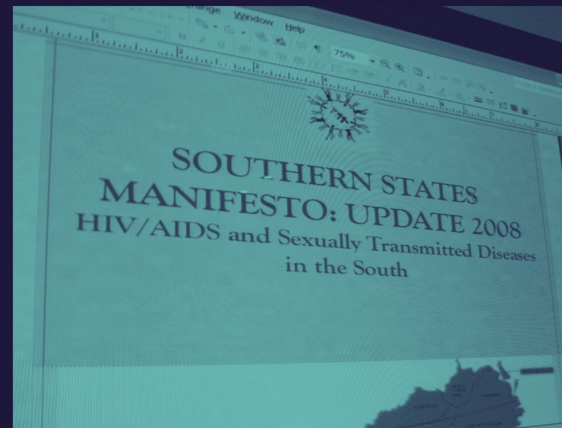
SOUTHERN AIDS COALITION

SOUTHERN STATES MANIFESTO 2024 UPDATE

STANDING ON THE SHOULDERS OF THE PAST



THE SOUTHERN AIDS COALITION MISSION

To end the HIV and STI epidemics in the South by promoting accessible and high-quality systems of [HIV and STI] prevention, treatment, care, housing, and essential support services.

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STANDING ON THE SHOULDERS OF THE PAST

This report is dedicated to the southerners we have lost to HIV and AIDS over four decades, to those living and thriving with HIV and AIDS in the region, and to the committed workforce across healthcare, social service, public health, advocacy and more who refuse to accept that things in our region can't change—and must change.

It has been over ten years now, since I first called the South my home. In that time, I was fortunate to have witnessed so much of its profound beauty and the many challenges we face.

The challenges we face today are not unlike those faced by the generations that came before us. The fight for justice, equity, and health in the South has and will continue to be an uphill battle, that often has been met with resistance and shaped by a history steeped in the stain of discrimination and stigma. Yet, despite these barriers, Southerners have consistently shown strength in the face of adversity and an unwavering commitment to progress. The South reminds us, all Americans, that even when the path is uncertain, perseverance can lead to transformation.

For me, the South has been a place of profound growth and self-discovery. Despite its complex history, it has been where my own personal exploration of self-identity has found its grounding – a fusion of culture, heritage, and lived experience that shapes how I view the work ahead. It is the same intersectional understanding that drives the Southern States Manifesto 2024 Update, a document rooted in the voices, struggles, and hopes of those who call this region home.

The Manifesto also serves as a tribute to the countless lives touched by the HIV epidemic in the South – those we've lost, those who continue to fight, and those living with HIV who embody strength and resilience every day. Their stories, their advocacy, their unbounding courage in the face of challenges has shaped this work and are woven into the fabric of this document.

As we look to the future, let this Manifesto serve as a reminder of what we can achieve when we stand together, grounded in purpose strengthened by the lessons of the past, and united in our vision for a South that is healthier, more equitable, more just, and free of the burdens of the HIV epidemic. The challenges ahead are great, they demand courage and collaboration, but I believe deeply in the power of community to rise to the occasion and create lasting change.

Will Ramirez, MPA
Director, Public Policy & Advocacy
Southern AIDS Coalition

Resilient. Responsive. Resistant. When asked what we must do in this moment—I point to these when I can't find other words. We are the heirs to a region that has a complex history, once of unimaginable violence and hatred, and one of inextinguishable hope and bravery. The South is of all these things and more.

We are ***resilient*** when we are robbed of opportunities and equitable resources. Resilience bringing along with it justifiable feelings of resentment, resentment that we are repeatedly required to fight for basic human rights and resources for our communities.

We are ***responsive*** when making our voices heard, showing up to support one another, and meeting the needs of our communities. From community organizations who time and again cobble together resources to make miracles happen, to policymakers and advocates who, armed with science and facts, push for change.

We are ***resistant***, whether quietly, or in public protest, our community stands boldly in the face of injustice. We are in a moment where our resistance is one of our greatest assets. We must resist being trapped in hopelessness, we must resist being distracted from our priorities, we must resist the urge to take on this fight alone.

As this report is published, I am drawn to the opening line of the first Southern States Manifesto released over twenty years ago in 2002:

"There is an emergency underway in the southern states of the United States."

Twenty-plus years later, there is still an emergency underway. While the circumstances are different, the urgency looms. When the original Manifesto was published by a group of southern public health advocates, they probably couldn't have imagined the level of national focus that would come, as more attention was drawn to the southern HIV epidemic. Their sounding of the alarm changed the response to HIV. There has been great progress, and yet, the urgency remains. A systemic dismantling must take place to create the change that the original Manifesto authors dreamed of. Intersecting systems perpetuating inequity must be challenged—tearing down racism, sexism, homophobia, xenophobia, and transphobia. Systems and practices of discrimination that are literally killing Southerners living with and affected by HIV every day. Willful ignorance to science coupled with deep seated discrimination has resulted in policy decisions that instead of acting on principles of public health, assault human rights.

The HIV epidemic in the South does not exist in isolation and our efforts must also recognize the syndemics of STIs, viral hepatitis, and substance use disorders. We are witnessing unprecedented attacks on women's healthcare and reproductive freedom, gender-affirming healthcare, the very existence of transgender persons, and continued state-sanctioned violence against marginalized communities. We are bracing ourselves for federal policies that could deepen these divides and cause more harm.

There is no response to HIV without addressing the connected systems of oppression that fuel HIV disparities. This report not only documents the challenges people living with and affected by HIV in the South face, but also celebrates community innovation and the tenacity of leaders from all walks of life.

This report is a ***call to action***, with a set of priorities for federal and state policymakers and HIV funders. This report is a reflection on the history of HIV advocacy in the South, and the history of human rights movements in the region that continue to inform our work today. This report is not our full story as a region and a movement—that story is too great for one document to tell. But we hope that it can be a launching point for conversations, a resource for cultivating resources, a reference for policymakers who are committed to public health, and a reminder that the tireless work in this field truly matters.

Until all of us are free,

Dafina Ward, JD
Executive Director
Southern AIDS Coalition

REFLECTIONS FROM THE PAST

INSIGHTS FROM THE ORIGINAL AUTHORS OF THE FIRST SOUTHERN STATES MANIFESTO (2002)

Since the first Southern Manifesto was published in 2002, the United States has seen a sea shift in federal commitment to ending the HIV epidemic. In 2010, President Obama announced the first-ever National HIV/AIDS Strategy (NHAS), a federal roadmap for coordinated funding and support that has been updated through 2025.[1] In 2019, President Trump announced a bold new plan, the Ending the HIV Epidemic (EHE) initiative, aiming to put the U.S. on a path to reduce new HIV transmissions by 90% by 2030.[2] Building off of the NHAS, the EHE initiative included a significant amount of new federal funding to Ryan White HIV/AIDS Program recipients, community health centers, and CDC HIV prevention grantees. The EHE initiative in particular includes a geographic focus that prioritizes jurisdictions with highest need, including a disproportionate number of southern states and counties.[3]

Despite these advances, it is clear, more is needed to mount an equitable and effective response to HIV in the South.

[1] NHAS, https://www.hiv.gov/federal-response/national-hiv-aids-strategy/national-hiv-aids-strategy-2022-2025/
[2] HIV.gov, EHE, https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview/
[3] https://www.cdc.gov/endhiv/jurisdictions.html

The first Southern States manifesto assured that those voices in concert with the voices of ASOs, CBOs, state HIV public health leaders, industry partners, and other national HIV-focused organizations also working to end HIV in the South, worked together to advocate for more equitable state and federal funding to implement evidence-based best practices within care and prevention strategies. Together, we advocated for funding to increase access to community-based HIV/ STI testing, early referral to effective care and treatment, and increased critical wrap-around and supportive services such as case management, transportation, and housing. Today, the result of that successful advocacy is still noticeable. Southern state partners, used those past SAC Southern Manifesto reports to secure additional state, and federal funding and thus were able to implement strategies highlighted in those reports. Since, the first release of the SAC Southern Manifesto, Southern states have noted overall decreases in new HIV/AIDS diagnoses including deaths, and increased viral suppression of people living with HIV. Although we have celebrated victories, and progress together across the national HIV landscape, unacceptable health disparities, HIV-related stigma, and discrimination disproportionately affecting people of color and LGBTQI people are still apparent in the South. It is time for an updated and deliberate Southern AIDS Coalition Manifesto and Call to Action so the work and progress we have made in the South continues, with facts, and strategy in hand.

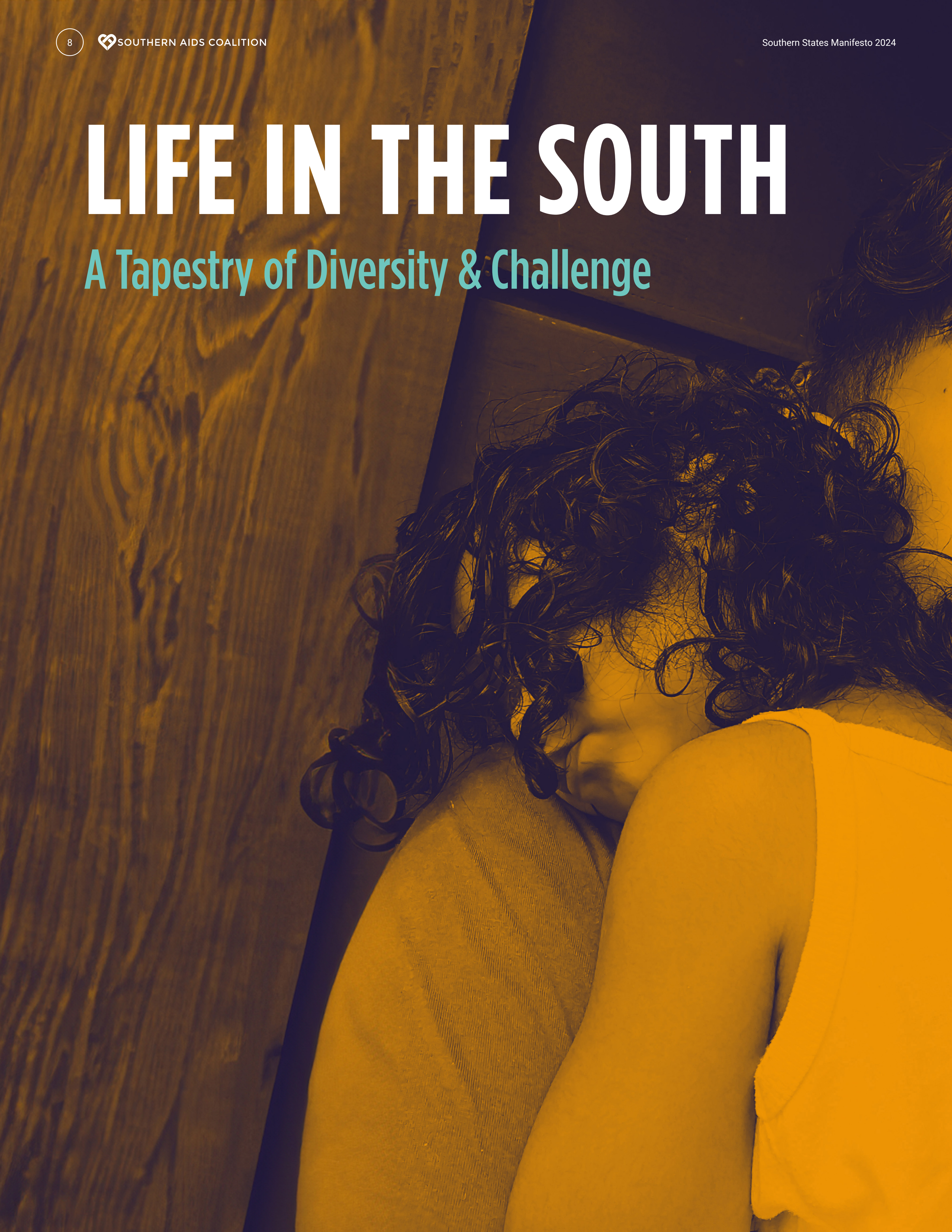
Evelyn M. Foust MPH CPM
North Carolina Communicable Disease Branch Head Epidemiology Section Division of Public Health

Twenty years ago HIV leaders in the southern states wanted to change the toll that HIV was having in the South. A lot of thought went into crafting the Southern States Manifesto in order to bring great awareness of the epidemic in the South, impact federal agencies related to leadership and funding priorities and mobilizing new organizations and leaders in Southern states. I believe those goals were obtained but the job was far from finished. I am hopeful the 2024 report will again mobilize our communities, recharge our leaders, and in the end and most importantly reduce new infections in Southern states that have taken a disproportionate share of the domestic epidemic for years.

Thomas Liberti
Florida HIV/AIDS Director (Retired)

"The first manifesto was actually published on my birthday- March 2, 2002...It remains my best birthday gift ever- as it empowered us as AIDS Directors, who were at the time, powerless. We made a lasting difference. I am very proud of the work of SAC, but in the beginning we were all just AIDS Directors without enough funds to keep our friends alive."

Drema Hill
Tennessee Department of Health/ Infectious Disease Section (2002)



LIFE IN THE SOUTH

A Tapestry of Diversity & Challenge

The Southern United States, a region as diverse as it is complex, stands as a testament to the multifaceted tapestry of American life. The story of America began in the South in 1607 and since then, the region has undergone a multitude of triumphs and tribulations marked with battles against issues such as poverty, racism, and social stigma. The American South, a melting pot of cultures and traditions, is defined by its strikingly different environments: from its bustling cities like Atlanta and Houston, expansive rural communities such as the Delta region spanning from Kentucky to Alabama, picturesque coastal regions, and the rugged and beautiful terrain of the Appalachians. Each region in the Southern United States tells a different story of life in the South, reflecting a rich blend of cultures and experiences. Yet this diversity also highlights stark disparities in the South. Access to healthcare, education, and economic opportunities often vary dramatically between these regions, with rural, minority, LGBTQIA+, and other marginalized communities frequently facing the brunt of these inequalities. The South's history is the cradle of American history, a source of pride and shame – a complex legacy, with historical events profoundly shaping its socio-economic landscapes.

“The South is a repository for American sins and American magnificence.”

Imani Perry

Racism’s impact on the South cannot be understated. It has been a persistent force, influencing the region’s societal and political structures for centuries. The vestiges of slavery, segregation, Jim Crow, Redlining, and ongoing racial discrimination have left indelible marks, contributing significantly to the health, economic, and social disparities seen today. In the book, “South to America: A Journey Below the Mason-Dixon to Understand the Soul of a Nation,’ author Imani Perry insightfully remarks, “The South is a repository for American sins and American magnificence.” This statement encapsulates the dual nature of the South – a place of profound cultural richness and painful historical scars. Addressing these disparities requires a nuanced understanding of the South’s complex tapestry. The story of HIV in this region is told through a complex interplay of socioeconomic dynamics and cultural nuances. It is not merely a medical issue but a reflection of the region’s broader socio-political struggles and unrelenting resilience. In the process of examining this narrative, the varied contexts of the region will be explored: its economic landscapes, historical factors, and the diverse experiences of its people. This report will weave together the many elements that shape the Southern tapestry in particular, the pervasive impact of race and racism, on the region. Through this approach, the report will present a story of HIV in the South that authentically represents the region’s unique character and complexities.

As the region continues to evolve, there’s an ever-growing emphasis on acknowledging its diverse history and working towards a future where all its residents have equal access to opportunities and positive health outcomes. This evolution is not just vital for the South but for understanding the soul of the nation as a whole.

Sign for “colored” waiting room at a Greyhound bus terminal in Rome, Georgia, 1943. Photo by Esther Bubley

The story of HIV in this region is told through a complex interplay of socioeconomic dynamics and cultural nuances.

A SNIPPET IN HISTORY

A LEGACY OF SYSTEMIC RESISTANCE

The original Southern Manifesto, crafted in 1956, was more than a political statement - it was a calculated act of defiance by segregationist legislators in Congress against the desegregation mandates of the Supreme Court's landmark decision in Brown v. Board of Education. This document, signed by 19 senators and 82 representatives, a total of 101 lawmakers, was instrumental in rallying resistance against racial integration, particularly in public schooling systems. It symbolized the deep-rooted challenges to civil rights advancements and exemplified how legislative powers were leveraged to sustain racial divides. The manifesto not only reinforced the segregationist agenda but also demonstrated the pervasive nature of institutional racism that extended far beyond education into every facet of public life, including healthcare.

Today's Southern AIDS Coalition (SAC) version of the Southern States Manifesto seeks to confront and dismantle these historical legacies. While it does not inherit its spirit from the segregationist document, the SAC manifesto acknowledges the profound effects those historical attitudes continue to have on public health today. It directly addresses the systemic barriers that perpetuate health disparities, particularly in the realm of HIV/AIDS, where the South sees disproportionately high rates. The manifesto champions a comprehensive approach to health equity, advocating for policy changes, enhanced community engagement, and broader access to healthcare services. By doing so, it redefines the narrative, turning a legacy of division into a united front against health inequities and aiming to heal the wounds inflicted by a history of systemic racism.

FOR RELEASE MONDAY, A.M., MARCH 12, 1956

PRESENTED TO THE UNITED STATES SENATE BY 19 SOUTHERN SENATORS AT NOON, MONDAY, MARCH 12, 1956.

DECLARATION OF CONSTITUTIONAL PRINCIPLES

The unwarranted decision of the Supreme Court in the public school cases is now bearing the fruit always produced when men substitute naked power for established law.

The Founding Fathers gave us a Constitution of checks and balances because they realized the inescapable lesson of history that no man or group of men can be safely entrusted with unlimited power. They framed this Constitution with its provisions for change by amendment in order to secure the fundamentals of government against the dangers of temporary popular passion or the personal predilections of public office holders.

We regard the decision of the Supreme Court in the school cases as a clear abuse of judicial power. It climaxes a trend in the Federal judiciary undertaking to legislate, in derogation of the authority of Congress, and to encroach upon the reserved rights of the States and the people.

The original Constitution does not mention education. Neither does the Fourteenth Amendment nor any other Amendment. The debates preceding the submission of the Fourteenth Amendment clearly show that there was no intent that it should affect the systems of education maintained by the States.

The very Congress which proposed the Amendment subsequently provided for segregated schools in the District of Columbia.

When the Amendment was adopted in 1868, there were 37 States of the Union. Every one of the 26 States that had any substantial racial differences among its people either approved the operation of segregated schools already in existence or subsequently established such schools by action of the same law-making body which considered the Fourteenth Amendment.

As admitted by the Supreme Court in the public school case (Brown v. Board of Education), the doctrine of separate but equal schools "apparently originated in Roberts v. City of Boston ... (1849), upholding school segregation against attack as being violative of a State constitutional guarantee of equality." This constitutional doctrine began in the North -- not in the South, and it was followed not only in Massachusetts, but in Connecticut, New York, Illinois, Indiana, Michigan, Minnesota, New Jersey, Ohio, Pennsylvania and other northern States until they, exercising their rights as States through the constitutional processes of local self-government, changed their school systems.

In the case of Plessy v. Ferguson in 1896 the Supreme Court expressly declared that under the Fourteenth Amendment no person was denied any of his rights if the States provided separate but equal public facilities. This decision has been followed in many other cases. It is notable that the Supreme Court, speaking through Chief Justice Taft, a former President of the United States, unanimously declared in 1927 in Lum v. Rice that the "separate but equal" principle is ". . . within the discretion of the State in regulating its public schools and does not conflict with the Fourteenth Amendment."

This interpretation, restated time and again, became a part of the life of the people of many of the States and confirmed their habits, customs, traditions and way of life. It is founded on elemental humanity and common sense, for parents should not be deprived by government of the right to direct the lives ond education of their own children.

Though there has been no constitutional amendment or act of Congress changing this established legal principle almost a century old, the Supreme Court of the United States, with no legal basis for such action, undertook to exercise their naked judicial power and substituted their personal political and social ideas for the estab-

- 1 -

The Declaration of Constitutional Principles (The Southern Manifesto), 1956

DESCRIBING THE HIV EPIDEMIC IN THE SOUTH

It has been over forty years since HIV was first discovered in the U.S. Since that time, remarkable gains have been realized in the development of HIV treatment and prevention antiretrovirals, the growth of a system of care for underinsured individuals and a dedicated network of community-based organizations, researchers, healthcare workers, and advocates. However, that progress has not been felt equally amongst all populations and regions.

HIV continues to disproportionately impact racial and ethnic minorities, gay, bisexual, and other men who have sex with men, Black women, transgender individuals, and people living in the Southern region[4] of the U.S.

[4]The U.S. Census Bureau defines the South region as: Alabama, Arkansas, Delaware, the District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia.

The South holds rich historical, cultural, and geographic significance. However, due to the legacy of slavery, Jim Crow, segregation, and ongoing structural racism it is also a region with stark inequities and disparities. These factors have limited economic mobility and led to persistent poverty, which in turn leads to poorer health outcomes. More than half (59.4%) of people living with persistent poverty live in the South, far exceeding the South's share of the U.S. population (38%). Of the 341 counties identified in persistent poverty by the U.S. Census Bureau, 80% were in the South.[5] Fifty-six percent of Black Americans live in the Southern region. The South also has a diverse set of rural, urban, and suburban areas making the delivery of healthcare challenging and increasing the demands on non-medical services such as transportation, case management, and housing.

The Epidemiology of HIV in the South

The South experiences a higher burden of HIV compared to other regions. In 2022, nearly half (49%) of all HIV diagnoses were in the South, far exceeding all other regions - 23% in the West, 14% in the Northeast, and 14% in the Midwest.[6] Out of the top 10 jurisdictions with the highest rates of new diagnoses in 2022, only one state was not located in the South. Between 2010 and 2016, the South represented 50% of all undiagnosed HIV.[7] As a sign of progress, the South was the only region that saw a decline in overall new estimated transmission between 2018 and 2022.[8] The higher rates in the South are driven by many factors including socioeconomic causes such as poverty, unemployment, lack of access to care, etc. The South also has the lowest median household income and the highest rate of poverty among the four U.S. regions. Nearly half of all Americans without health coverage live in the South.[9]

Within the most impacted populations, these disparities are even more exacerbated in the South. In 2022, Black individuals made up 48% of new HIV diagnoses in the South while only accounting for 19% of the South's population.[10] Women accounted for 18% of new diagnoses, with Black women accounting for 50% of those transmissions, even though they are 13% of the U.S. population.[11][12] Hispanic/ Latinx persons aged 13 and up made up 57% of the Southern population, but 23% of new diagnoses. Among gay, bisexual, and other men who have sex with men, 43% of HIV diagnoses were Black/ African American men in 2023.[13] Between 2018 and 2022, the disparity in HIV diagnosis rates increased for all racial/ethnic groups compared to White people, except for American Indian/ Alaska Native and Asian populations.

Top States, Including DC, by HIV Diagnosis in 2022

Rate per 100,000

State	Rate
Washington D.C.	34.1
Georgia	26.2
Louisiana	23.3
Florida	21.7
Nevada	18.9
Texas	18.0
Mississippi	17.0
North Carolina	15.5
South Carolina	14.8
Alabama	14.7

[5]U.S. Census Bureau, Persistent Poverty: Identifying Areas with Long-Term High Poverty, https://www.census.gov/library/stories/2023/05/persistent-poverty-areas-with-long-term-high-poverty.html, accessed October 25, 2023.
[6]Centers for Disease Control and Prevention. (2024). HIV in the United States [Infographic]. Retrieved from https://files.hiv.gov/s3fs-public/2024-08/CDC-HIV-in-the-US_2024-25.jpg
[7]Centers for Disease Control and Prevention. (2024). HIV Surveillance Report, 2022. Retrieved from https://stacks.cdc.gov/view/cdc/156509 .
[8]Centers for Disease Control and Prevention. (2024). HIV Surveillance Data Tables: Diagnoses, Deaths, and Prevalence of HIV in the United States and 6 U.S. Dependent Areas, 2022. Retrieved from https://stacks.cdc.gov/view/cdc/156513
[9]Kaiser Family Foundation. (2024). Health insurance coverage of the total population. Retrieved August 30, 2024, from https://www.kff.org/other/state-indicator/total-population/
[10]AIDSVu. (2024). PrEP in Black communities [Infographic]. Retrieved from https://aidsvu.org/wp-content/uploads/2024/06/PrEP-Black-Communities-06242024.png
[11]AIDSVu. (2024). Black women and PrEP [Infographic]. Retrieved from https://aidsvu.org/wp-content/uploads/2024/06/Black-Women-and-PrEP-06182024.png
[12]Flourish. (2024). HIV infections, Black women, Retrieved from https://public.flourish.studio/visualisation/19152011/
[13]Centers for Disease Control and Prevention. (n.d.). NCHHSTP AtlasPlus: Tables. Retrieved August 30, 2024, from https://gis.cdc.gov/grasp/nchhstpatlas/tables.html

Transgender women are also disproportionately affected by HIV. Of the 994 HIV diagnoses among transgender individuals, 44% were residing in the Southern U.S.[17] A recent study of transgender women found that residence in the South was associated with both higher risk of seroconversion and perfectly predicted deaths in the study population.[18]

Nationally, 37% of new HIV diagnoses in 2022, were found amongst individuals 25-34 years old, the most impacted age group. The next most impacted population, were those between the ages of 35 - 44, with 22%, and 19% in ages 13 - 24. The epidemic in the South tends to be a bit older with 37% of new diagnoses in 2022 seen in ages 25-34, 21% in ages 35-44, and 20% in ages 13-24.[19]

HIV-Related Health Outcomes in the South

For individuals living with HIV in the Southern United States, the challenges they face are intertwined with the region's unique and structural issues. The South, which accounted for 48% of all HIV-related deaths in 2021, presents a particularly harsh landscape for those managing the disease.[20] The experiences of many individuals living with HIV in this region underscore how social determinants and systemic barriers such as pervasive HIV-related stigma, poverty, higher levels of illnesses transmitted through sexual contact, racial inequality, bias, fear, and laws that further HIV-related stigma contribute to worsened health outcomes.

Mississippi, for instance, is one of five states where a higher percentage of people received a late-stage diagnosis rather than an earlier-stage diagnosis. While states with higher rates of a stage-3 AIDS classification at the time of diagnosis are spread throughout the United States, a large concentration of states with elevated rates are located in the South. This delay is not just a statistic but a reflection of real-life struggles.

The statistics also highlight that while 82% of individuals diagnosed with HIV in 2021 were linked to medical care within one month, only 80% of those in the South achieved this timely linkage.[21] This slight but critical disparity underscores the everyday realities faced by many in the region. The fact that the disparity isn't greater can likely be attributed to local community and public health efforts to ensure linkage in the face of access challenges in the region.

For many people in the South, accessing timely and effective HIV care is complicated by a constellation of socioeconomic factors. Southern states generally face lower educational attainment, higher poverty rates, and lower median incomes, compared to other regions in the US. These socioeconomic challenges exacerbate health disparities, making it harder for individuals to obtain consistent insurance, medical care, and support.

Viral suppression, a key indicator of effective HIV management, reveals another layer of disparity. The national viral suppression rate for people diagnosed with HIV in 2021 was nearly 66%, yet only 64.9% of individuals in the South

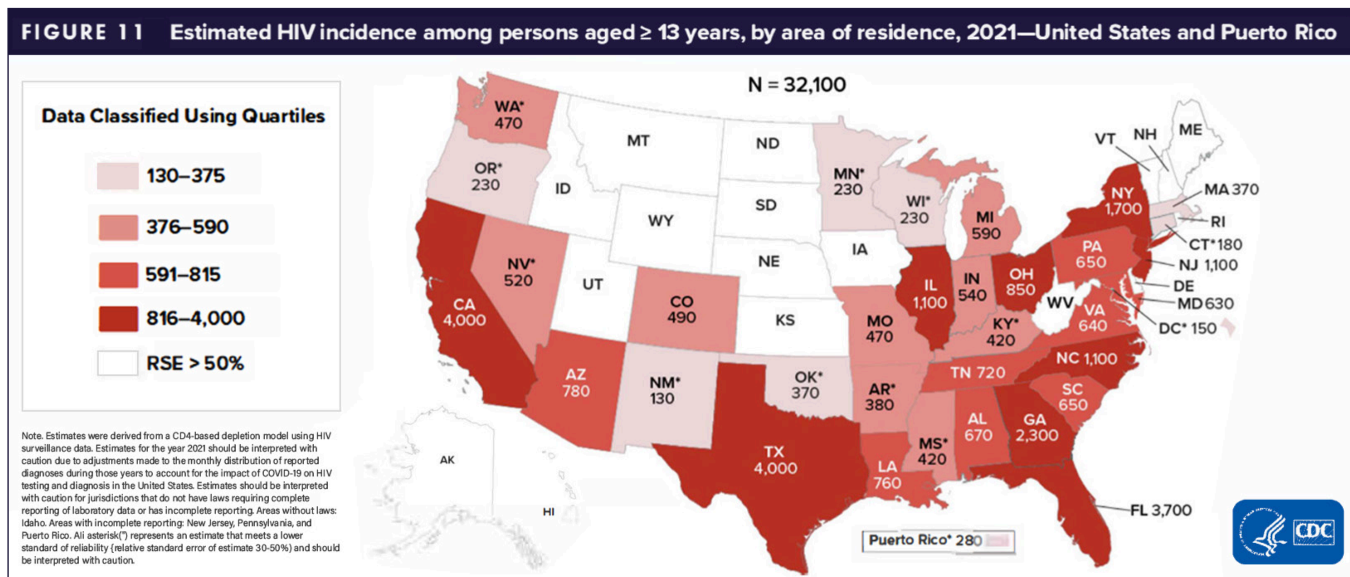
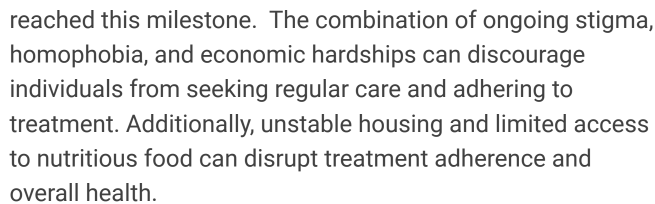


FIGURE 11 Estimated HIV incidence among persons aged ≥ 13 years, by area of residence, 2021—United States and Puerto Rico

Note. Estimates were derived from a CD4-based depletion model using HIV surveillance data. Estimates for the year 2021 should be interpreted with caution due to adjustments made to the monthly distribution of reported diagnoses during those years to account for the impact of COVID-19 on HIV testing and diagnosis in the United States. Estimates should be interpreted with caution for jurisdictions that do not have laws requiring complete reporting of laboratory data or has incomplete reporting. Areas without laws: Idaho. Areas with incomplete reporting: New Jersey, Pennsylvania, and Puerto Rico. Ali asterisk(") represents an estimate that meets a lower standard of reliability {relative standard error of estimate 30-50%) and should be interpreted with caution.

[14] Centers for Disease Control and Prevention. HIV Surveillance Report, 2021; vol. 34. http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published May 2023. Accessed July 20, 2023.
[15] Randolph, Schenita D. PhD, MPH, RN*; Golin, Carol PhD; Welgus, Hayley MPH; Lightfoot, Alexandra F. EdD; Harding, Caressa J. MA, CHC; Riggins, Linda F. MPH. How Perceived Structural Racism and Discrimination and Medical Mistrust in the Health System Influences Participation in HIV Health Services for Black Women Living in the United States South: A Qualitative, Descriptive Study. Journal of the Association of Nurses in AIDS Care 31(5):p 598-605, September-October 2020. | DOI: 10.1097/JNC.0000000000000189
[16] Flourish. (2024). HIV infections, Black women, Retrieved from https://public.flourish.studio/visualisation/19152011/
[17] Centers for Disease Control and Prevention. (2024). HIV Surveillance Data Tables: Diagnoses, Deaths, and Prevalence of HIV in the United States and 6 U.S. Dependent Areas, 2022. Retrieved from https://stacks.cdc.gov/view/cdc/156513
[18] Wirtz AL, Humes E, Althoff KN, Poteat TC, Radix A, Mayer KH, Schneider JS, Haw JS, Wawrzyniak AJ, Cannon CM, Stevenson M, Cooney EE, Adams D, Case J, Beyrer C, Laeyendecker O, Rodriguez AE, Reisner SL; American Cohort to Study HIV Acquisition Among Transgender Women (LITE) Study Group. HIV incidence and mortality in transgender women in the eastern and southern USA: a multisite cohort study. Lancet HIV. 2023 May;10(5):e308-e319. doi: 10.1016/S2352-3018(23)00008-5. Epub 2023 Feb 28. PMID: 36868260; PMCID: PMC10164681.
[19] Centers for Disease Control and Prevention. (n.d.). NCHHSTP AtlasPlus: Tables. Retrieved August 30, 2024, from https://gis.cdc.gov/grasp/nchhstpatlas/tables.html
[20] Ibid.
[21] Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2021. HIV Surveillance Supplemental Report, 2023; 28(No. 4). http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html. Published May 2023. Accessed July 20, 2023.

reached this milestone. The combination of ongoing stigma, homophobia, and economic hardships can discourage individuals from seeking regular care and adhering to treatment. Additionally, unstable housing and limited access to nutritious food can disrupt treatment adherence and overall health.



Recent additions to the National HIV/AIDS Strategy, including indicators for self-rated health status, mental health, hunger, unemployment, and unstable housing, highlight the broader context of living with HIV.[22] For many in the South, these indicators are pressing concerns that affect their overall well-being. The struggles with mental health, driven by stigma and social isolation, and the daily challenges of hunger and unstable housing, further complicate their ability to manage their health effectively.

The personal stories of those living with HIV in the South reveal the profound impact of these structural issues. They face a daily battle not only against the virus but also against a backdrop of socioeconomic disadvantages and systemic barriers. Addressing these disparities requires a comprehensive approach that goes beyond medical care, incorporating efforts to tackle stigma, improve access to resources, and address the broader social determinants that affect health outcomes.

By acknowledging and addressing these personal and systemic challenges, work can be done to reduce the health inequities faced by individuals with HIV in the Southern United States and improve their quality of life.

Injection Drug Use and HIV Transmissions

Injection drug use also continues to be a significant factor for new HIV transmissions, particularly in non-urban areas of the South. In 2021, 2,521 diagnoses of new HIV transmissions were attributed to injection drug use. Forty-four percent of those new infections were in the South, an increase of 15% in new diagnoses attributed to injection drug use compared with 2017. A 2016 assessment of counties vulnerable to HIV and hepatitis C outbreaks identified 220 counties, 68% of which were located in the South. Between 2019 and 2021, West Virginia experienced a significant and rapid increase in HIV transmission across several counties related to injection drug use. In 2022, West Virginia had 141 new HIV transmission with nearly 69% occurring among individuals who reported injection drug use. As of June 2022, 13 states have laws that bar syringe service programs (SSPs) from operating, including three Southern states (Alabama, Mississippi, and Texas).[23] Additionally, local politics in Southern states have seen long-standing programs forced to curtail hours and services provided or even close.

PrEP Access in the South

Pre-exposure prophylaxis (PrEP) – where an individual can take an oral or injectable antiretroviral medication regularly and prevent the acquisition of HIV – is a key intervention to decrease new HIV infections by 90% by 2030. PrEP utilization data for 2023 from AIDSVu shows a 52% increase in usage from 38% in 2022, an improvement from 30% in 2021 and 13% in 2017. Despite substantial progress, PrEP coverage remains deeply inequitable, varying significantly by race/ethnicity and

[22] The White House, National HIV/AIDS Strategy for the United States 2022 – 2025, https://files.hiv.gov/s3fs-public/NHAS-2022-2025.pdf.
[23] Legislative Analysis and Public Policy Association, Syringe Service Programs: Summary of State Laws, June 2022, http://legislativeanalysis.org/wp-content/uploads/2022/09/Syringe-Services-Programs-Summary-of-State-Laws.pdf, accessed July 24, 2023.

by sex.[24][25] While White populations saw an uptake from 74% in 2021 to 94% in 2022, Black/African American individuals accounted for only 22% of PrEP users in 2023.[26] Women made up only 8% of PrEP users, reflecting a 2% increase since 2018.[27] Hispanic/Latinx persons had only 18% PrEP coverage in 2023. Among those aged 13-24 years, the PrEP-to-Need Ratio (PnR) was 9, meaning that for every person diagnosed with HIV, there were 9 using PrEP.[28] In 2023, only 39% of PrEP users resided in the South, which had the highest unmet need for PrEP in the U.S. based on the number of people indicated for PrEP compared to those prescribed it.

A study in 2020 found that only one-quarter of PrEP-providing clinics exist in the South and only 30% of PrEP users were in the South.[30] Stigma and awareness of PrEP are two notable barriers to access. In a focus group conducted from 2021-2022, involving 19 staff members and 17 PrEP-eligible patients at Mississippi FQHCs, it became evident that a lack of information about PrEP was a common theme for both groups. One staff member admitted, "I probably know the bare minimum about PrEP," while another noted, "Well, they kind of explained to me what PrEP is..." Patients also observed the medical staff's lack of knowledge, which further deepened their mistrust.[31] One patient shared, "She Googled PrEP right in front of me and asked, 'Is this for treatment?'"[32] Another concern was the fear of side effects, influencing patients' decisions to use PrEP: "I'm afraid of gaining weight..." and "...most pills have allergic reactions and side effects..." Additionally, those aware of an oral pill to prevent HIV expressed the perception that HIV prevention was "for homosexuals," with some doctors reinforcing this stereotype.[34] One patient stated, "Heterosexual healthcare providers feel like they have the right to lecture you, 'You know you're gay, so you should be—' and it's so offensive."[35] The same barriers that prevent people from accessing HIV treatment in rural areas (lack of anonymity, lack of resources) also create barriers to accessing PrEP. Yet another systemic barrier to PrEP uptake is among persons experiencing homelessness and the unstably housed population. Of youth experiencing homelessness in the South, only 29% knew about PrEP and a mere 4% had discussed PrEP with a provider.[36] Sexual health clinics can be a key partner in expanding access to PrEP education and prescriptions, yet only one-fifth of Title X Family Planning Program clinics in the South were ready to administer PrEP.[37] As part of their mission to provide comprehensive family planning and related services, Title X clinics are a critical access point for prevention of HIV and Sexually Transmitted Infections (STIs), education, screening, and treatment, as well as PrEP.

The same barriers that prevent people from accessing HIV treatment in rural areas (lack of anonymity, lack of resources) also create barriers to accessing PrEP.

[24] HIV Hepatitis Policy Institute. (2023). New CDC PrEP data demonstrates importance of federal funding. Retrieved from https://hivhep.org/press-releases/new-cdc-prep-data-demonstrates-importance-of-federal-funding/ ,accessed August 28th, 2024 2
[25] AIDSVu. Deeper Look, PrEP, https://aidsvu.org/resources/deeper-look-prep/, accessed, August 27, 2024
[26] AIDSVu. (2024). AIDSVu releases new PrEP data and launches PrEPVu.org, a new PrEP equity platform. Retrieved from https://aidsvu.org/news-updates/aidsvu-releases-new-prep-data-and-launches-prepvu-org-a-new-prep-equity-platform/#:~:text=Nationally%2C%20there%20are%2014%20PrEP,for%20PrEP%20of%20all%20regions. 3,6
[27] Flourish. (2024). HIV infections, Black women, Retrieved from https://public.flourish.studio/visualisation/19152011/
[28] AIDSVu. (2024). PrEP Youth Infographic. Retrieved from https://aidsvu.org/wp-content/uploads/2024/06/PrEP-Youth_06252024.png
[29] AIDSVu. (2024). AIDSVu releases new PrEP data and launches PrEPVu.org, a new PrEP equity platform. Retrieved from https://aidsvu.org/news-updates/aidsvu-releases-new-prep-data-and-launches-prepvu-org-a-new-prep-equity-platform/#:~:text=Nationally%2C%20there%20are%2014%20PrEP,for%20PrEP%20of%20all%20regions.
[30] Mayer, K. H., Agwu, A., & Malebranche, D. (2020). Barriers to the Wider Use of Pre-exposure Prophylaxis in the United States: A Narrative Review. Advances in therapy, 37(5), 1778–1811. https://doi.org/10.1007/s12325-020-01295-0
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[32] Ibid.
[33] Ibid.
[34] Ibid.
[35] Ibid.
[36] CDC. (2022, December 1). Issue Brief: The Role of Housing in Ending the HIV Epidemic . Retrieved December 20, 2022, from https://www.cdc.gov/hiv/pdf/policies/data/cdc-hiv-issue-brief-housing.pdf
[37] Sales, J. M., Escoffery, C., Hussen, S. A., Haddad, L. B., McCumber, M., Kwiatkowski, E., Filipowicz, T., Sanchez, M., Psioda, M. A., & Sheth, A. N. (2021). Pre-exposure Prophylaxis Implementation in Family Planning Services Across the Southern United States: Findings from a Survey Among Staff, Providers and Administrators Working in Title X-Funded Clinics. AIDS and behavior, 25(6), 1901–1912. https://doi.org/10.1007/s10461-020-03120-9

Syndemics & Health Justice

HIV does not exist in a vacuum, instead, HIV is part of a syndemic. The National HIV/AIDS Strategy defines a syndemic as, "a set of linked health problems that interact synergistically and contribute to excess burden of disease in a population. Social determinants of health and stigma also play a significant role in this syndemic."[38] The CDC defines social determinants of health as "the conditions in the environment where people are born, live, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risks."[39] HIV, viral hepatitis, STIs, alcohol and substance use, and mental health disorders are all related, and efforts to interrupt their impact must go beyond disease-specific interactions and examine root causes such as employment, access to healthcare and food, stable housing, and other social determinants of health.

The U.S. has a growing STI epidemic, with more than 2.4 million cases of chlamydia, gonorrhea, and syphilis reported in 2022.[40] In 2022, half of the reported cases of STIs were among adolescent and youth adults aged 15 – 24. Additionally, STIs, like HIV, also disproportionately impact Black communities with 31% of all cases of chlamydia, gonorrhea, and primary/secondary syphilis reported within this group. The southern region of the U.S. is heavily impacted by high rates of STIs.[41]

Injection drug use, predominantly in more rural areas of the Southern states, impact HIV, hepatitis C, and overdose deaths. Drug overdose deaths have been rising over the past two decades, with 107,543 overdose deaths occurring in 2023.[42] Substance use treatment also lags in the South as access is extremely dependent on health coverage. Medicaid is the largest payer for substance use treatment in the U.S., but unfortunately seven of the 10 states who have chosen not to expand Medicaid are in the South.[43]

Hepatitis C affects an estimated 2.4 million people in the U.S. and 51% of individuals do not know they are living with the virus. The incidence of acute hepatitis C has doubled since 2013 and increased 20% from 2020 to 2023.[44] In 2023, 66% of the acute hepatitis C cases reported to the CDC were attributed to injection drug use. Florida, Kentucky, West Virginia, Louisiana, District of Columbia, and Tennessee, are in the top ten states with the highest rates of reported cases in 2022.[45]

Studies have consistently shown that the social determinants of health are linked to HIV outcomes. The importance of stable housing in HIV prevention, care, and treatment outcomes has been widely demonstrated. As mentioned earlier, individuals receiving services from the Ryan White HIV/AIDS Program had a viral suppression rate of 89.7%, however, for individuals with unstable housing only 77.3% were virally suppressed.[46] CDC's Medical Monitoring Project (MMP) estimated that the prevalence of homelessness or unstable housing among people with HIV was 17%, with the estimated prevalence of homelessness at 8%. Homelessness is not the only type of unstable housing. The same study found that approximately 12% of people with HIV had moved in with other people due to financial problems, 8% moved two or more times, and 2% had been evicted in the past 12 months. In a recent study that examined the effect of being unhoused on viral suppression in middle Tennessee, it found that 45% of persons living with HIV and experiencing housing instability were not virally suppressed.[47]

MMP also found that approximately 19% of people with HIV dealt with food insecurity, 35% were unemployed, and 33% had incomes below the federal poverty line (FPL) threshold.[48] Further, 55% of women living with HIV have experienced intimate partner violence, making them more susceptible to unplanned pregnancies and/or unable to access healthcare due to partner intimidation and control.[49] People with HIV in rural areas often have added transportation challenges accessing prevention, care and treatment services.

[38] The White House. (2022). National HIV/AIDS Strategy for the United States 2022–2025. Retrieved from https://files.hiv.gov/s3fs-public/NHAS-2022-2025.pdf
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[41] Centers for Disease Control and Prevention. (2023, July 24). 2022 STD Surveillance - Figures. U.S. Department of Health and Human Services. https://www.cdc.gov/std/statistics/2022/figures.htm
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[44] Centers for Disease Control and Prevention. (2023, August 9). Hepatitis C Surveillance in the United States – 2022. U.S. Department of Health and Human Services. https://www.cdc.gov/hepatitis/statistics/2022surveillance/hepatitis-c.htm
[45] Centers for Disease Control and Prevention. (2023, August 9). Figure 3.3. Acute Hepatitis C - Case Rates by Jurisdiction, 2022. U.S. Department of Health and Human Services. https://www.cdc.gov/hepatitis/statistics/2022surveillance/hepatitis-c/figure-3.3.htm
[46] Health Resources and Services Administration. (2023). Ryan White HIV/AIDS Program annual client-level data report 2022. U.S. Department of Health and Human Services. https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2022.pdf
[47] Berthaud, V., Johnson, L., Jennings, R., et al. (2022). The effect of homelessness on viral suppression in an underserved metropolitan area of middle Tennessee: Potential implications for ending the HIV epidemic. BMC Infectious Diseases, 22(144). https://doi.org/10.1186/s12879-022-07105-y
[48] Centers for Disease Control and Prevention. (2024). Behavioral and clinical characteristics of persons with diagnosed HIV infection—Medical Monitoring Project, United States, 2022 Cycle (June 2022–May 2023). U.S. Department of Health and Human Services. https://stacks.cdc.gov/view/cdc/159149
[49] KFF. (2020, March 9). Women and HIV in the United States. Retrieved December 2022, from https://www.kff.org/hivaids/fact-sheet/women-and-hivaids-in-the-united-states/

Highest Rates of Sexually Transmitted Infections, 2022

Rate per 100,000

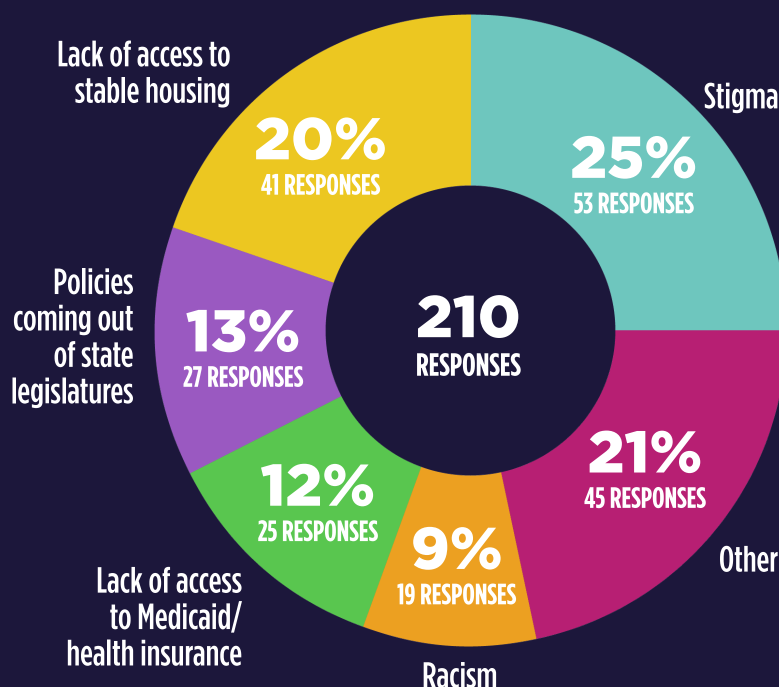
Rank	Chlamydia	Gonorrhea	Primary & Secondary Syphilis	Congenital Syphilis
1	District of Columbia	District of Columbia	South Dakota	New Mexico
2	Alaska	Mississippi	District of Columbia	Arizona
3	Mississippi	Louisiana	New Mexico	Nevada
4	Louisiana	South Carolina	Oklahoma	Louisiana
5	Alabama	Alaska	Arizona	Texas
6	Arkansas	Missouri	Mississippi	California
7	South Carolina	Alabama	Nevada	Alabama
8	Georgia	Arkansas	California	Florida
9	Florida	Delaware	Missouri	Mississippi
10	Texas	Maryland	Arkansas	Georgia

HIV IN THE SOUTH: CHALLENGES, OPPORTUNITIES, & COMMUNITY VOICES

VOICES FROM THE SOUTH

Over 200 Southerners were asked to contribute to a survey about HIV in the South. A large contingent of these respondents were people living with HIV. The feedback provided proved pivotal in understanding how our communities view HIV in the South.

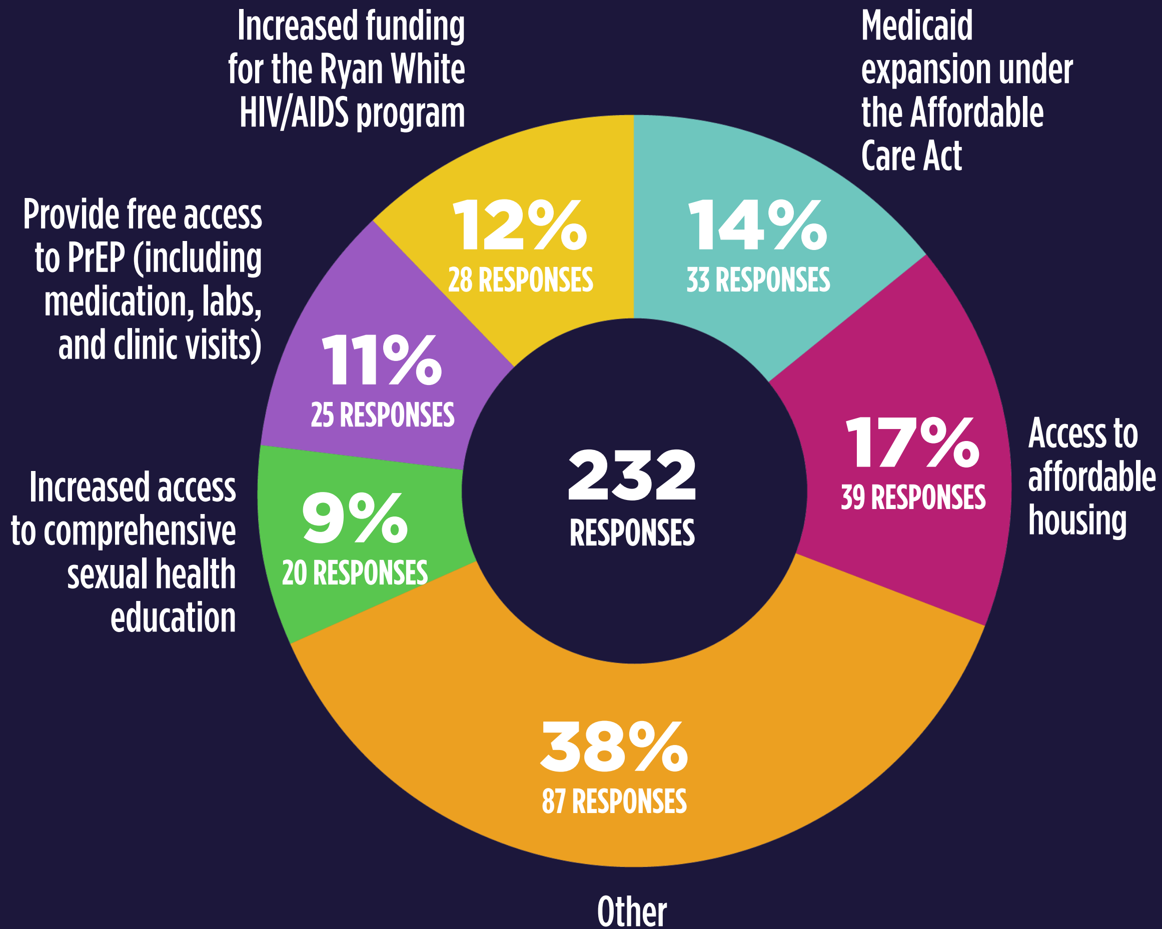
WHAT ARE THE BIGGEST BARRIERS TO ACCESS TO HIV PREVENTION, CARE, AND TREATMENT IN THE SOUTH?



> “We must get our governor to understand that expanding Medicaid is essential, especially for desert communities where there is no department of health, hospitals, or any form of health care assistance. We have to put money where there are no healthcare facilities.”

> “Many communities in the South are heavily stigmatized by the very word HIV. Normalizing HIV through campaigns and advertisements is key to reducing this stigma and increasing access to care.”

WHAT POLICIES DO YOU THINK WOULD IMPROVE HIV PREVENTION AND CARE IN THE SOUTH?



"Decriminalizing HIV and ensuring equitable access to prevention, care, housing, and economic resources are essential. HIV is a health issue, not a criminal one."

We must increase the awareness of organizations, hospitals, and public health clinics providing HIV care, expansion on Medicaid increasing health coverage reducing the medical expenses falling on Ryan White funds, and normalizing HIV (leads to de-stigmatization) advertisements throughout metropolitan areas.

SYSTEMS DRIVING HIV ACCESS & OUTCOMES

Intersecting systems and institutions – including public health, healthcare, education, housing, and criminal justice – are driving the HIV epidemic in this country. It is only by interrogating and reforming, and in some cases dismantling, these systems that we will begin to address the HIV disparities most apparent in the South.

HIV Funding in the South: Interrogating whether Funding is Following the Need

HIV prevention, care, and treatment services in the U.S. are funded by a complicated set of federal, state, and private funders. The southern region has often had fewer resources due to state funding priorities, lack of private funders focused on the South, and federal resources that focused on the places the HIV epidemic began rather than areas where the epidemic later emerged (including rural locations). Over the last decade, there have been notable changes in funding priorities to equalize some of the funding discrepancies, however, significant underfunding of HIV infrastructure in the South remains.

Ryan White HIV/AIDS Program

Many states in the South are overly reliant on funding from the Ryan White HIV/AIDS Program (RWHAP), mainly due to the non-expansion of Medicaid. In FY2023, the federal funding for the RWHAP was $2.57 billion. The Ryan White HIV/AIDS Program serves over 576,076 clients living with HIV. Seventy-three percent (73%) of RWHAP clients are racial/ethnic minorities and 60% are at or below 100% FPL. When adjusted for inflation, Ryan White Program funding has not increased since 2001, and funding has slowly decreased since 2013 based on 2001 dollars.[50] However, program costs and increased demand have continued to grow. Meanwhile, the growing divisions within Congress have made appropriations decisions more fraught, with extreme proposals to zero out Ending the HIV Epidemic Initiative (EHE) and Minority AIDS Initiative (MAI) funding and drastically reduce funding for other HIV programs.[51]

The AIDS Drug Assistance Program

The AIDS Drug Assistance Program (ADAP), a component of Part B RWHAP funding which is granted to all states, the District of Columbia, and territories, is a particularly crucial component of RWHAP as it funds medications and insurance purchasing for under- and uninsured individuals living with HIV. In FY2023, Congress appropriated $900 million for ADAPs, but state discretionary funding and rebates and program income contribute to many states' overall spending on ADAPs. The total amount spent by ADAPs in FY2021 was $2.1 billion.[52]

[50] Kaiser Family Foundation, The Ryan White HIV/AIDS Program: The Basics. 2022, Nov 3; https://www.kff.org/hivaids/fact-sheet/the-ryan-white-hivaids-program-the-basics/
[51] Andy Miller and Sam Whitehead, KFF Health News, In Move to Slash CDC Budget, House Republicans Target Major HIV Program Trump Launched (September 2023), available at https://kffhealthnews.org/news/article/cdc-budget-house-appropriations-hiv-epidemic-program-cuts/
[52] NASTAD, 2023 National RWHAP Part B ADAP Monitoring Project Annual Report, https://nastad.org/2023-rwhap-part-b-adap-monitoring-report/section-3.

FROM THE FRONT LINES

NAVIGATING CHALLENGES AND CHAMPIONING CHANGE IN HIV ADVOCACY IN THE SOUTH

Denford Galloway

Planning Council Manager, Ryan White Program Shelby County Health Department, Tennessee

The Memphis Ryan White Program operates under the city's Transitional Grant Area (TGA), which includes parts of Tennessee, Arkansas, and Mississippi. In Memphis, like other Ryan White jurisdictions, there is a Planning Council. Denford Galloway, born and raised in Memphis, manages the TGA's Ryan White Planning Council. With over two decades of personal experience living with HIV, Galloway offers profound insights into the challenges and effective strategies necessary for eradicating the HIV epidemic in the South.

Central to Mr. Galloway's approach is the empowerment of individuals living with HIV through advocacy and active participation in policymaking. He argues for meaningful representation on planning councils and in leadership roles to ensure the voices of those most affected are instrumental in shaping policies and practices. Inclusion and representation become even more important, according to Galloway, when engaging in specific advocacy efforts such as HIV decriminalization. There is a critical need for addressing HIV criminalization laws to remove barriers that exacerbate the stigma and hinder public health efforts. When it comes to people living with HIV, Galloway argues that participation in these efforts should ensure that efforts are "community-member-led" and going further, they must ensure they "have someone that's living with HIV a part of that."

Education is a crucial catalyst for change in any strategy aimed at ending the HIV epidemic in the South. One of the major obstacles is the pervasive stigma associated with the virus, exacerbated by a widespread lack of awareness. Mr. Galloway emphasizes the urgent need for broad-based education about HIV to dismantle misconceptions and alleviate fears that fuel stigmatization. "Educating the community about HIV is imperative," Galloway asserts. We must encourage those who are unaware of their HIV status to get tested. Awareness and knowledge are our best tools in stopping the spread of the virus." According to Mr. Galloway lack education on topics surrounding HIV is even present within planning councils as many members are unaware of the processes of how decisions are made. Education and awareness campaigns for the general public are necessary but that should not be the end all be all. These sorts of campaigns must also take place within institutions like planning councils, agencies, and any other that interact with the public.

Mr. Galloway is a staunch advocate for comprehensive healthcare that extends beyond the mere medical management of HIV. "Being undetectable is great, but it is not the end of the story," he states. He proposes a holistic approach encompassing mental health, physical well-being, and emotional su pport. Like others, Mr. Galloway recognizes that effectively addressing HIV involves more than just managing viral loads – it demands nurturing the mind, body, and soul.

Stable housing remains one of the most significant barriers to adopting a holistic healthcare approach. Mr. Galloway highlights that without a stable living condition, managing HIV becomes an insurmountable task for many. "Housing and homelessness are big barriers. We need to be more aggressive in reaching out to homeless populations, providing them with stable housing and consistent healthcare,' he explains.

Nationally, 20 states contributed state discretionary funding to the ADAP programs totaling nearly $106.4 million. Seven Southern states (Florida, Georgia, Louisiana, North Carolina, South Carolina, Tennessee, and Texas) were responsible for 55% of the total state funds contributed to ADAP nationally. This demonstrates the powerful advocacy conducted by communities in the states as the federal funds were severely insufficient to meet demands of people living with HIV in need of life-saving medications.

A key component of ADAP budgets are rebates and program income. Rebates are payments received from pharmaceutical manufacturers and program income is generated from third-party payers. In FY2021, ADAP estimated rebates amounted to $802 million or 38% of the overall ADAP budget. Program income from the same period was $81.4 million (4% of the overall ADAP budget). States who can support their clients in another form of prescription drug coverage (Medicaid, Medicare, private insurance) and those who have the staff resources to chase after all possible rebates and program income are able to realize the greatest amounts of funding back into their programs. Of the Southern states who provided data for an annual report on ADAP programs, only four had a higher percentage of rebates and program income above the national average contributing to their ADAP budgets (Florida, D.C., Kentucky, and Louisiana).

CDC HIV Prevention Funding

In FY2023, the CDC's National Center for HIV, Viral Hepatitis, STD, and TB Prevention received a congressional appropriation of $1 billion. The Division of HIV Prevention received $755.6 million; this amount has remained stagnant for the last decade.

The Ending the HIV Epidemic

The Ending the HIV Epidemic in the U.S. Initiative began in 2019 and aims to accelerate local and state efforts with a goal to reduce new transmissions by 90% in 2030. The programmatic aims are focused on four key strategies – diagnose, treat, prevent, and respond. In 2019, President Donald Trump announced the *Ending the HIV Epidemic in the U.S.* initiative. The initiative was designed to provide additional funds to the 57 jurisdictions – 48 counties and seven states with substantial rural HIV cases - where over 50% of new HIV infections occurred in 2016 and 2017. Of those 48 counties, 48% are in the South, as well as seven of the eight priority states. (Alabama, Arkansas, Kentucky Mississippi, Missouri, Oklahoma, and South Carolina).[53]

In FY2022, federal agencies received $473 million for EHE activities, including:

- $195 million for CDC to implement HIV prevention programs
- $247 million for HRSA's RWHAP and $122 for the Bureau of Primary Health Care to expand HIV testing and PrEP at community health centers
- $5 million for the Indian Health Service for HIV, hepatitis C and STI programs
- $26 million for the NIH for implementation research projects

The inclusion of community health centers in the EHE Initiative has been a large part of federal PrEP support. With the program funding, 366 health centers have received funding to increase HIV testing, linkages, and PrEP prescriptions. In the South, 140 health centers (38%) received funding. However, it is clear that community health centers, while critical partners in PrEP access, are not enough by themselves to get PrEP out to communities who may not be interacting with traditional healthcare systems. PrEP infrastructure as a whole is poorly lacking in the South and is driving the low PrEP uptake in this region discussed above. In his FY2023 budget, President Biden called for a National PrEP Program to create a coordinated federal response to PrEP for people who are uninsured and underinsured and repeated that request in FY24.[54] Advocates have called for that program to include three pillars: federally negotiated public health prices for PrEP medications; negotiated prices for PrEP laboratory services; an expanded PrEP provider network that includes a hub and spokes model connecting clinical prescribers to non-clinical community based organizations.[55]

Philanthropy and Private Funding

A report from Funders Concerned About AIDS found that in 2020 corporate and philanthropic funders contributed $321 million to organizations within the U.S. Most of the funding (62%) had a national focus. The South and the West received more dedicated funding than other regions, but only 20% of total funding.[56]

In 2020, $64 million disbursed to the South, which was a 76% increase from 2019. Much of this is attributable to Gilead Science's COMPASS Initiative®. In 2017, Gilead Sciences announced their $100 million, 10-year investment in addressing the Southern HIV epidemic. This funding is disseminated through direct funding, as well as programming

[53] HHS, Priority Jurisdictions: Phase 1, https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/jurisdictions/phase-one/, accessed July 25, 2023.
[54] President's Budget FY2024, https://www.whitehouse.gov/omb/budget/
[55] Killelea A, Johnson J, Dangerfield DT, Beyrer C, McGough M, McIntyre J, Gee RE, Ballreich J, Conti R, Horn T, Pickett J, Sharfstein JM. Financing and Delivering Pre-Exposure Prophylaxis (PrEP) to End the HIV Epidemic. J Law Med
[56] Ethics. 2022;50(S1):8-23. doi: 10.1017/jme.2022.30. PMID: 35902089; PMCID: PMC9341207.
Funders Concerned About AIDS, Philanthropic Support to Address HIV and AIDS in 2020, https://www.fcaaids.org/inform/philanthropic-support-to-address-hiv-aids/.

and intermediary grantmaking by four Coordinating Centers (Southern AIDS Coalition, Emory University Rollins School of Public Health, University of Houston Graduate College of Social Work, and Wake Forest University School of Divinity).

Through COMPASS, community-led efforts have experienced significant funding to focused on a range of approaches, including "capacity building and shared knowledge, well-being, mental health, substance use and trauma-informed care, stigma reduction and culturally appropriate care, and faith-based advocacy and spiritually integrated capacity building."[57]

Private funders are critical, and heavily relied upon, partners in addressing the Southern HIV epidemic. ViiV Healthcare's Positive Action Southern Initiative began in 2010, and committed over $9M to southern organizations through 2021. Also notable is AIDS United's Southern HIV Impact Fund which has for years assembled funders for a collaborative funding model to support southern organizations. In 2024, AIDS United's Southern HIV Impact Fund awarded $1.2 M to its seventh cohort of southern grantees with funding provided via Gilead Sciences, ViiV Healthcare, and an anonymous donor. While some private funders have made significant investment in the South, there is a need for a broader base of support and long-term investments to support the infrastructure required to end the southern HIV epidemic.

Efforts are being made to increase businesses' commitment and investment in addressing HIV, particularly in southern communities. The success of newer initiatives, like the U.S. Business Action to End HIV, are critical. This initiative was founded in 2022 by the Health Action Alliance to mobilize a growing coalition of private sector partners "committed to filling gaps and accelerating progress to help end the HIV epidemic in the U.S." Two local chapters were established in southern cities in 2024—Atlanta and Houston—in an effort to engage local employers, chambers of commerce, and government entities.

Due to local and state-wide efforts to end the HIV epidemic and EHE Initiative, philanthropic funding to states has increased by 50%. Of the top ten jurisdictions targeted for philanthropic giving, six were in the South (Florida, Georgia, Texas, Alabama, Louisiana, and Washington, D.C.).

340B

The 340B Drug Pricing Program is a federal program requiring pharmaceutical manufacturers participating in Medicaid to sell outpatient drugs at discounted prices to certain public health entities. RWHAP recipients, as well as community health centers, and entities receiving CDC STD funding, are eligible to participate in the program. The 340B program also allows entities to generate revenue on discounted purchases. In other words, the 340B entity may purchase a medication at a heavily discounted price and then, for its insured patients, seek reimbursement from a public or private payer at a much higher price closer to the drug's list price. The ACA fundamentally changed the funding landscape for HIV clinics and service providers. As people with HIV became insured via the Affordable Care Act (ACA), the dollars eligible entities could collect from the 340B program increased. Organizations receiving RWHAP funding are statutorily mandated to invest all 340B savings and revenue back into their programs and may only spend those dollars on approved services. This has led to program growth despite stagnant federal funding, increased demand for services and growing healthcare costs. In the South, the effectiveness of 340B programs is especially pronounced, enabling organizations to mitigate some of the challenges posed by limited state funding and Southern policy environments that often resist expansive healthcare benefits. The political climate in Southern states, which frequently involves stringent healthcare regulations and varied acceptance of federal healthcare benefits, critically shapes access to and the impact of the 340B program, making advocacy and policy engagement even more vital for sustaining these essential services.

340B has also been central to the expansion of PrEP over the past 10 years. Because brand-name PrEP medications have been priced so high, 340B entities have been able to generate significant savings from their insured patients via the "buy low, sell high" spread discussed above. These savings are used to pay for the ancillary services needed such as laboratory testing, case management, education campaigns, and other services.

Uptake of PrEP has been hampered due to a lack of funding streams for under- and uninsured individuals and a lack of requirement for private health insurance to cover the intervention.

[57] Gilead Sciences, Compass Initiative, Coordinating Centers, https://www.gileadcompass.com/coordinating-centers/accessed July 26, 2023.

Organizations have had to rely on pharmaceutical safety net programs to provide free medications and look elsewhere for funds to cover ancillary services, making 340B revenue even more important.

Relying on 340B revenue as a significant portion of an organization's budget comes with risks. As more HIV medications become available in generic form less discounting is attainable. Furthermore, because of the tremendous growth of the 340B program over the past decade, there is intense scrutiny on the 340B program from Congress, industry partners and other drug supply chain players. If changes occur in the 340B program causing a decrease in revenue, organizations will be forced to scramble to make up potentially significant shortfalls.

340B revenue generation is a financing strategy that only works for clinics that qualify as covered entities under the rules of the program. Providers outside of the 340B system – including charity care entities – are critical to the HIV care and prevention system but are often left out of financing strategies so heavily reliant on 340B.

Health Access in the South

Health care access in the South is largely dependent on a patchwork of programs that are woefully inadequate to meet the needs of people living with and affected by HIV because of a combination of policy and funding decisions by state and local policymakers.

Medicaid

Medicaid is the single largest payer for HIV care in the United States, accounting for 45% of all HIV funding in 2022.[58] The role of Medicaid for people with HIV has increased since the passage of the Affordable Care Act (ACA) and massive expansion to the Medicaid program that went into effect in 2014. Under the ACA, Medicaid programs may extend eligibility to individuals up to 138% FPL based on their income alone. This was a significant shift from traditional Medicaid eligibility rules, which typically require individuals to meet a certain eligibility category (e.g., being disabled) in addition to meeting a very low-income threshold. Because Medicaid expansion is optional, however, not every state has chosen to adopt it. This is especially true of states in the Deep South. As of July 2023, ten states have not expanded Medicaid under the ACA, including Alabama, Georgia, Mississippi, North Carolina, South Carolina, Tennessee, and Texas.

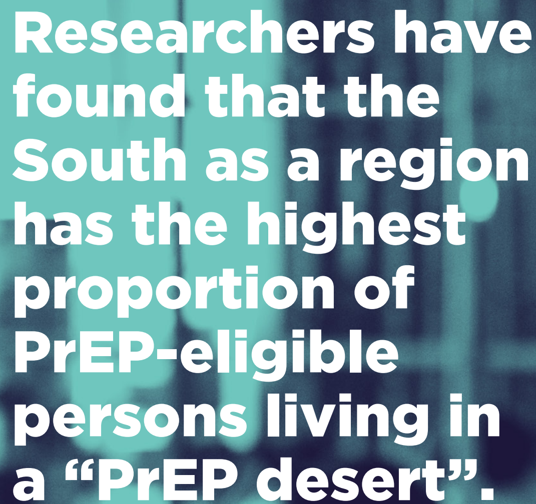
The decision not to expand Medicaid has had consequences for HIV access. Research shows that Medicaid expansion has increased access to HIV care and prevention services, including increased use of PrEP for HIV prevention.59 States that have expanded Medicaid have seen a reduction in new HIV diagnoses as well as a reduction in HIV mortality rates.60 Failing to expand Medicaid has also cost these states billions of dollars in healthcare infrastructure and services. Researchers estimate that Florida and Texas – two of the states with the largest uninsured rates – have each left over $66 billion in federal funding on the table by refusing to expand Medicaid under the ACA.[61]

Exacerbating the lack of Medicaid expansion is historically far more limited traditional eligibility categories. For instance, eligibility requirements for parents in the southern states that have not yet expanded Medicaid is, on average, 24% FPL.[62] This is just under $6,000 annually for a family of three.

April of 2023 marked the end of an important COVID-19 era protection, the Medicaid continuous coverage requirement, which had prohibited states from disenrolling individuals from Medicaid for the duration of the federally declared public health emergency (PHE). This protection resulted in the Medicaid rolls swelling over from March 2020 through April 2023. Since state processes to redetermine eligibility have begun, Kaiser Family Foundation estimates that 3.8 million people have been disenrolled from Medicaid.[63] State policies are having a major impact on how the unwinding is going and whether individuals are being disenrolled erroneously. Arkansas and Florida, for instance, have incredibly high rates of "procedural terminations," meaning individuals are being terminated because of a failure to file the appropriate paperwork, not because they were ultimately found ineligible for the program.[64] As people lose Medicaid coverage – many of whom are caught completely off guard by this coverage loss – the unwinding has the potential to cause harmful disruptions in HIV services and exacerbate existing disparities.

The lack of Medicaid coverage in the South is also a significant barrier to uptake to novel and innovative antiretroviral medications. Over the past several years, long-acting injectable forms of both HIV treatment and PrEP have come to market. However, navigating access to these novel (and expensive) medications for individuals without access to Medicaid is challenging.

[58] Kaiser Family Foundation, Medicaid and People with HIV, available at https://www.kff.org/hivaids/issue-brief/medicaid-and-people-with-hiv/#:~:text=Medicaid%20is%20the%20largest%20source,the%20nonelderly%20adult%20population%20overall.
[59] Suhang Song and James Kucik, "Trends in the Impact of Medicaid Expansion on the Use of Clinical Preventive Services," American Journal of Preventive Medicine 62 no. 5 (May 2022): 752-762, https://www.ajpmonline.org/article/S0749-3797(21)00595-X/fulltex
[60] Adam Searing and Ada Adimora, Georgetown University Center for Children and Families, HIV and Medicaid Expansion: Failure of Southern States to Expand Medicaid Makes Elimination of HIV Infection in the United States Much Harder to Achieve, available at https://ccf.georgetown.edu/wp-content/uploads/2021/01/HIV-and-Medicaid_map-fix_01-21-1.pdf
61 Urban Institute, https://www.urban.org/sites/default/files/publication/22816/413192-What-is-the-Result-of-States-Not-Expanding-Medicaid-.PDF
[62] Kaiser Family Foundation, Medicaid Income Eligibility Limits for Parents, 2002-2023, available at https://www. kff.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-parents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D
[63] KFF Unwinding Tracker, https://www.kff.org/medicaid/issue-brief/medicaid-enrollment-and-unwinding-tracker/
[64] CBPP, https://www.cbpp.org/research/health/unwinding-watch-tracking-medicaid-coverage-as-pandemic- protections-end



Provider access/availability

Though Medicaid expansion is arguably the biggest factor driving disparities in HIV in the South, it is by no means the only health system impacting HIV access. Southern states face particular challenges in maintaining and expanding an HIV workforce to meet the growing needs of the region.[65] HIV providers in the South cite lack of a pipeline of new infectious disease doctors, fewer infectious disease fellowships in the South, and an overall lack of HIV expertise in primary care as contributing factors to the growing workforce concerns. The COVID-19 pandemic exacerbated health workforce shortages across the country, particularly in rural areas.66 The pandemic stretched and depleted governmental public health departments as well, with the vast majority of local health departments around the country reporting challenges in responding to the pandemic and also carrying out regular functions.[67]

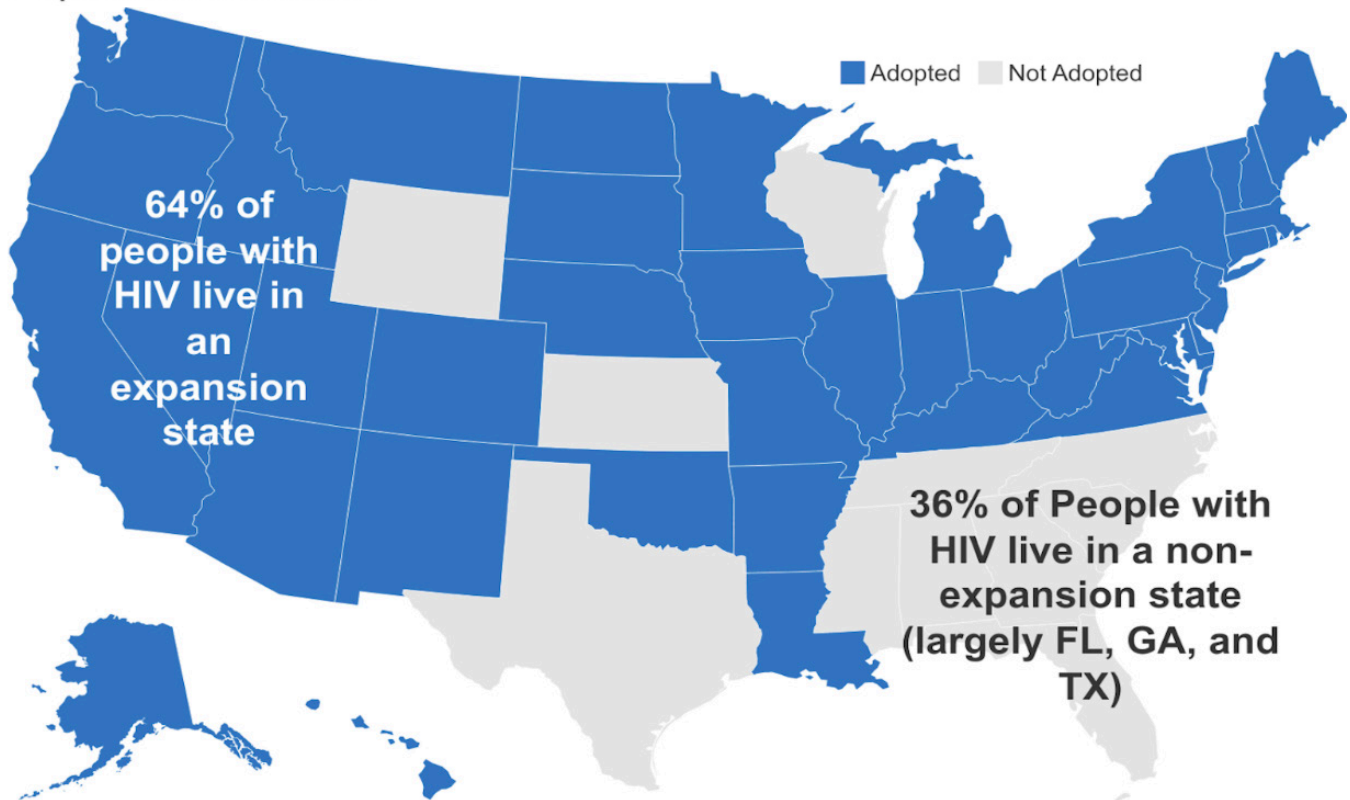
The federal metric for quantifying challenges in accessing providers is the designation of a county as a "health professional shortage area" (HPSA). The Health Resources and Services Administration (HRSA) calculates HPSAs by assessing the ratio of providers to people in a geographic area. In May 2023, the U.S. South had wide swaths of areas where an entire county was designated as primary care HPSA, meaning there are not enough primary care providers accessible to the people living in that given county.[68]

The high number of rural areas in the South is also a barrier for PrEP access. Researchers have found that the South as a region has the highest proportion of PrEP-eligible persons living in a "PrEP desert," defined as a 60-minute drive away from the nearest PrEP provider.[69]

Finally, scope of practice laws are typically more limited in the South, meaning that in areas with the least access to medical care, non-physician providers are not able to operate at the top of their licenses. Nurse practitioners – a critical part of the HIV workforce – have reduced or restricted ability to operate according to their license in every single southern state.[70] There have been recent efforts to expand the ability of pharmacists in particular to increase their ability to provide a range of HIV services.[71] As of July 2024, these efforts have seen successful in some states in the South, with Louisiana passing a law authorizing pharmacists to dispense HIV PrEP and PEP in June of 2024. In addition to expanding scope of practice laws, advocacy efforts to expand the role of pharmacists in HIV service delivery have also included securing reimbursement for clinical services, especially from Medicaid.

[64] CBPP, https://www.cbpp.org/research/health/unwinding-watch-tracking-medicaid-coverage-as-pandemic- protections-end
[65] Max Blau, Stateline, There Aren't Enough Doctors to Treat HIV in the South, August 5, 2019, available at https:// stateline.org/2019/08/05/there-arent-enough-doctors-to-treat-hiv-in-the-south/
[66] https://familymedicine.uw.edu/chws/wp-content/uploads/sites/5/2022/03/Covid-19-and-the-Rural-Health- Workforce-PB-2022.pdf
[67] https://www.naco.org/blog/naccho-releases-report-highlighting-impact-covid-19-response-local-public-health- departments
[68] https://bhw.hrsa.gov/workforce-shortage-areas/shortage-designation; https://www.ruralhealthinfo.org/ charts/5
[69] Sullivan PS, Mena L, Elopre L, Siegler AJ. Implementation Strategies to Increase PrEP Uptake in the South. Curr HIV/AIDS Rep. 2019 Aug;16(4):259-269. doi: 10.1007/s11904-019-00447-4. PMID: 31177363; PMCID: PMC7117066.
[70] https://www.aanp.org/advocacy/state/state-practice-environment
[71] Weidle, Paul & Brooks, John & Valentine, Sheila & Daskalakis, Demetre. (2023). The Future of Pharmacist- Delivered Status-Neutral HIV Prevention and Care. American journal of public health. 113. e1-e3. 10.2105/ AJPH.2022.307190.

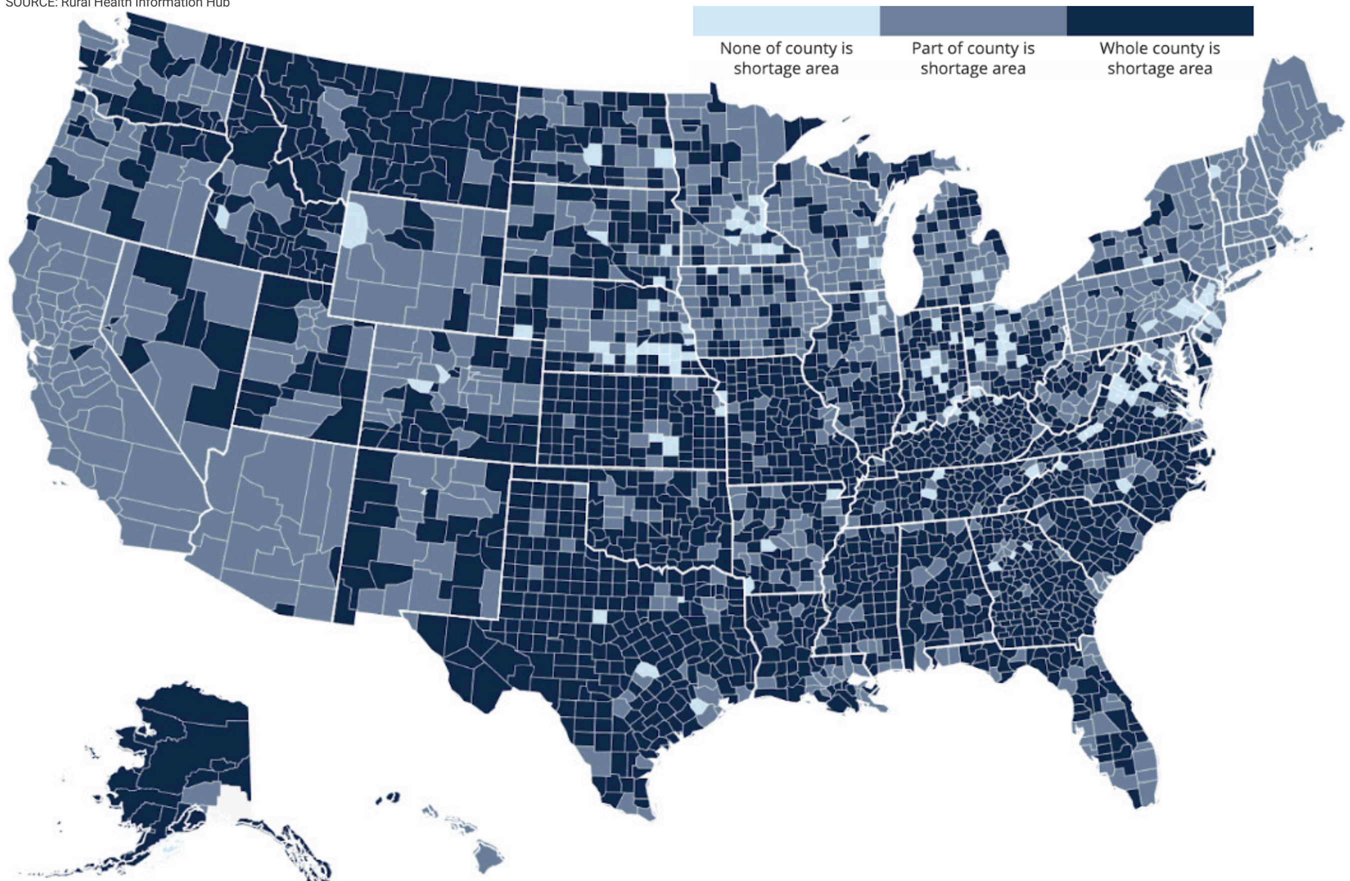
Over One-third of People With HIV Live in a State That Has Not Expanded Medicaid



SOURCE: Medicaid expnasion data: KFF. Status of State Action on the Medicaid Expansion Decision (as of March 2021). HIV prevalence data: All data 2018 from CDC Atlas except ND and WY which is 2017 from: Estimated HIV incidence and prevalence in the United States. 2014-2018. HIV Surveillance Supplemental Report 2020.:25(No. 1).Mav 2020.

Health Professional Shortage Areas: Primary Care, by County, 2023

SOURCE: Rural Health Information Hub



FROM THE FRONT LINES

THE PLIGHT OF FREE AND CHARITABLE CLINICS IN THE SOUTH

Angie Settle & Shayla Leftridge
WV Health Right

Angie Settle is the Chief Executive Officer of West Virginia Health Right. West Virginia Health Right is a free and charitable health clinic in the state of West Virginia. Free and charitable health clinics play a unique role in the HIV services landscape. These clinics serve as safety-net health care organizations that provide medical, dental, pharmacy, behavioral health, vision, and other services to people who are often uninsured and are experiencing economic hardships. As the oldest free health clinic in the state, this organization has long been a cherished member of the community. In an interview held by SAC about free and charitable clinics, Angie Settle shared that the struggle and barriers that her organization faces are not unique but more so a common theme throughout the South. She shares that where FQHCs, (Federally Qualified Health Centers) fail, Free and Charitable clinics have thrived. Shayla Leftbridge,WV Health Right Director of Community Outreach, Diversity, Equity, and Inclusion & West Side CommUNITY site Coordinator, also participated in the interview. During the conversation, Shayla mentions that "...free and charitable clinics are the ones that are making connections with the people that you're trying to reach. They are the ones that are making friends. They are making communities. They are out working in the communities. The FQHCs are not doing that. They're not capable of doing that, and that's not what they're there for, which is fine. They're there for a service, and they're great for that service, but they're not going to drive their mobile unit out and get up in them ditches and under those bridges and meet with people and go to these churches and meet with those people."

Angie Settle's group is a testament to the impact a committed team can have on a community, especially in West Virginia. They consistently reach out to the most vulnerable areas, tackling not only HIV but also addressing critical issues like substance use, workforce development, and housing. Despite these efforts and the strong data that supports their work, securing financial support remains a persistent challenge. As Angie puts it, "We're the first people you call when the feds come for an audit because our data backs up what we do. Yet, when it's time to distribute funding, we're left feeling like we're out on the corner begging." The organization has proven its value time and again, becoming the go-to resource for family planning and audits, but this recognition hasn't translated into the financial backing needed to sustain and expand their crucial work.

Leftbrige adds that even with these barriers they continue to "...act on faith. We're actually bringing people in to work with us that are from those communities so they can speak for those people. They're not just guessing what people need, we're actually finding out what they need." She also goes on to demonstrate the power of community, " It's so much better than," if we build it they will come.", because they come and they stay, and they participate in other things. They're getting a test and they're getting treatment and they're getting better. Then they're teaching others and they're eating better and they're getting financial wellness, and they're getting jobs."" All these things have made real community health, and yet we are still not getting the funding we need to continue that." Their hard work and passion has also expanded the list of who you

would expect to land in the term community, it's not just including the affected population to speak and represent but a vast network of professionals who volunteer their time and efforts to meet the needs of citizens that they otherwise may have never been able to treat. Settle says, "We do not pay physicians or dentists to care for our patients. They're all volunteers. We have a huge volunteer base of 600 specialists, so cardiologists, endocrinologists, dermatologists, you name it, dentists, and oral surgeons. We've built this network of trust over the years, and they'll come in and donate like a day, a month, three or 4 hours, but you have enough of those people. It makes a quilt of care."

It's very evident that the community is aware of the issues affecting their towns but the recurring theme is that they seem to be overlooked. Although FQHCs are there to provide a service it seems that they arrive after there are organizations who have already been doing the work." When I see groups getting that funding, and they're unable to meet what they've promised, it's frustrating."

Despite financial challenges, West Virginia Health Right is focused on the importance of every aspect of their work, driven by leadership committed to action and data-backed results. When asked about the key message for free and charitable clinics, Settle urges others to take more visible action: "You all getting major grants, get out there and do the work. We have teams on the most drug-ridden corners, facing dangers daily, yet we keep going. If you care, use your resources and show it. I don't want to hear about how much you care; I want to see it. The End."

"Free and charitable clinics are the ones that are making connections with the people that you're trying to reach. They are the ones that are making friends. They are making communities. They are out working in the communities."

Despite growing evidence of the link between housing and healthcare, people living with and affected by HIV disproportionately struggle with finding affordable and stable housing.

Housing access/availability

Despite growing evidence of the link between housing and healthcare, people living with and affected by HIV disproportionately struggle with finding affordable and stable housing. Research shows that individuals who are experiencing housing insecurity are less likely to get tested for HIV, less likely to be on PrEP, less likely to access HIV treatment if they are living with HIV, and less likely to be virally suppressed.[72] This is particularly true in the South.

In a research paper authored by the CDC and the National HIV/AIDS Housing Coalition, authors found that the South has the highest level of unmet housing need among people living with HIV.[73] Georgia ranked the highest with 62.3% of people living with HIV in need of housing assistance who did not receive it. The study, however, also showed that the South had more HOPWA (Housing Opportunities for Persons with HIV/AIDS) resources than any other region, with Mississippi having the most HOPWA funding in relation to people in need of housing and fair market rent costs. The dire reality is that even in Mississippi, there is only enough HOPWA funding to house each person in need for 2.95 months per year.[74] The housing challenges in the South are multifold. In some jurisdictions, despite having financial resources, those resources are simply not reaching persons in need of housing assistance and many people are not aware of what housing resources are available. In other areas, HOPWA resources are utilized to their full extent, but significant gaps remain in other funding sources (i.e. state and local government funding, corporate and philanthropic investments) that are far more robust in areas like New York, Washington state, and California.

Due to the HOPWA formula modernization that passed in 2016 and was implemented in 2017 with a hold harmless period, more housing funding for people living with HIV/AIDS is reaching many jurisdictions in the Southern United States. As this formula change is still new and has only seen two years of full implementation (FY 22 and FY23), the delivery methods of resources are still ramping up in some jurisdictions. However, the largest cut to the HOPWA program in modernization went to the city of Atlanta, which saw an average loss of $10 million or roughly 45%. Beyond HOPWA, states could be using the Ryan White program to fund housing (up to 24 months). However, because of the lack of Medicaid investments in most of the Southern states, most Ryan White HIV/AIDS Program recipients are spending almost all of their resources on clinical care and health care support and are unable to invest scarce RWHAP dollars into housing. Programs that thrive in the South have combined HOPWA funds along with CDBG and HOME funds and private funding investments to rehabilitate and/or build housing owned and operated by HIV housing programs. A.H. of Monroe County in Key West, AIDS Services of Dallas, AIDS Alabama, Broward House in South Florida, and Status: Home, Inc. in Atlanta are all community-based HIV-specific housing agencies that braid together funding to provide varied housing for people living with HIV/AIDS.

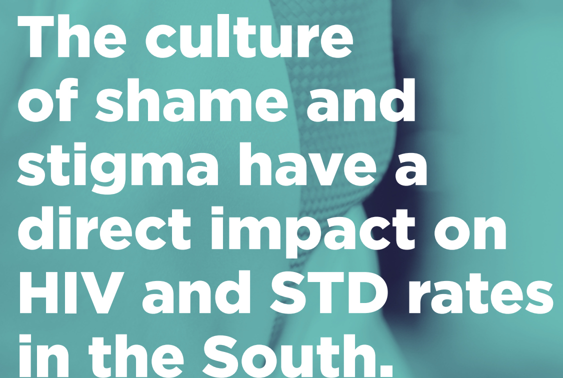
[72] Data compiled by CDC, https://www.cdc.gov/hiv/policies/data/role-of-housing-in-ending-the-hiv-epidemic.html#issue-brief-22
[73] Dasgupta, Sharodaa; Beer, Lindaa; Lu, Jen-Fengb; Weiser, Johna; Yuan, Xinb; Nair, Priyab; Banks, Laurenc; Marcus, Ruthannea. Needs for shelter or housing assistance among people with diagnosed HIV by jurisdiction: United States, 2015–2020. AIDS 37(3):p 535-540, March 1, 2023. | DOI: 10.1097/QAD.0000000000003460
[74] Ibid.

Sexual health and reproductive health access landscape

As of June 2023, 5 states in the South do not mandate sexual education in schools (Alabama, Arkansas, Louisiana, Texas, and Virginia).[75] Reports delving into the content of southern sexual education curriculum have found that it is woefully inaccurate when it comes to both science and what public health practitioners know works for the prevention of HIV and STD.[76] Since 2021, there have been scores of bills introduced in state legislatures all over the country that limit the ability of educators to discuss topics with direct impact on sexual health, including race, sexual orientation, and gender identity. Of the ten states with sweeping “don’t say gay” laws (laws that prohibit discussion of LGBTQ topics in schools altogether), six are in the South.[78]

The sexual health restrictions and the culture of shame and stigma have a direct and dangerous impact on HIV and STD rates in the South. As discussed above, amidst rising STD rates across the country, southern states consistently rank in the top ten states for chlamydia, gonorrhea, and syphilis.[79]

It is impossible to discuss HIV and sexual health access without acknowledging the ongoing assault on reproductive health in the United States. As a result of years of state restrictions on reproductive health providers and reduced federal funding for family planning clinics, one study found that between 2017 and 2021, women in the United States reported increases in barriers to accessing reproductive health care.[80] The study noted that barriers were disproportionately experienced by individuals with no high school diploma or General Educational Development test, those living at less than 100% of the FPL, and those born outside of the United States who took the surveys in Spanish. In addition, following the United States Supreme Court decision in *Dobbs v. Jackson Women’s Health Organization*,[81] state legislatures quickly enacted laws criminalizing abortion an already strained system of family planning and reproductive health access.[82]



[75] Guttamacher Institute, Sex and HIV Education, June 1, 2023, https://www.guttmacher.org/state-policy/explore/sex-and-hiv-education, accessed July 25, 2023.
[76] HRC Report, https://www.hrw.org/report/2020/07/08/it-wasnt-really-safety-it-was-shame/young-people-sexual-health-education-and-hpv
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[81] Dobbs v. Jackson Women’s Health Organization, https://www.supremecourt.gov/opinions/21pdf/19-1392_6j37.pdf
[82] Guttmacher Institute, Interactive Map of Abortion Laws After Roe, https://states.guttmacher.org/policies/?gad=1&gclid=Cj0KCQjw2qKmBhCfARIsAFy8buKWLPK3d6cPk8jc2-gyfQocC7HFVl3VqtuZUDGz6QKcm4lZtL5UdXMaAkDpEALw_wcB

Stigma and bias in the South

The HIV epidemic – like so many other infectious diseases – is driven by systems of oppression, including deeply embedded systemic racism.

Racism is a public health crisis

State sanctioned violence by the police, redlining and other restrictive housing practices, employment discrimination, poverty, and inadequate access to health care have been wielded against Black and African-American communities for centuries.[83] The original Southern Manifesto was written in 1956 by Members of Congress from southern states as an angry response to the Supreme Court's landmark ruling in *Brown vs. Board of Education* outlawing segregation in public schools. In the Manifesto, the drafters declared their steadfast resistance to desegregation. Decades later, public health leaders continue to face the legacy of the hatred and vitriol that animated this first Southern Manifesto and have reclaimed the title to reflect resilience and resistance in the face of such explicit racism.

These deep seeded systemic inequities are driving disparities in virtually all metrics of HIV prevention and care in the United States, including PrEP utilization, HIV testing rates, new diagnoses rates, linkage to care and treatment, and viral suppression rates.[84]

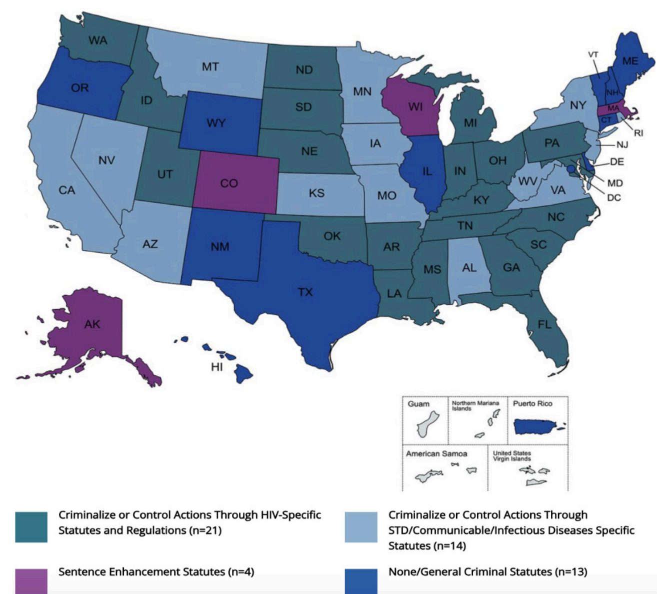
In recent years and particularly as part of the advocacy efforts arising in the wake of the horrific police murders of Breonna Taylor, who was gunned down in her home in Louisville, Kentucky and of George Floyd who was handcuffed and pinned down to the point of suffocation by police in Minneapolis. Communities have urged state and federal policymakers to identify racism as a public health crisis. Several state and local health departments have made public pronouncements declaring racism a public health threat and vowing to undergo internal assessment for health departments to determine if they are perpetrating or participating in racist systems and how they can work to dismantle them.[85] It is important for more southern institutions to center anti-racism efforts in their work and align resources toward not only service delivery, but also toward training and leadership development aimed at reforming health care and public health systems. It is more impactful and important to communities for these institutions to commit to the practice of undoing racism, which moves far past the public statement and performances but calls for realignment in the cultural foundations and practices.

HIV criminalization

HIV criminalization is the reliance on a person's positive HIV status, either under criminal laws that apply explicitly to persons living with HIV (PLHIV) or under general criminal laws or STI laws, as the foundation for criminalizing otherwise legal conduct or for increasing crimes and punishments related to solicitation or sex offenses.[86] Currently, 21 states have laws that specifically criminalize HIV exposure and/or transmission, with a significant number of these states located in the South.[87] These laws do not necessitate that transmission actually occur, nor do they require intent to transmit or that the conduct in question posed a real risk of transmission. In addition to HIV-specific statutes, states also criminalize HIV exposure and/or transmission through broader communicable disease statues or through laws of general applicability (i.e., prosecuting HIV transmission cases via a criminal assault statute).

These laws are disproportionately used to prosecute marginalized and disenfranchised communities, including sex workers and Black people.[88] HIV criminalization laws serve no public health purpose. Research has found again and again that HIV criminalization laws do not lead to fewer new HIV diagnoses. With more than 30 years of these statutes on the books and the increase in transmission rates, it is hard to justify HIV criminalization as a tactic that has ended the epidemic.

HIV and STD Criminalization Laws 2022



[83] https://www.ucsf.edu/news/2021/06/420716/aids-40-hiv-covid-19-history-racism-hits-communities-color-hardest
[84] HHS, https://www.hiv.gov/hiv-basics/overview/data-and-trends/impact-on-racial-and-ethnic-minorities/
[85] Cornell, Racism as a Public Health Crisis, https://health.cornell.edu/initiatives/skorton-center/racism-public-health-crisis
[86] https://hivlawandpolicy.org/resources/hiv-criminalization-united-states-sourcebook-state-and-federal-hiv-criminal-law-and
[87] CDC, HIV and STD Criminalization Laws, https://www.cdc.gov/hiv/policies/law/states/exposure.html
[88] CHLP, https://aidsvu.org/catherine-hanssens-on-hiv-criminalization-in-the-u-s/

IN HER OWN WORDS

THREE DECADES OF LEADERSHIP

Leisha McKinley-Beach
Black Public Health Academy

"I think the biggest challenge of ending HIV in the South is not tackling racism as a public health crisis head-on. Meaning, until we do that, we're not going to see the progress that we desire across treatment, prevention, nor care".

In the mid to late 90s, early 2000, there was an investment in capacity building to scale up the community based organizations. This was a period of focus in this country to try to build the capacity of Black and Latino organizations. During that time, I was in the state of Florida, and there was a company that filed a lawsuit against the state saying that we were discriminating against organizations that were white led, so to speak. And when the lawsuit came forward, what it said to me was a few things, as long as we would have been focused on outreach and hiring black and brown people to be outreach workers and health educators, no harm, no foul. But now we're talking about money and the redistribution of the wealth from HIV funding resources, and now, that's a problem.

For me, that's the first time I really saw racism rear its ugly head. At a time when we really needed to be focused on people who were dying, not living with HIV. They are dying. Why? Because they are out of care. They're dying because of the stigma. They are dying because of the way that they are treated when they go to the majority organizations. And so they're opting not to go, but we're not dealing with that. And so the language starts to shift, then comes in an influx of how we should do HIV prevention. And so the things that made these black and brown organizations stand out as the true grassroots, community driven projects that work for the people in need, we now shift right, to a more scientific, evidence based model. That shift then causes so many (community lead, grassroots, black and brown) organizations to close. There's no outcry, there is no analysis done. There is nothing that demonstrates the great burden or negative impact that it has. Almost overnight, we go from 60% of the organizations being black or brown majority to about 20% of the organizations. And so, I feel, if it was the reverse, if we went overnight to majority organizations representing 10% or 5%, there would have been an outcry about that and why did we not, my answer, systemic racism.

And so here we are in 2023, the United States Conference on HIV AIDS and for the first time it is focused on black women with the theme, A Love Letter To Black Women. And there were leaders, advocates that were upset, outraged that we would take the country's largest convening of the HIV workforce and center it on black women.

"I think the biggest challenge of ending HIV in the South is not tackling racism as a public health crisis head-on."

IN HER OWN WORDS

THE ROOT OF THE HIV EPIDEMIC

S. Mandisa Moore-O'Neal

The Center for HIV Law & Policy

"The biggest challenge to ending the epidemic is the unwillingness of our elected officials and institutions (including some ASOs) to dismantle the legacies of white supremacy that are often the root of the HIV epidemic. If we know that racism is a public health issue and the HIV epidemic is also a matter of public health, then what is the commitment to address the racist institutions and systems that we exist in- from housing to education to health care to even the right to exist in public space? An actual, measurable commitment to end racism and an actual,measurable commitment to building equitable, just institutions instead would make a huge difference."

Furthermore, these criminalization laws have been associated with higher stigma for Black men who have sex with men.[89]

Mass Incarceration

In addition to laws that specifically criminalize HIV, communities of color, particularly Black men, are disproportionately affected by mass incarceration in this country.[90] Black people make up 33% of people in prison while only representing about 14% of the entire U.S. population.[91] The Bureau of Justice Statistics released a report in 2023 documenting HIV incidence in the U.S. prison population in 2021.[92] The findings were alarming. While overall numbers of people living with HIV in state and federal prison has been on the decline, the HIV prevalence rate in prison is still triple that of the total U.S. Rate.[93] The correlation between the number of Black men in prison and this country and the disproportionate share of Black men living with and at higher risk of HIV is not coincidental. Indeed, the same systems of racial oppression drive both statistics, and it is only when we dismantle those systems that we will begin to improve health equity in HIV access and outcomes.

LGBTQ stigma and discrimination

A recent survey fielded by Vanderbilt University asked LGBTQ southerners to report on their experiences.[94] The findings pointed to widespread discrimination and stigma:

- 83% of respondents reported being subjected to slurs or jokes because they are, or are perceived to be, LGBTQ
- One in 10 reported experiencing efforts to "convert" or change their sexual orientation and/or gender identity ('conversion therapy').
- 54% of respondents reported having been harassed or bullied for being LGBTQ+ in school
- 55% of respondents avoided discussing personal topics with coworkers, supervisors, or bosses to avoid discrimination or harassment at work for being LGBTQ
- 31% percent of transgender respondents reported avoiding healthcare
- 43% of transgender respondents reported being misgendered or inappropriately named when trying to access healthcare this year

Importantly – and pointing to the strength and resilience of the LGBTQ community – 78% of respondents reported that their LGBTQ+ identity was something positive in their lives.

GLAAD, in partnership with the Gilead COMPASS Initiative, fielded a national study that found attitudes toward HIV continue to reflect stigma surrounding the condition.[95] Eighty-six percent of respondents reported that they believed stigma around HIV still exists. Eighty percent of respondents believed that non-disclosure of one's HIV status should be criminalized.

The impact of anti-LGBTQ stigma coupled with continued stigma of HIV itself – both of which are more pernicious in the southern states – is significant and prevents individuals from accessing necessary HIV services.[96]

[89] Baugher, Amy R.a; Whiteman, Aria,b; Jeffries, William L. IVa; Finlayson, Teresaa; Lewis, Rashundaa; Wejnert, Cypriana. Black men who have sex with men living in states with HIV criminalization laws report high stigma, 23 U.S. cities, 2017. AIDS 35(10):p 1637-1645, August 1, 2021. | DOI: 10.1097/QAD.0000000000002917
[90] Prison Policy Initiative, https://www.prisonpolicy.org/blog/2023/06/01/hiv_in_prisons/
[91] BJS, https://bjs.ojp.gov/sites/g/files/xyckuh236/files/media/document/p21st.pdf
[92] https://bjs.ojp.gov/library/publications/hiv-prisons-2021-statistical-tables
[93] Supra note 28
[94] Vanderbilt, LGBTQ Southerners Face Stigma, Yet Still Find the Positive, https://business.vanderbilt.edu/news/2023/07/19/lgbtq-southerners-face-stigma-yet-still-find-the-positive/
[95] GLAAD, 2023 State of HIV Stigma (2023), available at https://assets.glaad.org/m/2c897b961792f880/original/2023-State-of-HIV-Stigma-Study.pdf
[96] Odenburg CE, Perez-Brumer AG, Hatzenbuehler ML, Krakower D, Novak DS, Mimiaga MJ et al. State-level structural sexual stigma and HIV prevention in a national online sample of HIV-uninfected MSM in the United States. Aids 2015;29(7):837–45. 10.1097/qad.0000000000000622.

IN THEIR OWN WORDS

HOW A TRANS-LED ORGANIZATION IS SHIFTING THE NARRATIVE IN THE SOUTH

IN LATE 2023, SAC SAT DOWN WITH QUINTON REYNOLDS, QUAMI CRAWFORD, MALACHI ALLEN, KEON ANDERSON AND TYRELL LOWERY OF GAME-CHANGING MEN.

Game Changing Men is an organization led by and for masculine identities. It operates as a healing space for masculine identities, cis or trans to come together for healing, growth, and support. During this conversation, these individuals highlighted the numerous barriers they face within their communities, including stereotypes that lead to medical mistrust, challenges with community engagement and religious partnerships, and issues related to representation and access to spaces, grants, and media.The following is a snippet from our conversation.

Quinton Reynolds outlined some obstacles trans men encounter in overcoming medical distrust and the invasive questioning they face when seeking PrEP. He explains, "When I go to the doctor, I'm concerned about who is present and which doctor will see me. As a trans man, I've been asked, 'What do you need PrEP for?' Providers often question how I am having sex instead of recommending PrEP by default. This often happens because doctors assume, as a trans man, that I am in a relationship with a cisgender woman and therefore don't need such prevention methods. Their biases affect the access to care available to me."

Qaumi added, "Sometimes, doctors don't even offer the recommendation for PrEP when you visit the office. They

don't engage with you or ask if you're sexually active." Malachi suggested a proactive approach: "Routine HIV testing should be part of regular check-ups. Rather than targeting specific communities, increasing education across the spectrum will help. Children in middle school should learn about STDs, given their exposure to information online." Keon Anderson adds, "They should be informed about what happens after sex."

Quinton advocated for organizations to be proactive in bridging community gaps, stating, "We should engage with individuals and communities on a personal level, rather than just coming in with a request for participation."

Quami shifted the focus to faith-based communities: "We need to engage with churches to provide education and support. More education within churches and other frequented places is necessary so people feel safe returning to their communities and engaging openly about HIV without judgment. This will also facilitate intimate conversations with partners." He acknowledges, "I'm not sure if this is a complete solution, but many people carry shame and find it difficult to seek help."

Rell emphasized the importance of consistent support from religious communities, saying, "Many churches embrace our community, but often on the low. We need acceptance not just during funerals but also when we need healthcare support. We should be welcomed and supported in the same way we are invited to lead choirs." He also notes that trans masculine men are often overlooked within the LGBTQIA+ community, making it challenging to drive change without community acceptance.

Quami suggested expanding outreach beyond traditional channels: “We have numerous community centers, billboards, and bus stops, but we should also partner with coffee shops and grocery stores—places people frequent regularly.” Quinton underscores the importance of addressing basic needs: “Housing and food are primary concerns. Health becomes irrelevant if someone is homeless or struggling with basic needs. Transportation, access to food courts, or computers for applications are also crucial. Larger CPOs and health departments often don’t provide these necessities and may offer minimal support to smaller organizations while taking credit.”

The discussion revealed that barriers are multifaceted. Community members need to address internal biases, and organizations must ensure they are inclusive and intersectional. Rell pointed out that having employment-based insurance does not fully resolve access issues: “Many people fear disclosing their trans identity to employers, which affects their insurance coverage.” He also highlights the compounded challenges faced by black and trans individuals in the South, where resources are already limited.”Unfortunately people of color have a lot less resources, but if you’re a black person, whether you be a trans woman or trans man, your resources are cut in half, and then when you see what is available to you from there, you’re resources are cut in half again.”

Quami proposed that small organizations should be included in discussions about fund distribution. He suggested reversing the priority of funding from high to low, ensuring that smaller, grassroots organizations that effectively support the community receive adequate funding. “Federal budgets should mandate that smaller organizations be integral to HIV/AIDS prevention efforts.”
Representation is about more than inclusion; it involves dismantling existing barriers. Allyn asserted, “It’s time to change the face of the epidemic.” While Quinton added, “HIV criminalization laws are outdated and stigmatizing. Excluding trans men from the Ending the HIV Epidemic (EHE) plan creates gaps in addressing a universal virus.”

Self-representation was identified as a necessity, as Allyn explained, “No one should speak for us more than we speak for ourselves. We must be involved in these conversations to bridge gaps.” He advocates for community engagement, ongoing training, and inclusion of joy in discussions about HIV: “Include joy in the narrative. Having HIV doesn’t mean the end of one’s world. We should also highlight the positive aspects of people’s lives, not just the struggles.”

Despite the challenges, Game-Changing Men demonstrate resilience and a commitment to improving access to resources. They stress the need for coordinated action: “A call to action is needed from the government, policymakers, community organizers, providers, and the community itself.” They also emphasize the need to identify and address false allyship, which can harm rather than help communities., “Stop claiming support for our community based solely on symbolic gestures. Assess how effectively these organizations assist the LGBT community and address HIV-related issues, Quinton suggested”

POLICY PRIORITIES

Addressing the myriad factors that are driving the HIV epidemic in the South will take coordinated and bold policy approaches. Band-aid approaches that leave the systems driving inequities intact will not turn the tide in the South.

The following priorities should guide interventions from federal policy makers, state policy makers, and non-governmental partners.

ABOVE
Southern AIDS Coalition Board and community members strategize in the early days of the Coalition

LEFT
Long-time Southern AIDS Coalition Board member, and South Carolina advocate, Dr. Bambi Gaddist addressing a Southern AIDS Coalition meeting

1. MEDICAID MUST BE AVAILABLE TO ALL WHO NEED IT

Given the importance of Medicaid as a vital safety net for low-income people living with and affected by HIV, expanding Medicaid under the ACA in every state must be a priority. Currently, 10 states have not expanded Medicaid, with 7 of them located in the South. If state legislatures and governors will not act to protect the health and wellbeing of their citizens, the federal government must be prepared to create a federal safety net for the individuals in the Medicaid gap in holdout states. Congress came very close to including a federal fix for the Medicaid gap in its sweeping reconciliation legislation passed in August 2022.[97] Proposals that were ultimately dropped from what would eventually become the Inflation Reduction Act, would have expanded ACA subsidies to people living under the federal poverty level in non-Medicaid expansion states, providing a pathway to free or very low-cost private insurance for this population.

Because the current make-up of Congress precludes another major bill that can be passed without bipartisan support, there is not an immediate federal legislative pathway for closing the Medicaid coverage gap. Advocates working in southern states are working to assess more incremental measures, including ways to expand Medicaid in a more limited way just for people living with HIV.[98]

Similarly, some Southern states are pushing for Medicaid expansion with restrictions for access, including work requirements.[99] These overburdensome restrictions further complicate access to necessary healthcare services for those needing access to Medicaid in the South. While these more limited routes will certainly continue to leave communities out of expansion, it may be at least an incremental step to expand coverage for individuals living with HIV who desperately need it. Furthermore, expanding Medicaid helps eliminate insurance discrimination and stigma by ensuring that Medicaid reimbursement policies incentivize providers to offer services to PLWH.

The refusal to expand Medicaid has led to significant financial losses in holdout states, depriving them of federal funds that could support local healthcare systems.[100]

Additionally, Medicaid expansion is crucial for maintaining and expanding a diverse healthcare workforce to provide much-needed care in distressed rural communities where there are shortages. Medicaid expansion is vital for keeping local hospitals and healthcare centers open in rural areas where medical care is scarce.

2. PUBLIC HEALTH MUST BE DIVORCED FROM LAW ENFORCEMENT

Federal agencies, state and local governmental public health, medical providers, and communities affected by HIV must speak with one voice to repeal and/or reform laws that criminalize HIV exposure and transmission, which are not based on scientific evidence and reinforce harmful stigma. These laws are at odds with their purported goals of safeguarding public health and in fact serve as a barrier to effective HIV prevention strategies.

Many Southern states have laws that enhance criminal penalties for individuals living with HIV, including laws that result in incarceration for consensual acts or exposure scenarios without intent to harm. For example, some states prosecute individuals with HIV under general criminal statutes, applying harsher sentences due to their status. These laws disproportionately affect Black, Brown, and marginalized communities by perpetuating cycles of incarceration and stigma that hinder effective public health responses.

Examples of such laws include those impacting immigration and legal status, regulations reminiscent of the Ryan White authorization's overly punitive measures, and policies that allow health information shared in confidence to be accessed by law enforcement. Laws that have no basis in science and that only serve to reinforce stigma should be eradicated from state statutory schemes and regulation. Moreover, state laws, regulations, and policies must create a firewall between public health programs and law enforcement, prohibiting any data collected by a governmental public health agency from being the subject of law enforcement request an investigation or prosecution. This includes preventing the misuse of health data to support discriminatory practices that can lead to unnecessary discrimination and even death.

Additionally, there is a critical need to foster a deeper understanding of the intersection between law enforcement, the criminal legal system, and public health perspectives to ensure policies genuinely reflect and support public health goals rather than undermining them.

[97] Inflation Reduction Act, https://www.congress.gov/bill/117th-congress/house-bill/5376/text
[98] https://www.gpb.org/news/2023/02/20/proposed-bill-would-expand-medicaid-georgians-hiv
[99] KFF, https://www.kff.org/medicaid/issue-brief/tough-tradeoffs-under-republican-work-requirement-plan-some-people-lose-medicaid-or-states-could-pay-to-maintain-coverage/
[100] https://www.commonwealthfund.org/publications/issue-briefs/2020/may/impact-medicaid-expansion-states-budgets?utm_source=chatgpt.com

3. HIV FUNDING IN THE SOUTH MUST BE FLEXIBLE

Over the past two decades, an enormous advocacy effort led by southern communities has ensured that federal HIV funding follows HIV need and that the South receives its fair share of funding. Despite progress in reforming funding formulas across RWHAP and HOPWA, there is still more to be done to recognize the growing gaps in access in the South because of gaping infrastructure disparities. Policymakers should target investments – including but not limited to EHE initiative funding – to support a regional approach to HIV and in recognition of the vastly under resourced public health infrastructure in the South as compared to other regions of the country.

EHE funding should also be re-tooled for more immediate impact, with federal agencies working more collaboratively to allow for braided funding across partners. Braided funding is a method that combines funds from multiple sources to fund a single cause. All the while, ensuring that each funding source maintain their own respective compliance requirements and can be tracked separately.

A barrier to the impact of the EHE initiative, particularly in the South, has been the challenge of building innovation on top of HIV systems of prevention and care that are underfunded. RWHAP funding, for instance, has remained flat for over a decade, while HIV prevalence has increased.[101] In the South, where programs are hamstrung by political decisions not to expand Medicaid and far less generous state general fund support for HIV, expecting new and innovative approaches without increasing the base level of support for HIV care and prevention has been frustrating for communities and funding recipients. Congress should recognize the need to invest in the entire HIV care and prevention infrastructure so that EHE dollars have a foundation on which to build innovative programming.

Funding must include an emphasis on PrEP access. Southern states could stand to benefit the most from an intentional federal investment in a National PrEP Program. In the event that a National PrEP Program is rolled out incrementally, southern states should be first in line for state implementation. Instead of maintaining the status quo, which merely keeps programs running, there should be a shift towards demanding full funding for these programs to ensure they can expand and enhance services effectively.

Prioritizing flexibility in funding, is critical for supporting proven community-driven solutions to HIV disparities in the region. There is often a tension between strict funding guidelines, and the actual needs that organizations to meet the needs of their communities.

Advocacy efforts must include the voices of those living with and impacted by HIV. Organizations must engage more intensely in advocacy training for community members to equip them with the skills needed to effectively communicate with legislators. This includes educating individuals on how to find out who their legislators are and what to say during calls or in correspondence to advocate for comprehensive HIV policy.

4. WE MUST EXPAND THE HIV WORKFORCE IN THE SOUTH

There are significant HIV provider shortages in the southern United States. Federal programs must support a provider pipeline to the South, including through better inclusion of infectious disease training in medical schools and investment in loan forgiveness programs that incentivize southern locations. At the state level, scope of practice laws often limit the ability of non-physician providers to practice to the full extent of their licensure and training. This is particularly constraining for nurse practitioners and pharmacists, who are critical but underutilized in the healthcare workforce. States should work to expand their scope of practice to enhance their ability to provide comprehensive HIV prevention and care services.

Expanding the scope of practice for pharmacists is a prime example of how the HIV workforce can be augmented. Considering that close to 9 in 10 Americans live within 5 miles of a community pharmacy[102], leveraging this accessibility could significantly increase PrEP uptake. By enabling pharmacists to prescribe and manage PrEP, we can utilize this community resource to make a substantial impact on HIV prevention in regions most affected by the epidemic.

Similarly, expanding the scope of practice for nurses trained in providing PrEP and HIV care is vital. In the South, where access to HIV prevention and care is often limited, empowering nurses to prescribe and manage PrEP would allow for greater outreach in underserved communities. Nurse-led models of care have been shown to increase PrEP uptake and retention, demonstrating the critical role nurses can play in addressing the HIV epidemic when enabled to work to the full extent of their training and licensure.

[101] KFF, https://www.kff.org/hivaids/slide/ryan-white-funding-relatively-flat-for-more-than-a-decade-while-share-of-people-living-with-hiv-has-grown/
[102] https://www.japha.org/article/S1544-3191(22)00233-3/fulltext

5. WE MUST INVEST IN HOUSING AS HEALTH CARE

Housing must be integrated into all plans to end HIV in the South. Housing providers must adopt Housing-First models that are trauma-informed, stigma-free, anti-racist, and free from homophobia and transphobia. Further, dedicated HIV housing resources are limited; HIV agencies need to work with existing housing entities and resources to leverage funds and create new housing opportunities for PLHIV. This strategy will also require advocating for state and local governments to allocate funds for the development and use of housing for PLHIV, ensuring housing support is flexible and accessible.

Recognizing housing as a critical element of prevention, it is essential to protect and expand access to housing to effectively combat the HIV epidemic. Collaborative efforts are necessary, involving connecting and engaging with legislators and working through housing-focused coalitions. This comprehensive approach will address housing issues through collaboration, aiming to enhance the stability and health outcomes of those affected by HIV.

Dedicated HIV housing resources are limited; HIV agencies need to work with existing housing entities and resources to leverage funds and create new housing opportunities.

6. WE MUST INVEST IN SUSTAINABLE HIV MEDICATION FUNDING IN THE SOUTH

We must bolster sustainable funding for HIV medications in the South. While savings generated from the 340B program are vital, allowing entities to purchase drugs at discounted prices and get reimbursed at higher rates, this system supports essential HIV services delivery. Without these savings, many clients who rely on these services would face significant challenges. This reliance on the 340B program underscores the complexity of funding HIV infrastructure - higher drug prices, while beneficial for generating savings, simultaneously fuel the debate over drug cost reductions.

We must protect the 340B program and ensure that HIV safety neT providers can continue to access discounted prices and reinvest savings into core services. Yet, we must also expand our approach. It is crucial to advocate for increased federal, state, and philanthropic funding to support HIV infrastructure with less dependency on the pricing structures of medications. As we anticipate the impact of brand-name and generic competition, which should lower the prices of many antiretroviral medications, relying solely on high drug prices to fund HIV infrastructure through 340B savings presents a dilemma.

Investing in advocacy and policy-based research is essential. Most current research focuses on direct services, but the South needs robust policy research to develop sustainable funding models that do not rely exclusively on drug pricing discrepancies. We should actively engage with and support initiatives that promote this kind of research, ensuring that our funding strategies are both sustainable and equitable.

Collaboration with local legislators and housing-focused coalitions is crucial. By working together, we can address these complex issues through informed policies and innovative solutions that prioritize the wellbeing of those living with HIV.

7. PHILANTHROPIC ENTITIES MUST PRIORITIZE BUILDING AND SUSTAINING COMMUNITY MOBILIZATION AND POWER IN THE SOUTH

The voices of community representatives in the South, as well as those living with or affected by HIV, are unequivocal; they require sustained investment to amplify their collective power through intensive community mobilization and advocacy training. Currently, federal and state public health funds typically do not support the advocacy necessary to effect changes in state laws and policies that could broaden access to HIV services. The role of non-governmental funders, particularly philanthropic organizations not affiliated with industry, becomes indispensable in supporting the advocacy and policy infrastructure crucial for overhauling ineffective healthcare systems.

To enhance the impact and reach of advocacy efforts, it is essential for petitioning organizations to leverage diverse relationships with multiple corporate and philanthropic funders. Creating networks of givers committed to reducing outcomes and stigma, and crafting messaging that resonates with private, for-profit companies outside of the HIV sector is vital. This strategy should include targeting funders most affected by the HIV epidemic and cultivating those relationships to ensure a broad, sustained support base.

While industry funding has historically been a significant source of support for many Southern organizations, it is ideal that advocacy and policy work be funded by entities without a commercial interest in policy outcomes to maintain integrity and focus on community needs.

Janeeka Muse answers audience questions at the 2024 Saving Ourselves Symposium hosted by SAC

IN HER OWN WORDS

TESTIMONY FROM A LONG-TERM HIV SURVIVOR

Miss El
Georgia

Please allow me to share my current perspective, shaped by my many experiences with HIV. After 32 years of living beyond my initial diagnosis—and the six-month prognosis given to me on my twenty-eighth birthday—I cannot speak from a "gloom and doom" or "sad love song" perspective. I have come too far as a seasoned (black) woman with information, applied knowledge, gained wisdom, and healthier choices.

One key lesson I've learned is that continuously revisiting past choices, behaviors, and decisions while trying to tell my story can be retraumatizing. On the other hand, embracing each experience as my own leaves me with valuable life lessons to pass on. So, my current perspective is that nothing is happening to me—everything is happening for me.

As I have matured in my relationship with HIV, my concerns about my health and well-being have also evolved. Where I once focused on viral load and CD4 counts, I now consider the long-term use of medication, weighing both its helpfulness and its harmful effects, and choosing the lesser of the evils. Now, as I enter the fourth quarter of my life, I find myself facing the fullness of life, including aging and its physical challenges.

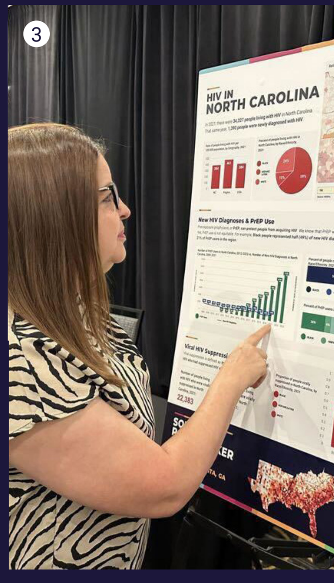
I am learning to eat differently, having CEO-level conversations with those who help me make informed decisions regarding my health, and exploring other health options. In my personal experience, and having the privilege of sharing in others' experiences and perspectives regarding their diagnoses, I believe that a major contribution to successful treatment is one's belief in the process. For me, the medication works because I believe it does. My true desire is to reverse the process of HIV within me. I have a dream for HIV and me.

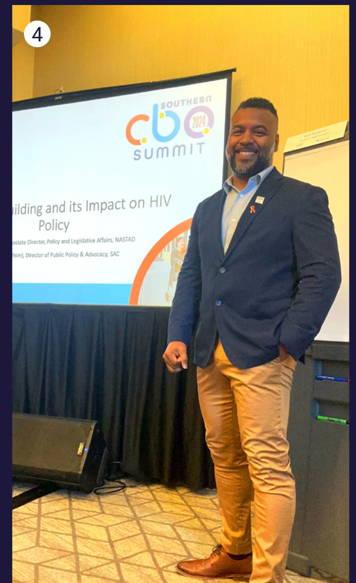
"My current perspective is that nothing is happening to me—everything is happening for me."

AS WE CONCLUDE THIS MANIFESTO, IT IS IMPERATIVE TO REFLECT ON THE POWERFUL PERSONAL JOURNEYS SHARED WITHIN THESE PAGES.

This manifesto itself is a journey that transcends beyond the statistics and challenges we've faced in the South. The stories found within it are only a part of the region's story, as there are thousands more—many that will never be told. There are so many experiences that tell of the enduring strength and determination of those living with HIV in the region and serve as poignant reminders of why our work is so vital. They illustrate not only the progress we've made but also the ongoing need for dedication and unwavering commitment in our fight to end the HIV epidemic. The Manifesto series –from 2002 to the present–serve as a historical roadmap of the challenges and successes that embody the spirit of perseverance and hope in the region. It is most importantly a tool for advocacy and action, to create a pathway forward that centers those most impacted by HIV. To truly end the HIV epidemic, we must remain steadfast in our commitment, continue innovating our approaches, and amplify the voices of those who have lived through these experiences. Their stories inspire us to stay the course, knowing that every step forward is a testament to our shared resolve and unwavering determination.

To truly end the HIV epidemic, we must remain steadfast in our commitment, continue innovating our approaches, and amplify the voices of those who have lived through these experiences.





1 Southern Policymaker Academy in Atlanta on July 2024. From left; Kim Jackson, State Senator, District 41, State Senate, GA; Park Cannon, Representative, District 58, House, GA;Liliana Bakhtiari, City Councilmember, District 5, Atlanta, GA; DaShawn Usher, Senior Director, Communities of Color & Media, GLAAD, Founder & ED, Mobilizing Our Brothers Initiative (NY).

2 Southern Policymaker Academy in Atlanta on July 2024. From left; Charles Stephens, Executive Director, Counternarrative Project; Arianna Inurritegui-Lint, Executive Director, Arianna's Center (FL), Venton Jones, Representative, House District 100 (TX), CEO, Southern Black Policy & Advocacy Network; Marnina Miller, Co-Executive Director, Positive Women's Network; Tim Santamour, Interim Executive Director, Florida Harm Reduction Collective.

3 Aleida Fernández, NC Community Organizer for Latinos in the South, reviewing the data on SAC's North Carolina HIV stat sheet at Encuentro 2024 in Charlotte, North Carolina

4 Director of Public Policy & Advocacy, Will Ramirez presents at the Southern CBO Summit in 2024 in San Antonio, TX

5 Executive Directors, Kathie Hiers (AIDS Alabama) and Dafina Ward (Southern AIDS Coalition) at 2024 Alabama HIV Advocacy Day (Montgomery, AL)

6 Southern AIDS Coalition team strategy session during a staff retreat in 2024 in Atlanta, GA

7 Southern HIV Advocates for Progress cohort at AIDS United's AIDS Watch 2024.

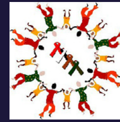
SOUTHERN AIDS COALITION

Southern AIDS Coalition Historical Timeline

2002

JUNE Southern State AIDS Directors Meet 14 Southern State AIDS/STD Directors met in Nashville, Tennessee to discuss the unique and critical challenges shared among the southern states to develop a corrective plan that later became the Southern States Manifesto.

NOVEMBER Southern States Summit on HIV/AIDS & STD's: A Call to Action Southern States Directors Work Group (SSDWG) met in Charlotte, NC during the summit to review the draft of the first Southern States Manifesto.



DECEMBER Southern AIDS Coalition is Born! SSDWG formed The Southern AIDS Coalition in collaboration with community members & governmental leaders.

2003

JANUARY PEPFAR Announcement President George W. Bush announces the President's Emergency Plan for AIDS Relief (PEPFAR) during the State of the Union speech. PEPFAR was authorized to provide $15 billion over five years to fund prevention, treatment, and care globally.

2007

HIV Prevention and Care Gets Flat Funded by Federal Government Despite the South being continually the hardest hit region, federal funding for HIV prevention, care, treatment, and housing remained flat during 2007 and 2008.

2008

SOUTHERN STATES MANIFESTO: UPDATE 2008
HIV/AIDS and Sexually Transmitted Diseases in the South
July 21, 2008

JULY PEPFAR Reauthorization The reauthorization expanded the budget to $48 billion and including in its targeting not only HIV but tubercolosis and malaria.

JULY The Southern States Manifesto: Update 2008 Released This second iteration served as an update to the original. It highlighted ongoing challenges in adressing the HIV crisis in the South, such as continued high transmission rates, woefull underfunding, poor healthcare infrastructure, and barriers to testing and treatments. The update was a call to action to adress the ongoing inequities in HIV funding and the impact caused by a lack of it.

2011

SEPTEMBER HIV Prevention Trials Network (HPTN) 052 Study This trial demonstrated that adherence to antiretroviral therapy (ART) could reduce HIV transmission by 96%, marking a breakthrough in the role of treatment as prevention.

2012

JULY Southern States Manifesto: Update 2012 Policy Brief and Recommendations is Released This second update, emphasized the impact of national policy shifts such as the Affordable Care Act and the National HIV/AIDS Strategy. It focused on reducing health disparities in the South, promoting treatment as prevention and highlighted the need for federal funding allocated to address the disproportionately high rates of HIV in the region.

JULY FDA Approval of PrEP The FDA approved the first medication for HIV prevention, pre-exposure prophylaxis (PrEP). While PrEP had the potential to drastically reduce new HIV transmissions, particularly among communities of color, access was limited in the South, due to ongoing healthcare inequities and stigma around HIV.

2015

Ryan White HIV/AIDS Program Turns 25 In the 25 years of its existence, RWHAP played a pivotal role in reducing HIV-related mortality and improving the quality of life for hundreds of thousands of Americans.

2019

FEBRUARY EHE Announced President Donald J. Trump announces the new initiative, Ending the HIV Epidemic: A Plan for America, during his State of the Union address.

SOS SAVING OURSELVES SYMPOSIUM

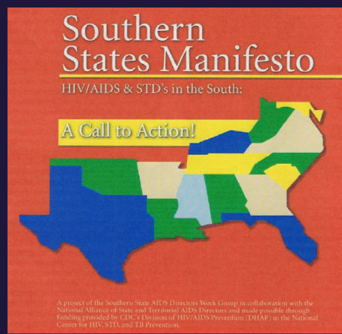
SAC Becomes Home of SOS SAC was selected by The Red Door Foundation to become the new home to The Saving Ourselves Symposium (SOS), an annual conference founded by Marvell L. Terry, II to educate and empower the Black LGBTQIA+ community in the South.

2020 2022

npr
THE CORONAVIRUS CRISIS
Strides Against HIV/AIDS In The U.S. Falter As Resources Diverted To Fight COVID-19
APRIL 21, 2021 · 5:00 AM ET
By Sarah Varney

COVID 19 Impacts HIV Services The COVID-19 pandemic disrupted HIV services, leading to delays in testing, treatment, and prevention. However, as the pandemic receded, there was a renewed focus on advancing EHE goals and reinvigorating HIV prevention and care services.

MARCH Southern States Manifesto: HIV/AIDS & STDs in the South: A Call to Action! Officially published March 3, 2003.



2004

HIV/AIDS Surveillance Report Released Data from the CDC highlights the stark racial disparities in HIV rates. The report brought on calls for greater funding and tailored interventions to adress the epidemic's disproportionate impact on minority communities.

2006

DECEMBER Ryan White Care Act Reauthorized The Ryan White CARE Act was renamed the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (RWHATMA) after H.R. 6143 passed. This reauthorization, following three years of discussions, introduced major changes, including shifting the funding formula from cumulative AIDS data to actual living HIV and AIDS cases, and redirecting approximately $30 million to the South.

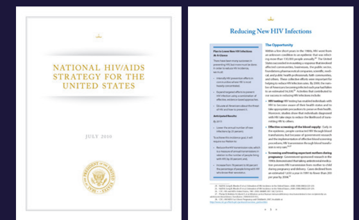
2009

OCTOBER Lifting of the HIV Travel Ban The HIV Travel ban, which had prevented people living with HIV from entering the U.S., was officially lifted.

2010

MARCH Affordable Care Act (ACA) The Affordable Care Act is signed into law by President Barack Obama. Under the new law, insurers were prohibited from denying coverage based on pre-existing conditions like HIV and expanding Medicaid elegibility in states that opted for it.

JULY National HIV/AIDS Strategy (NHAS) Released First-ever National HIV/AIDS Strategy was released, outlining three key goals: reducing HIV transmissions, improving access to care, and reducing HIV-related health disparities.



2017

NOVEMBER HOPWA Formula Modernization HUD implemented the Housing Opportunity Through Modernization Act Changes to the Housing Opportunities for Persons with AIDS (HOPWA) Program. The revised formula changed how localities became eligible for funding and at what levels.

2018

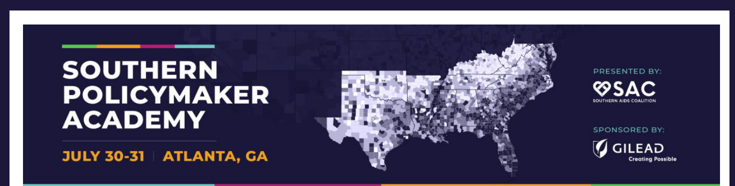
Gilead COMPASS Initiative® launched SAC becomes one of three Coordinating Centers who launch a collective impact model to implement GIlead Sciences' historic commitment to addressing HIV in the southern United States.

2022 2023

Change the Pattern SAC partners with National AIDS Memorial on a historic multi-city tour to "Change the Pattern" by expanding the presence of Southerners in the Quilt, raise public awareness about the HIV crisis in the South, and amplify policy changes necessary to "change the pattern" of HIV disparities in the region.

2024

JULY Southern Policymakers Academy SAC held the Southern Policymakers Academy in Atlanta. It was a pivotal event designed to educated and engage southern policymakers on the critical issues surrounding HIV in the South.



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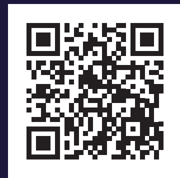

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