and we must provide opportunities for education, training and mentoring for good, wage-earning jobs that provide economic stability and afford the opportunity to live in safe neighborhoods.

Brian Castrucci, CEO of the de Beaumont Foundation, said, "There is a growing recognition that medical care alone cannot address what actually makes us sick." We must also meet individual and social needs.

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