

2021 STATE OF HIV STIGMA



FOREWORD

I will never forget that night standing at her bedside, holding her hand as she took her final breaths. My dear childhood friend, who at just barely forty, was coming to the end of her life surrounded by her children, partner, and close friends. Cancer had ravaged her body and she had known for some time that it would come to this. What others standing around her bed did not know—that I had been charged to hold in secret—was that she was also living with HIV. Before the cancer diagnosis, she learned of her HIV status, and had not really shared it with anyone.

She was so afraid of what others would think. Whether she would be shunned at church, whether her children would be mistreated at school, whether her family and friends would turn their backs on her. She even stopped attending support groups for women with cancer because, as she described to me, she felt like a “fraud.” They had cancer, but she had cancer AND HIV—how could she be worthy to share that space and risk possibly being exposed? My heart ached for her—and it still does.

I often wonder how she might have engaged in care differently if she hadn't felt the need to hide her HIV status. She often missed appointments or didn't access certain services, because she was afraid of being “found out.” How could her life—so many lives—be transformed if our communities were better educated and HIV was not whispered in secret? I miss her so much. She was light and love wrapped up in a petite frame, with a big laugh, and always a kind word. She deserved to be seen in her fullness, accepted, loved, and supported.

I will always see her and fight for her. And I hope you will as well.

Southern AIDS Coalition (SAC) was founded twenty years ago with a mission to end the HIV epidemic in the South, particularly to demand that federal resources be equitably allocated to meet the region's needs. SAC's work continues today with the same mission, and with a focus on addressing HIV stigma. We recognize that addressing stigma requires the unpacking of untruths through open dialogue, the demystification of sex, and the end of shaming and judgment based on one's sexual orientation, gender identity, or otherwise.

Through the Gilead COMPASS Initiative®, SAC provides grants to organizations to address HIV-related stigma. “Stigma” is not a one size fits all problem—and neither is there a single solution to address it. In Wetumpka, Alabama, one solution was Central Alabama Alliance, Resource, and Advocacy Center's community-led Because I Love You billboard campaign, which



DAFINA WARD
Executive Director
Southern AIDS Coalition

A handwritten signature in black ink, appearing to read "Dafina Ward".

highlighted the loving relationships of persons living with HIV with family members and friends. In Texas, one solution was Amigos por Vida (“Friend for Life”), a peer-mentor program serving Latinx same-gender loving men facing cultural stigma and sexual orientation discrimination within their communities. In North Carolina, it was Circle of Friends Taskforce's LAMPS (Leaders, Advocating, Mentoring other leaders for Personal Growth and Support) Project, a peer program that educated people of color living with HIV to mentor, train and support one another.

The GLAAD 2021 State of HIV Stigma Study paints the picture of the challenges we must overcome to end HIV-related stigma. The findings reflect a vast lack of understanding of HIV and how it can be prevented, as well as significant discomfort and unfounded fear about people living with HIV. The Deep South has the highest rates of HIV diagnosis, yet the study reveals that the U.S. South also has some of the highest discomfort levels pertaining to the virus. This is a perfect storm for the perpetuation of misinformation.

While that is disheartening, and driven by a number of factors, the Study also provides a glimmer of hope. Captured are a range of strategies that leaders in southern communities offer in response to the issue. These calls for action require improving provider/patient relationships, increasing access to tangible and accurate information, and applying the lessons we continue to learn from COVID. Most of all, these strategies remind us once again that our communities hold the answers. It is my hope, my belief, that we can turn the tide on HIV stigma. That together we can build a region, and nation, in which my dear friend would have thrived.

INTRODUCTION

2021 marks the 40th year since the first AIDS cases were reported in the U.S. Decades later, HIV/AIDS continues to be an epidemic with complex characteristics. The spread is fueled and complicated by misinformation and lack of information about the remarkable progress science and medicine have made to make HIV not only preventable, but when treated properly, untransmittable.

People living with HIV continue to experience stigma, and stigma thrives in silence. Stories and voices of people living with HIV are not prioritized regularly to humanize the epidemic, reduce stigma around it, and illustrate how HIV is preventable. Their stories must be told to show how people with HIV lead long and healthy lives, and cannot sexually transmit HIV when on proper treatment.

Groundbreaking biomedical advances in HIV care and prevention have transformed the epidemic, yet HIV stigma remains, often in nuanced ways. GLAAD's 2021 “Where We Are On TV” report found that stories about living with HIV/AIDS decreased in scripted entertainment programming over the last year, as did the number of characters living with HIV or AIDS, dropping from 9 to 3. The only characters living with HIV appeared on FX's Pose, framing a much bigger issue around lack of visibility, stigma and media responsibility. When Pose aired its final episode earlier this year, the number of TV characters living with HIV dropped to zero. In our report, GLAAD is calling on the TV industry to introduce three new

regular or recurring LGBTQ characters living with HIV each year. The 2021 State of HIV Stigma Study is a national survey in partnership with the Gilead COMPASS Initiative measuring American attitudes toward HIV and people living with HIV. In this report, we also systematically review the history of HIV stigma in the media to document the current state of research and offer recommendations for media to increase and improve coverage of HIV and people living with HIV. This report also offers strategies from leaders in HIV education and treatment for defeating stigma in all areas of society.

GLAAD was created on November 14, 1985, by journalists and writers determined to hold the media accountable for grossly defamatory and inaccurate media coverage of HIV and its earliest patients.

Over 35 years later, GLAAD has transformed into a dynamic LGBTQ media advocacy organization with an outsized role in accelerating acceptance for all members of the LGBTQ community and other marginalized groups. Advocating for people living with HIV remains a core tenet of GLAAD's purpose. Educating media professionals, fighting stigma and pushing for 100% acceptance for those living with HIV will always be a critical centerpiece of GLAAD's work.



SARAH KATE ELLIS
President & CEO, GLAAD

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2021 STATE OF HIV STIGMA STUDY

GLAAD.org/EndHIVStigma

KEY FINDINGS

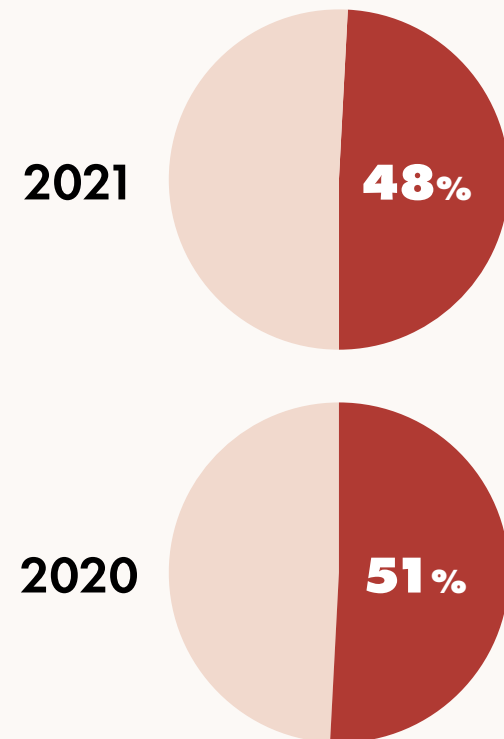
The findings paint a troubling picture of the general US population's overall awareness about HIV, including low levels of accurate knowledge around HIV transmission, and persistent stigma toward people living with HIV.

METHODOLOGY

The 2021 State of HIV Stigma Study was conducted through an online survey between January 14, 2021 to January 29, 2021, among a sample of 2517 U.S. adults, 18 years or over. The sample was sourced and aggregated through CINT, the world's largest consumer network for digital survey-based research with access to 144 million panel members globally, was consistent with the inaugural 2020 sample survey.

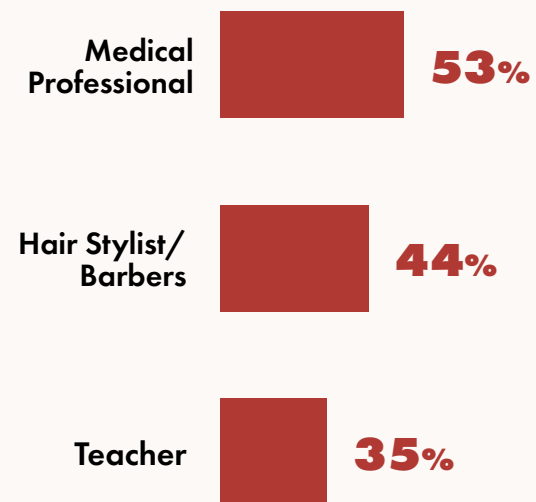
Feel Knowledgeable HIV

The study found less than half of Americans, 48%, feel knowledgeable about HIV, down three points from a year ago.



Discomfort around People Living with HIV

There is still unfounded fear about people living with HIV, even though those receiving proper medical treatment cannot transmit HIV. The study asked about feeling discomfort in interactions with the following people with HIV.

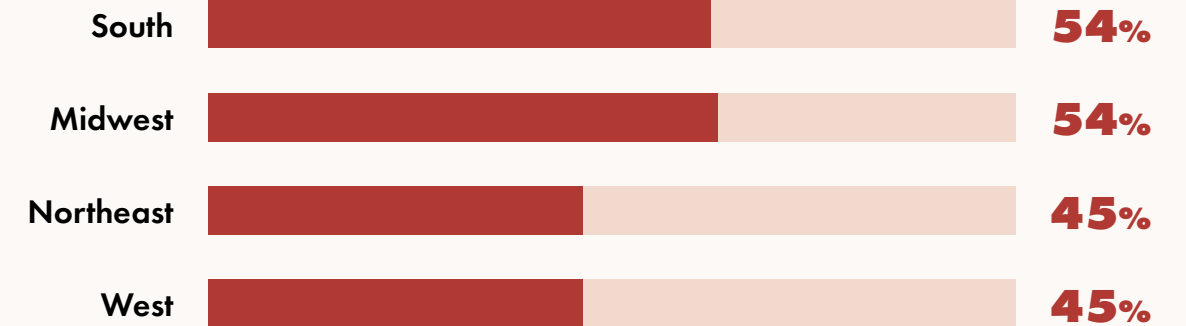


Regional Differences:

Discomfort levels around people living with HIV are higher in the Midwest and highest in the U.S. South.

Discomfort around Medical Professionals Living with HIV

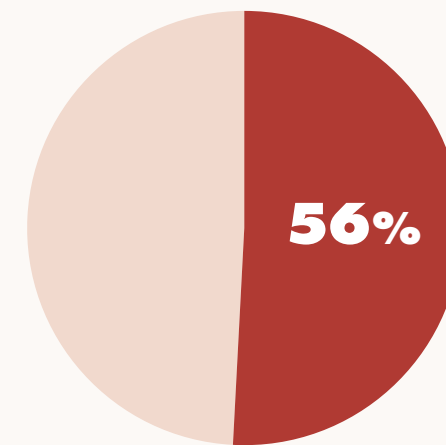
Among non-LGBTQ respondents nationwide



HIV Media Coverage

On a more positive note, 56% of non-LGBTQ respondents noted they are seeing more stories about people living with HIV in the media, up four points from 2020.

of Americans have seen stories about people living with HIV



Agree with Statement

Only 64% of those surveyed agree with the true statement that medications exist to protect someone from contracting HIV; only 42% agree with the true statement that people living with HIV who are on proper medications cannot transmit the virus.



STRATEGIES TO COMBAT STIGMA

The Gilead COMPASS Initiative® is working to address the HIV/AIDS epidemic in the Southern U.S. by collaborating with local community organizations to meet the needs of people living with and impacted by HIV/AIDS. The following COMPASS network leaders are calling for specific actions to reduce stigma.

1. Provide tangible and accessible information to counter misinformation

“People fear what they don’t know,” states Kia Colbert, Director for the COMPASS Coordinating Center at Rollins School of Public Health at Emory University. “Stigma is rooted in fear, thus for every accurate piece of information and knowledge that is available, there is an equal amount of misconceptions based on preconceived notions about the virus.”

2. Build trust between healthcare provider and patients

“The doctor/patient relationship - like all relationships - takes work,” notes Ian L. Haddock, Founder and Executive Director of The Normal Anomaly Initiative. “Each person comes with a wealth of knowledge - one with medical experience and the other with lived experience. Physicians often don’t recognize the patient’s expertise.”

3. Confront fear with facts and honest conversation

“People still see HIV and AIDS as a death sentence,” says Tatiana Williams, Co-Founder & Executive Director of TransinclusiveGroup. “We have to normalize the conversation surrounding HIV, and how HIV impacts the entire community, not just certain communities and/or sub-groups.”

4. Apply lessons from COVID-19 response

“The urgency of addressing COVID-19 revealed our ability to swiftly build infrastructure for a response that is comprehensive and accessible,” shares Dafina Ward, Executive Director of Southern AIDS Coalition. “COVID-19 has provided an opportunity for dialogue regarding transmission of viruses, vaccines research and more, while making more people receptive to the conversation. COVID-19 has also demonstrated the layered impact of diagnosis on all aspects of a person’s life, and the inequities that must be addressed to ensure that every person impacted receives the same level of care.”

5. Consider internal and external factors

“It’s important to remember that stigma is not an issue that only manifests itself externally,” says Sandra C. Melvin, Chief Executive Officer of the Institute for the Advancement of Minority Health. “We have to think about the ways it impacts one’s mental health and their self esteem. We must remember, even with all the COVID-19 conversations, that discrimination and human rights violations are major factors that drive HIV stigma in today’s society.”

A STUDY OF STIGMA IN THE MEDIA

Jonathan P. Higgins, Ed.D.



GLAAD Media Consultant & Researcher Dr. Jonathan P. Higgins studied the impact of media coverage on HIV stigma.

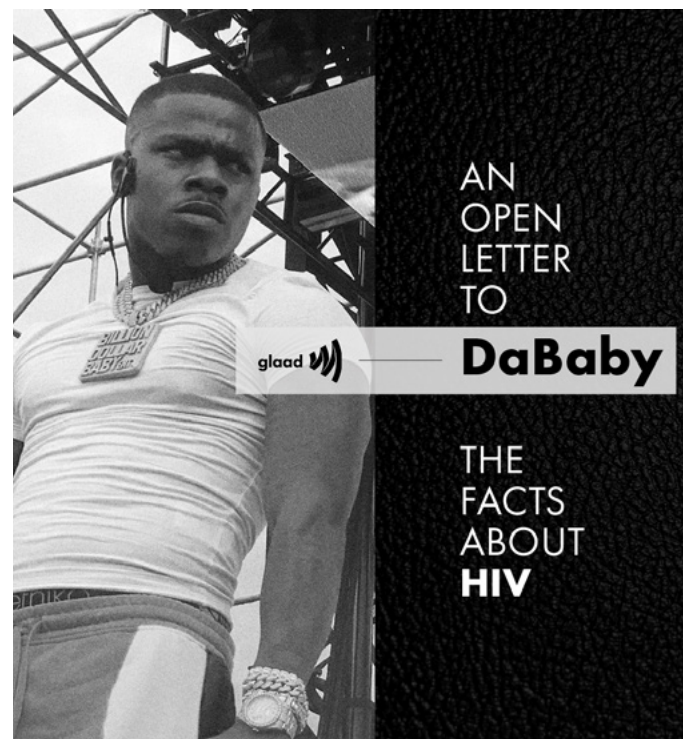
Musical artists have historically led the way in raising awareness about HIV and accelerating acceptance of people living with HIV. Pop culture icons like Elton John, Madonna, Sheryl Lee Ralph, Naomi Campbell, Magic Johnson, Paula Abdul as well as the late Princess Diana and Elizabeth Taylor used their platforms to elevate understanding and compassion.

Unfortunately, stigma, lack of education, and hate speech around HIV/AIDS continues to fuel fear. After Easy-E, the iconic frontman of N.W.A. died in 1995 from HIV-related health complications it became clear that HIV and AIDS impacted everyone- not just white gay men. Forced to address the impact HIV/AIDS has, particularly on the Black community, artists and emcees reckoned with their duty to use the powerful political potency of hip hop to shift mainstream conversations about the pandemic. The 1996 collaborative album *America is Dying Slowly* centered Black male youth and featured acts such as Common, Wu-Tang Clan, Goodie Mob, Spice 1, Mobb Deep, and De La Soul. These artists affirmed the influence and power of musicians to shift public opinion and intervene in a global health crisis.

In July 2021, DaBaby, legally Jonathan Kirk, a new school rapper from Charlotte, North Carolina, reignited conversation about stigma and the spread of misinformation. On stage at the “Rolling Loud” music festival in Miami, DaBaby instructed: “If you didn’t show up today with HIV/AIDS, or any of them deadly sexually transmitted diseases that’ll make you die in two to three weeks, then put your cell phone light up.”

These statements only fueled stigma, proving that there is still a great amount of work to be done in dismantling fear and misinformation about HIV/AIDS, especially among those with fanbases, platforms and across media at large. Misinformation at this level of influence has serious implications for educating the broader public on the reality that HIV is extremely treatable and does not discriminate based on race, sexuality, or any other demographic information.

GLAAD and over ten HIV organizations responded to DaBaby in an open letter, noting: “At a time when HIV continues to disproportionately impact Black Americans and queer and transgender people of color, a dialogue is critical. We must address the miseducation about HIV, expressed in your comments, and the impact it has on various communities.”



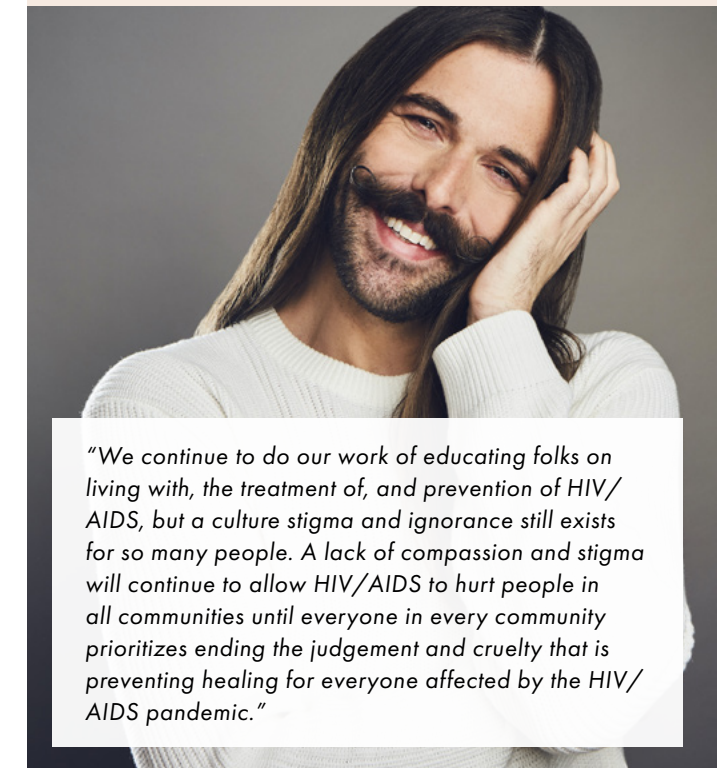
FIGHTING STIGMA IN MEDIA

Transparent star Alexandra Billings is a longtime survivor of HIV.



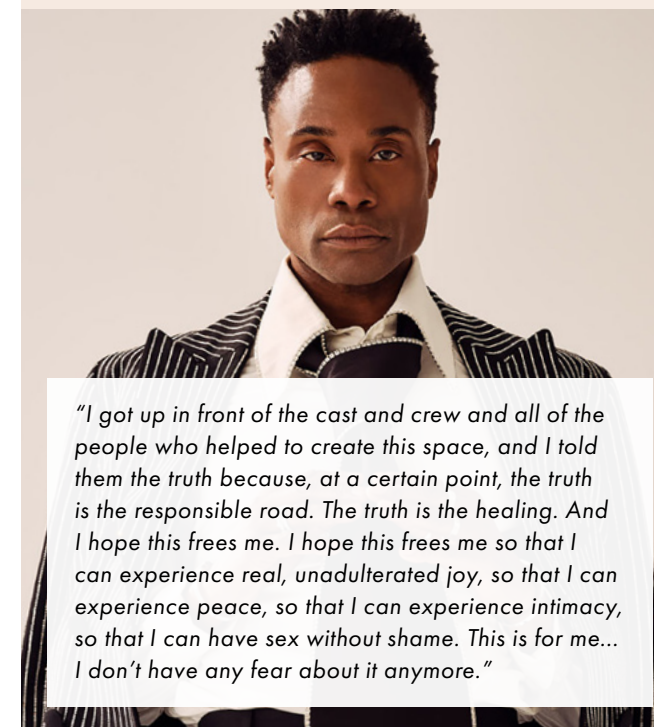
“This is who I am, this is part of my makeup, this is the thing that fuels me, is my AIDS, because it reminds me that I’m still here on the planet, and that’s a gift. I would like to see more people who have this disease come forward, I would like them to speak more, be more verbal... I’d like to see it represented, on television, on film, on stage, in art in general, that would be great. But we gotta get louder.”

Queer Eye star Jonathan Van Ness, who announced in 2019 he has HIV, is using his platform to advocate.



“We continue to do our work of educating folks on living with, the treatment of, and prevention of HIV/AIDS, but a culture stigma and ignorance still exists for so many people. A lack of compassion and stigma will continue to allow HIV/AIDS to hurt people in all communities until everyone in every community prioritizes ending the judgement and cruelty that is preventing healing for everyone affected by the HIV/AIDS pandemic.”

Emmy-winning actor Billy Porter, whose character on *Pose* has HIV, announced in May that he is living with HIV, 14 years after his diagnosis.



“I got up in front of the cast and crew and all of the people who helped to create this space, and I told them the truth because, at a certain point, the truth is the responsible road. The truth is the healing. And I hope this frees me. I hope this frees me so that I can experience real, unadulterated joy, so that I can experience peace, so that I can experience intimacy, so that I can have sex without shame. This is for me... I don’t have any fear about it anymore.”

Over the last two decades, multiple reports [6] show why stigma continues to grow - specifically because of the decline of coverage. From 1981 to 2002 alone, studies showed that not only had there been a decrease in total media coverage of HIV and AIDS, but a significant drop in the involvement of media figures in HIV/AIDS-related campaigns.

Even while the world was paying close attention to the emerging HIV/AIDS epidemic in the early 1980s and 1990s, only a few stories were given ample attention. Magic Johnson’s HIV diagnosis accounted for the highest share of media coverage (3%), with even less coverage given to topics related to HIV and AIDS activism (2%) and vaccine development (2%).

Though the reason for the drop in coverage could be associated with “media fatigue” and how media initially covered topics related to AIDS/HIV, the downward trend may also reflect mainstream media implicit bias against the diseases’ predominantly minority community targets, including LGBTQ people, Black and Brown people, transgender people and intravenous drug users. Media coverage of breakthrough medical and pharmaceutical advances in treatment and prevention has been under-covered over the last 41 years.

A CULTURE OF SHAME

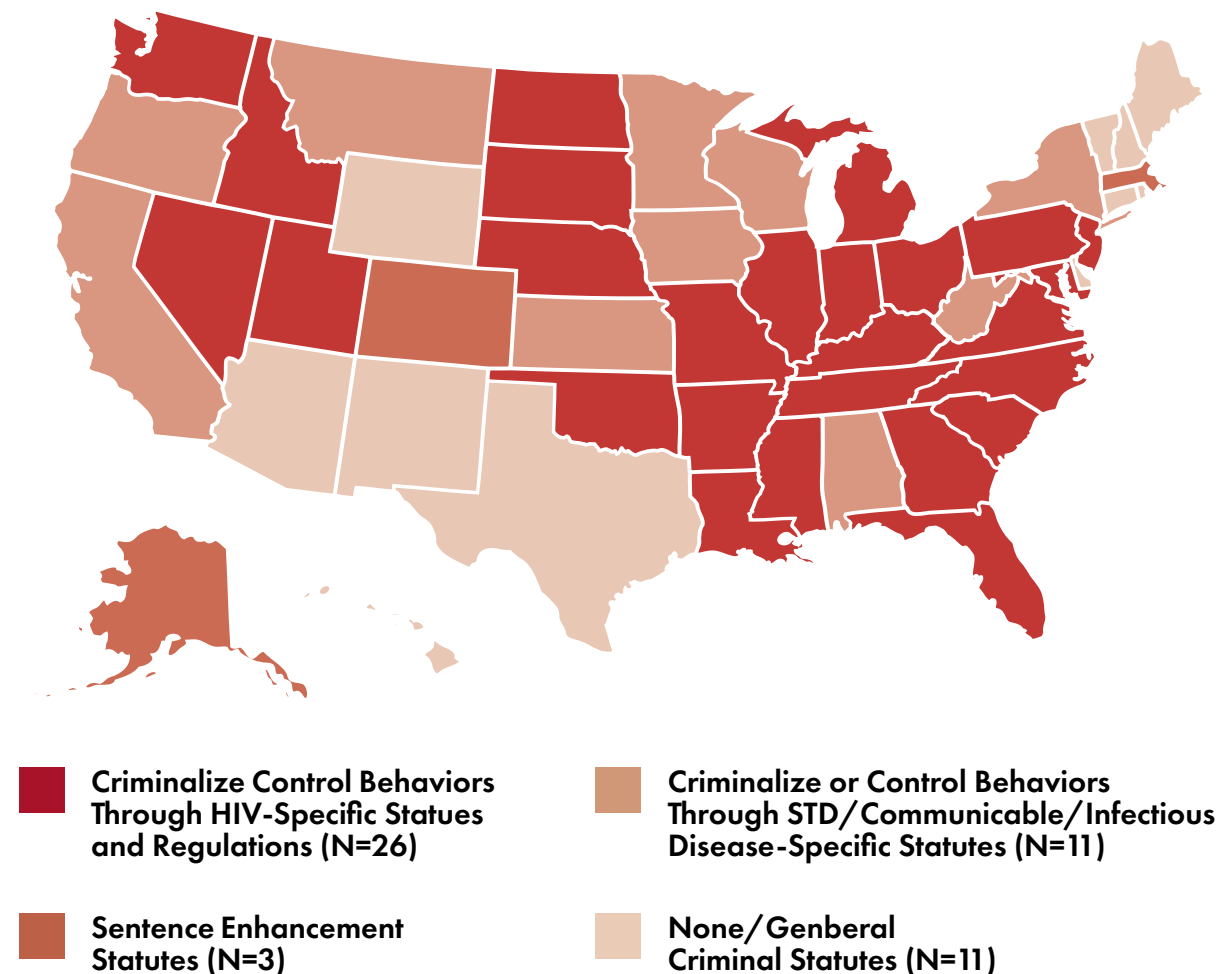
People living with HIV now live full lifespans, but the media has failed to create dynamic characterizations that transcend one-dimensional victimhood, or criminality. Black and Latinx communities not only make up a significant portion of HIV cases in the United States, they continue to suffer rampant criminalization.

The CDC says state laws against people living with HIV, many created in the early days of the epidemic when far less was known about the virus and before treatments were developed, are now outdated. State laws criminalizing HIV exposure do not reflect current research and advancements to prevent HIV transmission.

[37 states have laws that criminalize HIV transmission.](#) In the past two years, multiple individuals have been incarcerated in states like Tennessee for not disclosing their status.

Research consistently shows that Black gay men report the highest rates of stigma in states with strict and outdated HIV criminalization laws [5]. HIV/AIDS criminalization intersects with structural racism, homophobia, biphobia and transphobia [8]. An unequal application of disclosure laws across race reveals how these laws continue to prove that punishment is not a public health intervention and can actually worsen the stigma that fuels new infections.

STATES WITH HIV CRIMINALIZATION LAWS



MEDIA CASE STUDY: HIV CRIMINALIZATION, MISINFORMATION & RACE

Perhaps the most glaring recent example of mainstream media's complicity in this entanglement of criminalization, lack of accurate public knowledge about HIV transmission, and anti-Blackness is the heavily racialized coverage of former wrestler Michael Johnson.

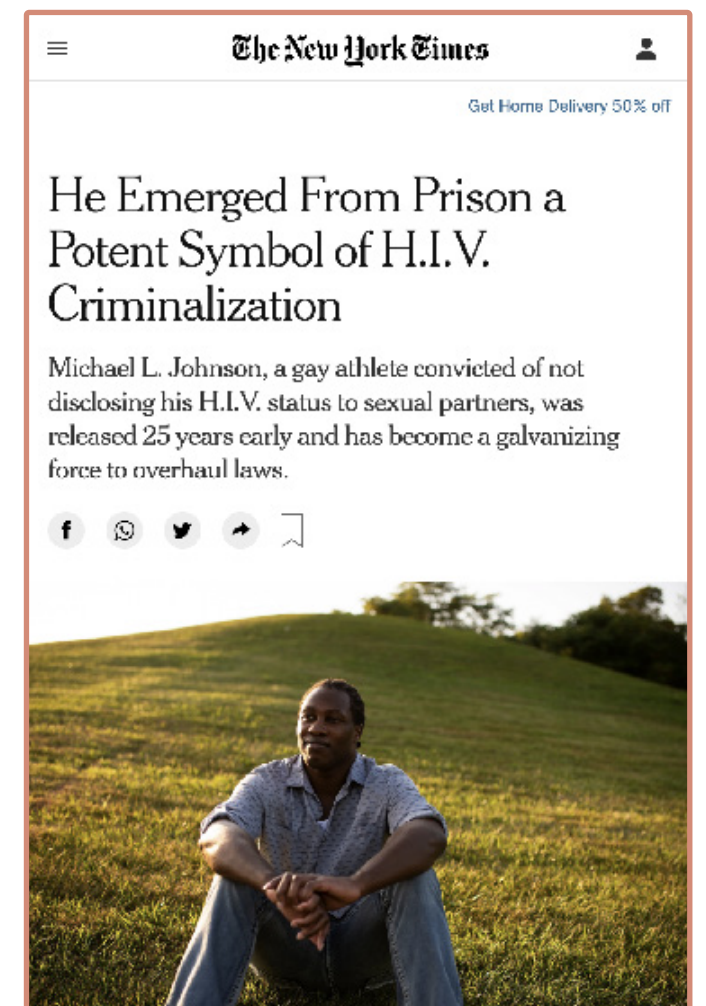
Media can also hyper-focus and sensationalize negative stories of people living with HIV, to the detriment of public health and efforts to decrease and defeat stigma.

In Missouri in 2013, Michael L. Johnson, a young Black man, was arrested for allegedly failing to report to a white male sexual partner that he was living with HIV before engaging in unprotected sex. In 2015, he was originally sentenced to thirty years in prison for "reckless transmission of HIV"-- a sentence longer than almost any other crime in the state including the state's average for second degree murder. The nexus of HIV stigma and the prison industrial complex continue to disproportionately impact Black gay men. According to the Centers for Disease Control, if current rates continue: 1 in 2 Black gay men who have sex with men will contract HIV in their lifetimes[4].

Journalist and Northwestern Professor Steven Thrasher detailed for BuzzFeed News how a "Black body" was put on trial and charged under a 1988 Missouri statute which remains one of the harshest HIV criminalization laws in the country. Thrasher reports how anti-gay and anti-Black animus often converge and come to the fore in HIV criminalization. Often referred to in news coverage by his social media screen name "Tiger Mandigo," the media also publicized photos of Johnson shirtless to accentuate a large muscular frame. Thus a college student quickly became the symbol of the deeply entrenched and troubled history of Black men's hypersexualization in America. A nearly all-white jury, all over the age of 40 and composed entirely of non-LGBTQ people not living with HIV, convicted Michael Johnson. He was sentenced to 30 years in prison, a longer sentence than that imposed on convicted murderers. An appeals court ordered him released after serving five years, ruling his trial was "fundamentally unfair." The perfect storm of anti-Blackness, homophobia, American shame around sex, and lack of reliable information around HIV created a media spectacle which misrepresented HIV as a "terminal illness" and went against best scientific practices.

Across all stories featuring or mentioning HIV, including coverage of crimes, journalists must do better to report the latest science and research showing HIV is preventable and when properly treated, untransmittable.

Media must also create opportunities for people living with HIV to tell their own stories, specifically around conversations about authentic experiences, full healthy sexual lives, and how antiretroviral therapies make it possible to thrive while living with HIV. This research shows that there is an opportunity for stigma to be lessened by showing in the media those who are living and thriving. People living with HIV need to be represented across race, sexuality, and gender identity to feel empowered to tell their stories and speak truth to power.



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GLAAD rewrites the script for LGBTQ acceptance. As a dynamic media force, GLAAD tackles tough issues to shape the narrative and provoke dialogue that leads to cultural change. GLAAD protects all that has been accomplished and creates a world where everyone can live the life they love.

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