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POLICY & ADVOCACY TEAM

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## **HIV/AIDS AND ITS ADVERSE IMPACT ON BLACK WOMEN, FEMMES, AND GIRLS**

When thinking of HIV/AIDS, many people think of the HIV/AIDS explosion on the scene on the West Coast in the 1980s and gay men contracting HIV, being treated like pariahs, and ultimately dying alone in isolated hospital rooms. While that has certainly been in the cultural zeitgeist for some time, it is not true that only gay men contract HIV/AIDS. HIV has historically been linked to “taboo” behaviors as defined by society. These behaviors include same gender sexual relations, drug use, sex work and perceived promiscuity. Currently, the statistics overwhelmingly support the idea that women, specifically Black women, femmes, and girls, are contracting HIV/AIDS at an alarming rate. While it is important to acknowledge the history of HIV/AIDS in this country and around the world and to acknowledge the major societal loss when many gay men were left to die in the 1980s, it is equally important to acknowledge that as recently as 2018, Black women, who made up only 13% of the US population make up 58% of new diagnoses of HIV infections.

All of the statistics point towards pouring more resources into Black communities, but that has not happened. Black women, femmes, and girls are seemingly invisible in the HIV/AIDS cultural discourse. This invisibility of Blackwomen, femmes, and girls in AIDS advocacy spaces is particularly concerning because erasure often means lack of access to resources. Black women, femmes, and girls are not viewed as vulnerable populations and as people who are worthy of protection, they are routinely excluded from the very HIV prevention trials that could help them live long and fulfilling lives. As a result of them being excluded from these trials, many of the most vulnerable Black women, those of the trans experience, who are lower-income and cannot afford medication on their own, the virus is able to fester, their immune system is weakened, and they are no longer able to protect their bodies from common illnesses like the common cold. This can, and oftentimes does, lead to their deaths.

Black women living with HIV also live at the intersection of their marginalized identities related to their race, gender identity and health, which is often complicated by stigma. That is where this policy brief comes in. We hope to use this document to continue to advocate for and influence policy towards providing more HIV prevention resources to Black women, femmes, gender-expansive folx, and girls.

We acknowledge that not only cisgender women are impacted by the AIDS epidemic. Because of the nature of our work, as an HIV reproductive justice organization that focuses on Black women, we wanted to highlight their experiences. That is why we are being intentional of including Black trans women and gender expansive folx.

### **Background: The history of AIDS globally and in this country.**

Despite Black women representing about 13% of the total female population, they account for 61% of new HIV diagnoses among women in the U.S. This is about 16 times the rate of diagnosis of HIV in white women. Black women also experience higher rates of morbidity and mortality. HIV is a widespread public health issue and Black women remain vulnerable. In addressing the impact of HIV on Black women, their intersectionality must be taken into account. A person's race contributes to their health outcomes here in America, especially as we look at the health outcomes of Black women living with HIV. Black people are the least likely to be tested, and are the least likely to be linked to care once they're found to be positive and also the least likely to be treated and virally suppressed. Those who are unaware of their status are at higher risk of illness and transmitting the virus. Improving the rates of viral suppression among Black women would reduce morbidity and mortality.

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Black women are more likely than other women in the U.S. to experience poor HIV-related health outcomes. Multiple levels of structural oppression influence Black women's sexual and reproductive health. Similarly trans women experience pervasive forms of oppression because of their gender identity.

### **HIV and Criminalization**

HIV criminalization are laws that categorize otherwise legal conduct as crimes, or laws that increase punishments based solely on a person's HIV-positive status. Georgia presently maintains a number of laws that target people living with HIV. Laws that criminalize behaviors based on a person's HIV status are ineffective as prevention measures. The focus when it comes to HIV should be on prevention and reduced transmission. Black people are already overpoliced and this type of legislation further stigmatizes persons who are living with HIV. Stigma is linked to low engagement in care. HIV is a public health issue, not one to be handled in our courtrooms. HIV criminalization contributes to the stigmatization of HIV, the laws perpetuate inaccuracies in the way that HIV is transmitted and holds people living with HIV accountable for engaging in activities that do not transmit the virus.

Research shows that the penalties associated with HIV laws are disproportionately imposed on the basis of race and gender. Most of these laws are outdated, and a lot of them leave out an intent requirement, meaning that they don't account for whether a person intended to cause harm or actual transmission. Despite these laws being outdated, people with HIV continue to be prosecuted each year. Black people are more likely to be arrested and convicted for HIV-related offenses. Specifically, in Georgia, Black people account for nearly  $\frac{3}{4}$  HIV related convictions.

Many of these laws target sex workers and have a disparate impact on Black women. With a conviction alone it makes it difficult for these women to live. Women who are prosecuted under these laws lose their homes, custody of their children and reputation in the community. In a study conducted by the Williams' Institute, more than six in ten people arrested under an HIV-related offense were Black. Black women are more likely to be arrested for these offenses than their white counterparts. In Georgia, Black women accounted for 16% of all HIV related arrests and 49% of HIV sex work arrests. The attack on Black women is severe, especially when it's hard enough to survive as is.

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HIV-criminalization laws are not updated with scientific facts or evidence. Most of them were crafted at the height of the HIV epidemic, fueled by a lethal combination of fear and homophobia. These laws criminalize behaviors that don't have a risk of transmission associated with them. Research has proven that undetectable equals untransmittable, which means that people who are virally suppressed cannot pass HIV onto their sexual partners. Nor do these laws account for HIV prevention measures, like condom use or a person committed to ART or using PrEP. Most people are unaware of the impact or even the existence of these laws. The continued criminalization of HIV undermines the efforts of community-based organizations that work to reduce barriers to care and stigma as it relates to HIV.

### **Restricting Access to Resources**

Black women have been disproportionately affected by the HIV epidemic since the very beginning and have been engaged in a fight for inclusion in trials and access to life-saving knowledge and resources. Despite advancements in medical care, some people living with HIV are not accessing the resources that are allowing others to live healthy lives. Some people don't know they have the virus because they may be asymptomatic, they may not be able to access care because they can't afford it, or don't have insurance. There are some people who may not seek care because of stigma, from how they contracted the virus or because they simply don't know. Black women are not getting access to crucial information about HIV prevention and tools. They also lack access to quality HIV treatment or prevention services.

Women with HIV diagnoses are less likely to be virally suppressed than men. Black women are more likely to be publicly insured and in the care of a physician in a clinic setting. Some of the research using a multivariable analysis, stated that factors that contributed to not achieving viral suppression included being young, Black and receiving care in a public clinic. The disparities in viral suppression between Black people and white people exist across the nation. Disparities that exist in undetectable viral loads have more to do with structural injustices, like homelessness, health insurance and a person's income. Black women have significantly lower rates of virologic suppression than white women.

PrEP or Pre-Exposure Prophylaxis is an HIV prevention drug for HIV-negative people. PrEP is a prevention strategy that exists for people who are considered at high risk of contracting HIV. Studies have shown that PrEP can reduce the risk of HIV transmission more than 90% for female-male partnerships and reduce the transmission among people who inject drugs by 70%. Anyone who can write a prescription can provide PrEP. However, only about 1% of the Black people who could benefit from PrEP have filled a prescription. Most people who could benefit from PrEP don't know about it. Most private and public insurance companies will cover the costs of PrEP and there are also medication assistance programs available for those who qualify. Black women are also severely underrepresented in PrEP users, representing only 8.2%.

### **Solutions**

Ending the HIV epidemic means that there need to be strategic policies put in place and an increase in funding. The key steps are: addressing stigma, increasing funding to community based organizations, modernizing HIV criminal laws and expanding Medicaid.

The stigma associated with HIV needs to be addressed, it has been a problem since the beginning of the epidemic and continues today. Black women living with HIV may be dealing with internalized stigma, or stigma from peers, partners and those working in our healthcare systems. Stigma impacts the lives of those living with HIV because it can lead to the loss of employment opportunities, housing, delays in seeking treatment or testing and overall poor health outcomes. Specifically among Black women, HIV stigma has been associated with decreased psychological functioning and isolation. Research suggests that HIV stigma and viral load are linked. Race and gender already come with associated stigmas that contribute to health disparities. When suffering compounding stigmas there can be a negative impact on medication adherence and thusly health outcomes. Reducing stigma starts with first addressing Black women's intersectionality and how the things that they face impact them on a variety of levels.

Community based organizations serve the role of educating the community, combating misinformation, and informing public policy. The painting of HIV as a virus that only impacts men engaging in same-sex relationships is problematic and inaccurate.

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There also needs to be a reframing of HIV and the people living with the virus as diseased and dying. Attacking the stigma means that we have honest conversations, in our schools, our communities, and in our doctors' offices'. The fear of disclosing perceived risky behaviors or even one's sexual orientation can prevent people from getting tested and delay or deny them from getting access to prevention and treatment services. This results in the most vulnerable communities failing to obtain crucial information about HIV prevention. Compassion from health providers is required to create a connection where their patient feels comfortable enough to share what they are enduring with them. For example, some Black women are engaged in sex work voluntarily, some for their survival. Some of these women are transgender which would further marginalize them as a gender minority and cause more stigma because they're Black, trans and engaged in sex work. Stigma and discrimination in HIV care are closely linked to racism and homophobia/transphobia.

Black transwomen are often misgendered and grouped in with gay Black men, this results in barriers to research and inclusion. The CDC notes that the numbers of transgender women are too small, which shows that they are not being engaged in research about HIV treatment and prevention. HIV campaigns largely focus on men in same-sex relationships or those who engage in intravenous drug use. Campaigns need to be designed and focused on Black women, including Black transwomen. Federal agencies need to work on improving the efficiency of outreach and engagement with those most impacted. There needs to be an intentional effort on behalf of providers to ensure that those living with HIV are directed to treatment and that people are tested.

Medicaid needs to be expanded. States that haven't expanded Medicaid also have less access to the medication that suppresses the viral load of HIV, which means that HIV is still able to be transmitted. Insurance is crucial for people who are living with HIV to have access to care and live healthy lives. The only way to continue improving healthcare outcomes is by expanding Medicaid. There needs to be an increase in access to PrEP for Black women. PrEP is a huge way for Black women to protect themselves from HIV. Excluding Black women from the solutions reinforces the inequities that our most marginalized communities face.

HIV needs to be completely decriminalized, or at the very least modernized so that it takes into account a person's intent. Laws criminalizing HIV distract from the issues that are impacting Black women's challenges that need to be addressed. HIV-criminalization statutes need to be amended or repealed.

## Conclusion

Throughout history, Black women have been subjected to cruel experiments and violations of their sexual and reproductive liberties. Black women have long lacked autonomy over their own bodies and deserve to be made a priority. Health inequalities come from the inequalities and inequities we see in society. Black women's maltreatment and neglect are historic, and the effects are evident in the HIV care of Black women today. The history of HIV/AIDS as it pertains to Black women is one of inattention, neglect and ultimately violence. The failure to include Black women, femmes, and girls in conversations about HIV only serves to disempower them.

Early HIV diagnosis and treatment are necessary to address and reduce the disparities that we see today. Culturally appropriate and stigma-free care is a requirement, especially in rural communities. There is a requirement to apply an intersectional lens to HIV advocacy. There must be inclusion of Black women, girls, femmes and trans-nonbinary people who were assigned female at birth. As Black women, we live intersectional lives; therefore, we seek intersectional solutions. Black transwomen are women. In order to attack the epidemic head on we must be gender inclusive and intentional in our engagement and recording of information about Black women's health. Black women deserve equity in healthcare accessibility and visibility in research and targeted outreach.

We must mobilize to focus on Black women and reduce HIV disparities and use all resources available to us, on federal, state, and local levels. The reformation of the healthcare system should help to decrease racial disparities in viral suppression and treatment of HIV. Primarily by increasing and facilitating access to adequate providers and coverage. Trauma, associated stigma, poverty, education, and access to care all contribute to the high transmission of HIV among Black women, along with low rates of treatment. As advocates for members in our community, it is our goal to make HIV treatment accessible to everyone living with HIV, safeguarding their health and reducing overall transmission.

Black women as a demographic, inclusive of femmes, women, and girls, and their respective interests deserve equitable inclusion in research and outcomes. There is an ethical responsibility on healthcare providers and researchers to not contribute further to the marginalization of Black women. Black women deserve to be included in the conversation and are more than an afterthought. This requires a complete overhaul of structural barriers.

The organizations engaged in doing the work need to be supported as we continue to navigate uncertainty around the COVID-19 pandemic and continue to engage our communities to address the health disparities of racial minorities here in Georgia specifically.

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