

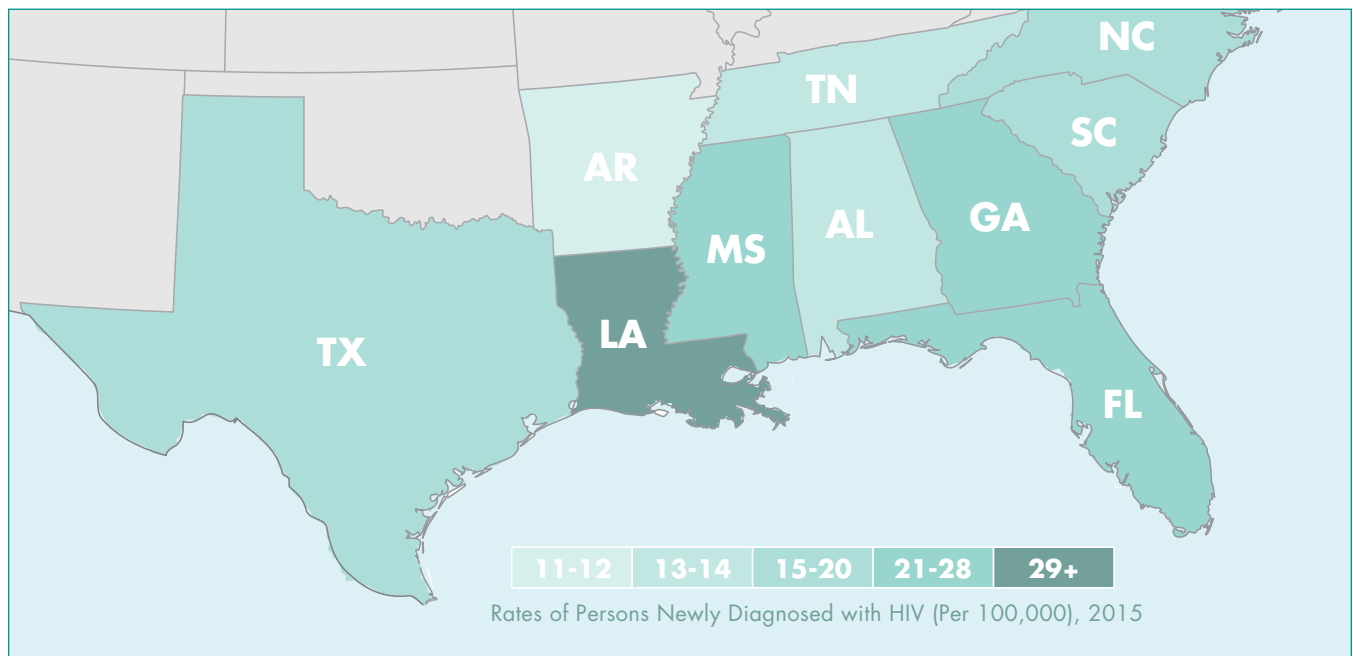
# ENDING THE HIV EPIDEMIC IN THE SOUTH: Exploring Current Conditions, Identifying Methods, and Implementing Strategies

May 2017 Regional Stakeholders Meeting Summary

The time to end the AIDS epidemic is NOW. And to end the epidemic in the United States, community leadership and mobilization to secure and advance critical public health resources is needed in the Deep South States.

## WHY THE SOUTH?

Despite comprising roughly a third of the entire U.S. population, more than half of new HIV and AIDS diagnoses in the U.S. occur in the South.<sup>1</sup> The nine states of the Deep South alone—Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas—are home to 42% of the country’s annual AIDS and HIV diagnoses.



AIDSVu. National HIV Testing Day 2017 [Internet]. 2017. <https://aidsvu.org/resources/nhtd2017/>

Disparities in HIV-associated mortality have also been reported. According to the CDC, of the 6,721 deaths attributed directly to HIV or AIDS in 2014, 3,570 (53%) were in the South.<sup>2</sup> From 2008 to 2013, 21,308 individuals died of HIV as the underlying cause of death in the Deep South, representing 43% of deaths in the U.S.<sup>3</sup> Racial disparities around mortality are dramatic in the Deep South. In 2013, HIV disease was not among the top 15 leading causes of death for white males or females, but it was the ninth leading cause of death for black men and the twelfth leading cause for black women.

Communities of color in the South, including rural communities, are particularly impacted. In 2014, Black people made up 54% of new diagnoses in the South. Of those infections, 59% of infections occurred among Black gay and bisexual men. Sixty-nine percent of new infections among women in the South occurred in Black women.

## OUR APPROACH:

In May 2017, Treatment Action Group, in collaboration with the Southern AIDS Coalition, the Southern HIV/AIDS Strategy Initiative, NASTAD, Sisterlove, and AIDS Alabama, convened 45 dedicated community leaders, advocates, and public health officials in the Deep South to discuss the potential of ending HIV as an epidemic in some of the hardest hit states, counties, and cities in America. Funded by the Elton John AIDS Foundation, Ford Foundation, MAC AIDS Fund, Gilead, ViiV, and Janssen Therapeutics, the gathering explored key opportunities and challenges facing the region and identified jurisdictions that are ready to move forward with developing strategies and forming stakeholder coalitions to end their epidemics.

Despite significant federal-level challenges ushered in with the 45th White House administration and the 115th Congress, meeting participants remained inspired, and indicated that now is the right time to mobilize local communities and develop jurisdictional action plans demanding that government officials, public health leaders, and other key stakeholders develop and implement strategies to bring new infections below epidemic levels and end one of the greatest humanitarian crises of our times.

Here we summarize group feedback on the opportunities and challenges for developing plans to end the epidemic in southern jurisdictions, as well as key stakeholders and allies that should be engaged in any ending the epidemic (EtE) planning.

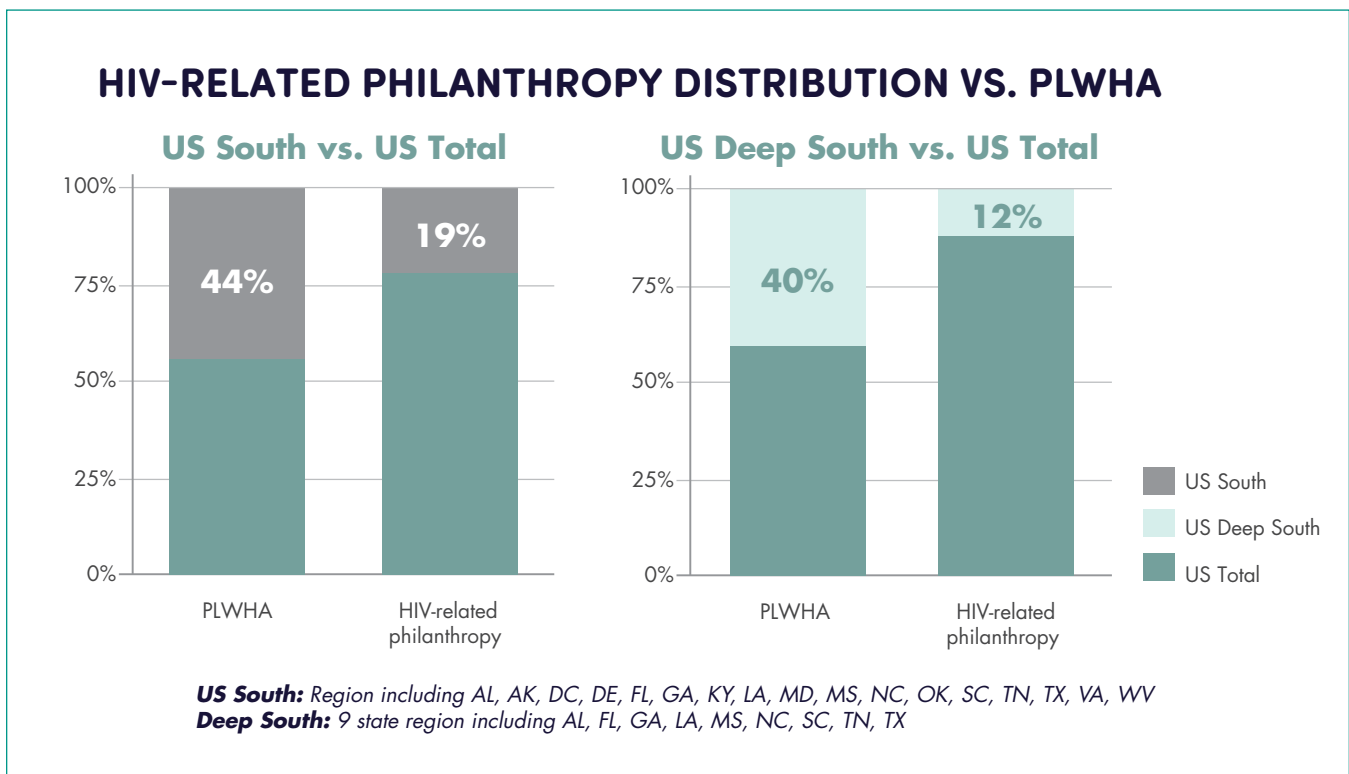
## WHAT ARE THE OPPORTUNITIES FOR ENDING HIV/AIDS IN THE SOUTH?

Participants identified several opportunities that contribute to the feasibility of developing sound, scientific, and feasible strategies to end HIV as an epidemic in the Deep South:

- **The science:** Since 2011, we have had the evidence-based tools to dramatically reduce the risk of infection among those vulnerable to infection and the risk of transmission, AIDS, and premature death among those living with HIV. As Tony Fauci, head of NIAID said in *Science* in 2011, "Let science inform policy."<sup>4</sup>
- **Building on emerging successes:** More than a dozen jurisdictions across the U.S. have launched their own EtE plans, including Houston, TX,<sup>5</sup> and Fulton County, GA (the Atlanta metro region).<sup>6</sup> We can learn, adapt, and implement these strategies, meaning that we can learn from the experiences of these other EtE planners. In addition to capitalizing on the EtE planning successes in flagship jurisdictions, we must continue to allow science to inform public health policy. Since 2012, the CDC has increasingly funded HIV prevention with a solid evidence base, including testing, early treatment for people living with HIV, and access to PrEP for HIV-negative individuals. In February 2017, the CDC reported that incidence in the U.S. has dropped significantly since they adopted this approach.<sup>7</sup> But the South as a region has benefited the least from these advances.
- **Better local and state politics:** The Deep South is highly associated with its conservative politics and right-wing government leadership, but progressive opportunities do exist. With a new Democratic governor who expanded Medicaid under the Affordable Care Act (ACA) and in collaboration with innovative public health officials, Louisiana is in a unique situation to make dramatic advances in ending the state's epidemic. Specific cities in the South, like Jackson, MS, and Nashville, TN, have political leadership that advocates can work with. In addition, throughout the U.S., the current opioid addiction crisis is softening Republican leadership perspectives of public health, as exemplified by lifting of the federal funding ban on syringe access programs at the end of 2015.<sup>8</sup> In Tennessee, a

recent law legalizing the establishment of syringe exchange programs passed with broad bipartisan support, with Republicans listed as the main sponsors in both the state senate and the state house.<sup>9</sup>

- **Passionate advocates:** The greatest resource and opportunity for the South is the extremely dedicated, talented, and hardworking community advocates who have kept services and political pressure alive in times of extreme adversity.
- **Engaging non-traditional partners:** Collaborative work with social justice leaders and activists that might not have prioritized HIV in the past is often a key component for the success of EtE strategy development and implementation. Workshop participants highlighted the engagement of these non-traditional partners as an opportunity that could be better addressed through an EtE planning process. Specifically, participants suggested connecting HIV advocacy to the escalating response to the opioid epidemic and broader healthcare coverage advocacy, as well as mainstream movements for racial justice and transgender rights.
- **Funding:** Philanthropic funders are becoming increasingly cognizant of grant award disparities in the South. According to an analysis conducted by SASI, the Deep South received \$35 per person living with HIV from private foundation funding in 2015, as compared with the U.S. average of \$116.<sup>10</sup> Funders Concerned About AIDS has recently put a spotlight on the issue, showing that, although the region has 44% of all people living with HIV/AIDS, the South receives less than a quarter of total HIV-related philanthropy. EJAF and AIDS United’s Southern REACH grants are leading the way in trying to rectify these inequities.



Funders Concerned About AIDS. HIV Philanthropy for the US South. Washington D.C.: FCAA; 2014. <http://www.fcaaid.org/wp-content/uploads/2016/11/USSouthInfographicFINAL-ULTIMATE.pdf>

- **Strategic use of surveillance:** A growing number of states are diversifying health data sources to ensure people living with HIV are receiving care and achieving viral suppression. The Louisiana Public Health Information Exchange (LaPHIE), for example, helps healthcare providers across the state identify those who may have fallen out of care and get them back into services.<sup>11</sup>
- **Budget Savings:** According to a recent analysis by Bruce Schackman of Weill Cornell Medical College and colleagues, every new HIV infection costs \$443,904 in health spending alone.<sup>12</sup> A 2015 analysis by Housing Works and Treatment Action Group found that the New York state plan, if successfully implemented and infections averted, would generate over \$6.8 billion in total Medicaid savings. Modeling that demonstrates short- and long-term cost savings will be essential to efforts to secure political buy-in.<sup>13</sup>

## WHAT ARE THE CHALLENGES FOR ENDING THE EPIDEMIC IN THE SOUTH?

- **A large, complex epidemic:** A history of conservative politics and funding deficits have dramatically worsened the epidemic in the South. To make real inroads, key stakeholders will have to battle a large epidemic brought on by a legacy of irresponsible political neglect.
- **Hostile political climates:** Although there are political opportunities in the South, much of the region remains hostage to conservative politics. As of June 2017, Louisiana is the only state to have adopted Medicaid expansion.<sup>14</sup> Attempts to pass anti-LGBT legislation remain commonplace; with HB 1523, Mississippi has passed one of the worst pieces of hate-based legislation targeting LGBT individuals in recent years.<sup>15</sup> Social and public health progress is also eroding on the federal level; HIV prevention, care, and service delivery funding cuts remain a considerably threat; the future of the ACA remains in jeopardy, and human rights abuses against marginalized populations are increasingly prevalent.
- **Racism:** A recent piece in the *New York Times* effectively depicted the role that misconceptions about race play in the U.S. HIV epidemic: <https://www.nytimes.com/2017/06/06/magazine/americas-hidden-hiv-epidemic.html>. In particular, amplifying racist perceptions of black gay male sexuality as the primary driver of the epidemic in spite of overwhelming evidence that structural factors and racism are the true culprits—stigma that has caused irreparable damage. Racism has consequences: 43% of Fulton County residents are black, yet 68% of HIV diagnoses occur in black individuals.<sup>16</sup> One in two black MSM nationally are likely to become HIV positive if current trends occur.<sup>17</sup>
- **Transphobia:** Stigmatization and discrimination toward transgender individuals undermines all of our efforts to treat and prevent HIV infections among gender non-conforming individuals in the South and across America. North Carolina’s discriminatory HB2 bill was a particularly crude example of the pushback by conservatives against the recent gains in transgender rights and visibility in America.<sup>18</sup>
- **The opioid epidemic:** Approximately 50,000 people are dying due to opiate addiction every year in the U.S., according to new CDC data. The ongoing crisis has opened up political opportunities, but far too late in the process. From 2010 to 2015, 11 states in the U.S. had increases in heroin death rates, with the greatest percent increases in death rates in South Carolina (57.1 percent), North Carolina (46.4 percent), and Tennessee (43.5 percent).<sup>19</sup>
- **City vs. County vs. State:** Tensions and differences between state, city, and county government bodies can greatly complicate EtE planning. A city may be more progressive and develop an EtE plan, but it may face challenges in implementation due to resistance from a conservative state government. Although Houston is a city housed within one county, the Atlanta metro region spans several counties, which is why it was considered less challenging to develop a plan for the more progressive Fulton County than it would be for the city as a whole.

- **Defining and evaluating success:** As with all EtE initiatives, defining the outcomes of success is both important and challenging. In New York, the target of less than 750 new infections per year by 2020 was set after determining what would be needed to bring HIV below epidemic levels.<sup>20</sup> In Fulton County, targets were tied to the National HIV/AIDS Strategy. In Houston, they have set a 50% reduction in the number of new HIV cases in five years—doubling the reduction called for in NHAS—as an ambitious target.<sup>21</sup>
- **Structural barriers:** Access to prevention, care, and treatment services is about much more than individual behavior change and education; with HIV and healthcare in general we need to always look at the context and the surrounding environment to see what physical and social barriers are restricting access. We cannot end epidemics when healthcare services are inaccessible due to transportation issues, lack of housing, educational barriers, etc. Looking at four key Deep South jurisdictions—Jackson, Baton Rouge, Jacksonville, and Columbia—SASI found significant challenges associated with structural barriers, including housing, jobs, education, transportation, and access to mental health/substance use support.<sup>22</sup> The four jurisdictions also had higher rates of poverty, STDs, teen pregnancy, infant mortality, heart disease death rate, and diabetes, indicating that healthcare access is a challenge across the board in the Deep South and emphasizing the need for collaboration with other healthcare advocates outside of HIV.
- **Stigma:** Stigma and discrimination based on issues related to HIV remain a powerful barrier to treatment and prevention. Religious institutions are of notable concern. Criminalization of HIV is particularly draconian in the Deep South, where laws carry harsh punishments even in cases where transmission is impossible.
- **Turf Wars:** In a number of jurisdictions, real or perceived competition for scarce resources between community-based organizations can create tensions. Prominent organizations may need to relinquish control or visibility in the EtE planning process in cases where that may create a barrier to cooperation among key stakeholders.
- **Integrating EtE plans with existing plans:** Many jurisdictions have comprehensive plans for Ryan White and CDC funding, and many locations recently completed substantial work to ingrate their care and prevention plans. Adding another planning process into the mix may lead to fatigue without careful planning.
- **Student education:** Comprehensive sexual education, including education relevant to LGBT individuals, is difficult to access in the Deep South.
- **History of lower funding:** Although some funders are finally working to correct inequities, a history of fewer resources, particularly in the rural South, has had lasting consequences. According to SASI, 100 percent of recent CDC funding in the Deep South went to metropolitan service areas with populations of over 500,000, meaning that rural communities remain in a lurch.<sup>23</sup> Given that around a third of people living with HIV live outside of MSAs in the South, and with some states like South Carolina and Alabama having over 70% of their HIV-positive populations living outside of MSAs, this is an enormous oversight.<sup>24</sup>
- **Showing the real South:** Although outsiders frequently talk about the South as a monolithic block, conditions and circumstances are actually very nuanced across the region. We need to avoid a one-size-fits-all approach to addressing HIV in the South and look closer at differences across states, cities, and populations.
- **Fostering New Leadership:** Key community leaders are often in short supply, leading to overreliance on the work and experience of a handful of individuals in highly affected jurisdictions.

- **ACA/Medicaid Expansion:** According to the Kaiser Family Foundation, more than 2.5 million poor uninsured adults fall in the ‘coverage gap’ that results from state decisions not to expand Medicaid, meaning their income is above current Medicaid eligibility, but below the lower limit for Marketplace premium tax credits.<sup>25</sup> A highly disproportionate 91% of people in the coverage gap live in the South. More than a quarter of the people in the coverage gap reside in Texas; 18% live in Florida, 12% in Georgia, and 8% in North Carolina. Lack of coverage is especially detrimental in Southern states that already put little to no funding towards HIV prevention—and it dramatically undercuts the provision of base healthcare coverage, increasing health-related jobs and ensuring existing healthcare institutions can maintain and expand care in urban and rural areas.
- **Drug War/HIV Criminalization:** According to the Center for HIV Law and Policy, 12 southern states impose criminal punishment for behavior related to HIV exposure or transmission.<sup>26</sup> People living with HIV are overrepresented in prison populations in the South.<sup>27</sup> Louisiana leads the nation in rates of incarceration, with 776 prisoners per 100,000 people.<sup>28</sup> Although people living with HIV make up significantly less than one percent of the population in Louisiana, in 2010, 3.5% of the state prison population was estimated to be HIV positive. Other states in the Deep South have similar disparities in their prison populations: Florida (3.2%), Mississippi (2.3%), Georgia (1.9%), South Carolina (1.8%), and North Carolina (1.8%).

## WHO DO WE NEED AT THE TABLE?

Participants listed several entities that should ideally be involved in any EtE planning.

- **Pharmaceutical companies:** Volume-based pharmaceutical discounts are likely necessary to ensure that a massive scaling up of treatment, PrEP, and PEP is affordable for public payers. Pharma also does considerable outreach and education work in heavily impacted areas; in some cases, arguably more so than community groups. ViiV’s Accelerate! initiative in Baltimore, MD, and Jackson, MS, is a particularly compelling example of effective synergy between community and an industry partner.<sup>29</sup>
- **Diverse community representation** from all disproportionately impacted communities. Existing state advocacy networks for people living with HIV, like Louisiana AIDS Advocacy Network in Louisiana, are of particular importance, and need more support to scale their member bases and advocacy impact.
- **Academia:** Public health and public policy scholars affiliated with universities, agencies, and organizations in the jurisdictions developing plans can be particularly useful in supporting EtE efforts. They can provide the kind of nonpartisan research in determining appropriate targets for EtE success, and developing surveillance and data related information to be use by advocates, policy makers, and EtE implementers.
- **Public Health officials:** As the primary stewards of public health funding, programs and strategies, state health department leadership must be willing to engage in EtE development and implementation plans, and value community engagement and input at all levels.
- **Ryan White/Prevention Planning Councils:** Although jurisdictions nationwide are developing integrated prevention and care plans, these are not a replacement for plans to end HIV as an epidemic. However, planning councils are important bodies for helping guide resources that support the targets of an EtE plan.

- **Elected Officials:** Most jurisdictions will need to think about policy, legislative changes, and funding allocations that will help facilitate access, engagement, and retention in care for HIV-positive individuals, as well as people most at risk. Southern legislators at the state level will need to be champions of policy changes that can support ending the epidemic plans.
- **Non-traditional partners:** With so many health-related crises in America, reaching out to new allies is essential. For example, mental health/substance use advocates; Hepatitis C advocates; non-HIV social justice advocates, including those focusing on reproductive justice, racial, and gender equality; and LGBT rights.
- **Service Providers and Healthcare Administrators:** Given that PrEP, PEP, and TasP all require access to informed, compassionate, and non-stigmatizing healthcare professionals, partnering early in the EtE process with hospital and primary care associations is particularly useful to develop comprehensive plans to educate and train the healthcare workforce on essential, up-to-date information on HIV care, treatment, and prevention.
- **Sororities/Fraternities:** Black fraternities and sororities play a critical role as social organizations in the South, at historically Black colleges as well as predominantly white institutions. They also have been active in HIV testing and information events, and may be essential conduits for mobilizing information and support for ending the epidemic strategies.
- **Police Departments:** Police departments are important in addressing substance use epidemics, increase access to harm reduction programs, including overdose prevention, and generally reducing criminal justice approaches to drug use, sex work, and ending HIV criminalization.
- **Faith-Based Institutions:** Churches are particularly influential sources of information and community support in southern jurisdictions and, as such, may be important allies in highly affected communities, including communities of color. Finding progressive religious leaders who are able to facilitate greater discussion between HIV advocates and religious institutions may increase broader community understanding of how to end the HIV epidemic.

## CONCLUSION: THE CHALLENGES ARE MANY, BUT SO ARE THE OPPORTUNITIES

It is right time to end the epidemic in the South, even in the face of new and long-standing challenges. The political context doesn't change the scientific fact that we can end epidemics, even though it may make that goal more challenging to achieve. Lessening our ambitions is the wrong response to oppressive politics; key stakeholders should continue to advocate just as strongly for what is best for people living with and vulnerable to HIV.

Several opportunities are clearly present across the South that make EtE planning possible and necessary; however, we will need to dramatically ramp up advocacy and stakeholder engagement to hold state, county, and local government officials accountable to the needs of people living with, and vulnerable to, HIV infection. This is especially important given that, with the ongoing national political crisis following the November 2016 elections, the long-standing focus on federal support must now be shifted to ensure protection and the advancement of EtE goals in the south.

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