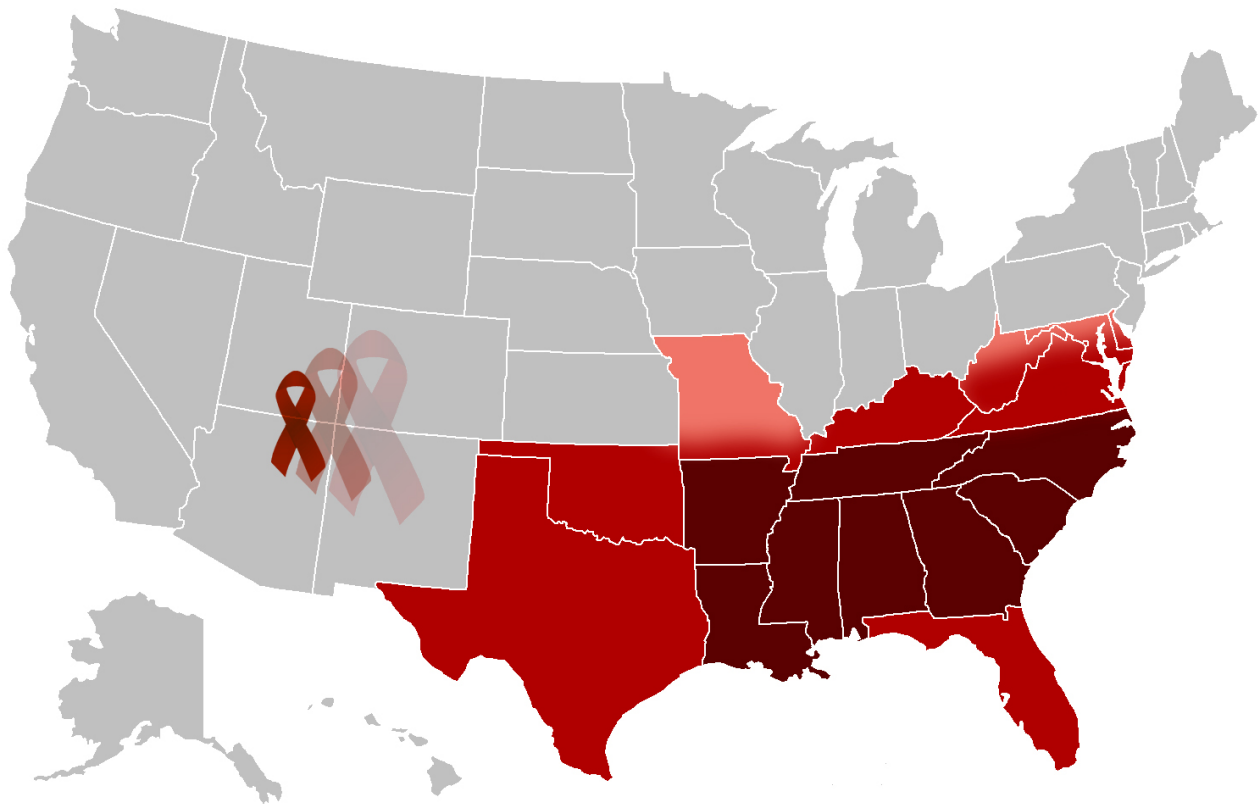


THE SOUTHERN EPIDEMIC:

Are the South's cultural, political and societal barriers making it difficult for public health programs, such as the AIDS Drug Assistance Programs, to function effectively in this region?

May 2014



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“We have half the epidemic in the South, but I can assure you that don’t get half of the money or have half of the people at the important tables, and that’s quite frustrating.”

- Kathie Hiers, President & CEO of AIDS Alabama, quoted in the Sidewalk Film, August 25, 2012.

The AIDS Drug Assistance Program (ADAP), which is authorized under Part B of the Ryan White CARE Act, has been extremely effective at linking people living with HIV/AIDS to care and treatment in the U.S. over the last two decades. One notable exception: ***The South***. Many public health programs – including ADAPs – have often fallen victim to cultural, political and societal barriers that have made it difficult for ADAPs to function effectively in this region of the country. This analysis examines the disproportionate impact of the barriers in the South, especially as they relate to access to care, in general, and ADAP waiting lists, specifically.

The Center for Disease Control and Prevention (CDC) estimates that there are approximately 1,144,500 people aged 13 years and older living with HIV infection in the U.S. today.¹ The groups that account for the largest proportion of HIV/AIDS are gay, bisexual, and other men who have sex with men (MSM). By race, African Americans are disproportionately affected by the disease. Also, the CDC estimates that one in four people living with HIV in the U.S. are women, and only 53% of them are staying in care.² Poverty is also central to the high HIV infection rates, as it affects those with lower socioeconomic status at a disproportionately high rate.³ Although new HIV infection rates have stabilized over the years (approximately 50,000 new cases a year) there is growing concern about HIV infection rates in the South.

The southeastern U.S. has seen a disproportionate impact of HIV/AIDS in its communities, especially over the last decade. In 2011, eight of the southeastern states accounted for the ten states with the highest new HIV infections in the country.⁴ Furthermore, southeastern states accounted for 50% of HIV infections that year.⁵ To put that in perspective, it is important to note that this region accounts for only 37% of the U.S. population. There are numerous contributing factors behind these alarming numbers. The region has historically retained a deep and distressing culture, evidenced by violent civil rights struggles, high poverty rates, poor education systems, deeply engrained religious traditions, and limited access to healthcare.

The South’s seeming inability to adequately invest in public health was no more evident during the last ADAP waiting list crisis – often referred to as “The Perfect Storm” by ADAP stakeholders – which occurred from 2008-2012. People living with HIV/AIDS in the South were considerably more likely to be denied access to care and treatment. In fact, during “The Perfect Storm” over ninety percent of the people living with HIV/AIDS on ADAP waiting lists resided in the South.⁶ The ADAP waiting lists reached its peak in August 2011, when 9,217 people living with HIV/AIDS were being denied care in 12 states. At that time, seven of these states were in the South, with 96.14% of the waiting list patients residing in these southern states.⁷

¹ "Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 U.S. Dependent Areas—2011." *HIV Surveillance Supplemental Report*. Centers for Disease Control and Prevention, 26 Mar. 2014. Accessed Apr. 2014. <http://www.cdc.gov/hiv/library/reports/surveillance/>

² "HIV among women." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 06 Mar. 2014. Accessed 29 Apr. 2014. <http://www.cdc.gov/hiv/risk/gender/women/facts/index.html>

³ Perry, M.J. "Gender, Race and Economic Perspectives on the Social Epidemiology of HIV Infection: Implications for Prevention." *The Journal of Primary Prevention* 19 (1998): 97-104. Print.

⁴ Reif, SS, K. Whetten, ER Wilson, C. McAllister, BW Pence, S. Legrand, and W. Gong. "HIV/AIDS in the Southern USA: A Disproportionate Epidemic." *AIDS Care* 26.3 (2014): 351-59. Epub, 2013. Web. Apr. 2014

⁵ "Home | Southern Aids Coalition." Southern Aids Coalition. N.p., n.d. Web. Apr. 2014. <http://www.southernaidscoalition.org/>

⁶ "The ADAP Watch." NASTAD. November 11, 2010. Accessed April 22, 2014.

⁷ "The ADAP Watch." NASTAD. August 5, 2011. Accessed May 2, 2014.

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ADAPs with Waiting Lists
(9,217 individuals in 12 states*, as of August 11, 2011)

State	Number of Individuals on ADAP Waiting List	Percent of the Total ADAP Waiting List	Increase/Decrease from Previous Reporting Period	Date Waiting List Began
Alabama	149	2%	+19	May 2011
Arkansas	51	0.6%	+0	December 2010
Florida	3,792	41%	+41	June 2010
Georgia	1,772	19%	+54	July 2010
Idaho	25	0.3%	+0	February 2011
Louisiana**	987	11%	+26	June 2010
Montana	29	0.3%	+0	January 2008
North Carolina	318	3%	+2	January 2010
Ohio	261	3%	+14	July 2010
South Carolina	905	10%	+9	March 2010
Utah	41	0.4%	+1	May 2011
Virginia	887	10%	+12	November 2010

(Source: National Alliance of State & Territorial AIDS Directors, 2001)

Needless to say the issue behind HIV infection rates being so high in the South is a complex one. It is commonly accepted that many socio-economic demographics influence health outcomes.⁸ These can include race, gender, class, and sexual orientation. In addition, cultural and attitudinal differences in a region can influence access to healthcare and health education. The following social determinants of health will be examined with regard to the HIV/AIDS rates and access to healthcare in the South: 1) race and discrimination, 2) poverty and education, and 3) sexual orientation and stigma.

Race & Discrimination

By race, African Americans are the largest group affected by HIV/AIDS. According to the latest U.S. Census data, African Americans account for 14% of the population, with 53% of the group living in the South.⁹ Yet, HIV/AIDS disproportionately impacts this community.

In 2010, African Americans had the highest rate of new HIV infections among any group; eight times that of white Americans.¹⁰ In 2008, African Americans comprised 48% of deaths among people living with HIV/AIDS.¹¹ In fact, for African Americans between the ages of 25-44, HIV/AIDS was the fourth leading cause of death in 2008.¹²

⁸ Braveman, Paula A. MD, MPH, et. al. (2006) Socioeconomic Status in Health Research: One size does not fit all. *Special Communications*. (2006)

⁹ "2010 Census Shows Black Population has Highest Concentration in the South." United States Census Bureau. September 29, 2011. Accessed April 28, 2014. https://www.census.gov/newsroom/releases/archives/2010_census/cb11-cn185.html

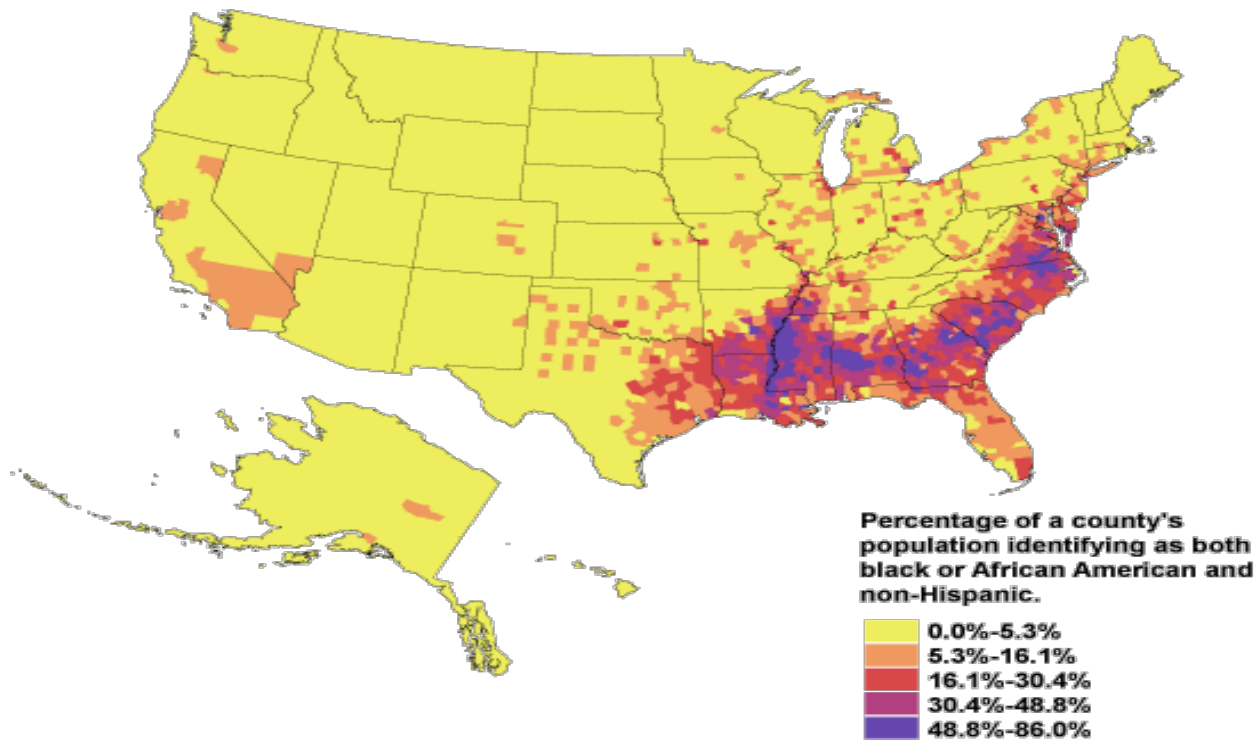
¹⁰ "HIV Surveillance Supplemental Report". Centers for Disease Control and Prevention. Vol. 17, No. 4; December 2012. Accessed April 19, 2014. <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>

¹¹ Kaiser, HIV/AIDS in the US.

¹² Kaiser, HIV/AIDS in the US.

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(Source: US Census, 2000)

A similar trend has emerged within the Latino community. Nowhere has the Latino population boomed like the South, evidenced by a 2013 Pew study reporting that all but one of the top 10 states with the fastest-growing Hispanic populations from 2000 to 2011 being located in the South.¹³ Latinos face the additional burden of language barriers and immigration repercussions as well.¹⁴ The Latino community also experienced explosive HIV-infection rates. In 2001, the AIDS rate among Latino adults and adolescents was more than 3 times that of whites (28 per 100,000 compared to 7.9).¹⁵ Of new HIV diagnoses among Latinos in 2008, 50% were reported in the South.¹⁶ Further, although Latino teens only account for 15% of the U.S. adolescent population, in 2001 they represented 21% of new AIDS cases in that group.

In this region of the country, communities of color face significant barriers that make the growing HIV/AIDS rates even more concerning. It's not just the geographic location of some of these high-risk groups that makes the implications of race so important when examining the South. The deeply engrained history of racism and discrimination in this region has had lasting effects that still resonate in the South. Social stratification and institutional inequalities still exist in the South and contribute to shortfalls in access to healthcare. Racial prejudice and the historical implications of segregation in the South are a part of the complex and overlapping social health disparities that keep this area on the radar in the public health community.

¹³ Maugh II, Thomas H. Poverty and HIV are strongly linked, CDC survey finds. (The Los Angeles Times, July 2010) Accessed April 2014. <http://articles.latimes.com/2010/jul/20/science/la-sci-aids-poverty-20100720>

¹⁴ The Deep South Project. (Southern AIDS Coalition, Southern States Manifesto, 2010) 11.

¹⁵ Trends, K. Latinos and HIV/AIDS (2003).

¹⁶ McAllaster, Carolyn. The Southern HIV/AIDS Strategy Initiative: Focusing White House Attention on the HIV Epidemic in the South (Webinar Farmworker's Justice, June 13, 2012).

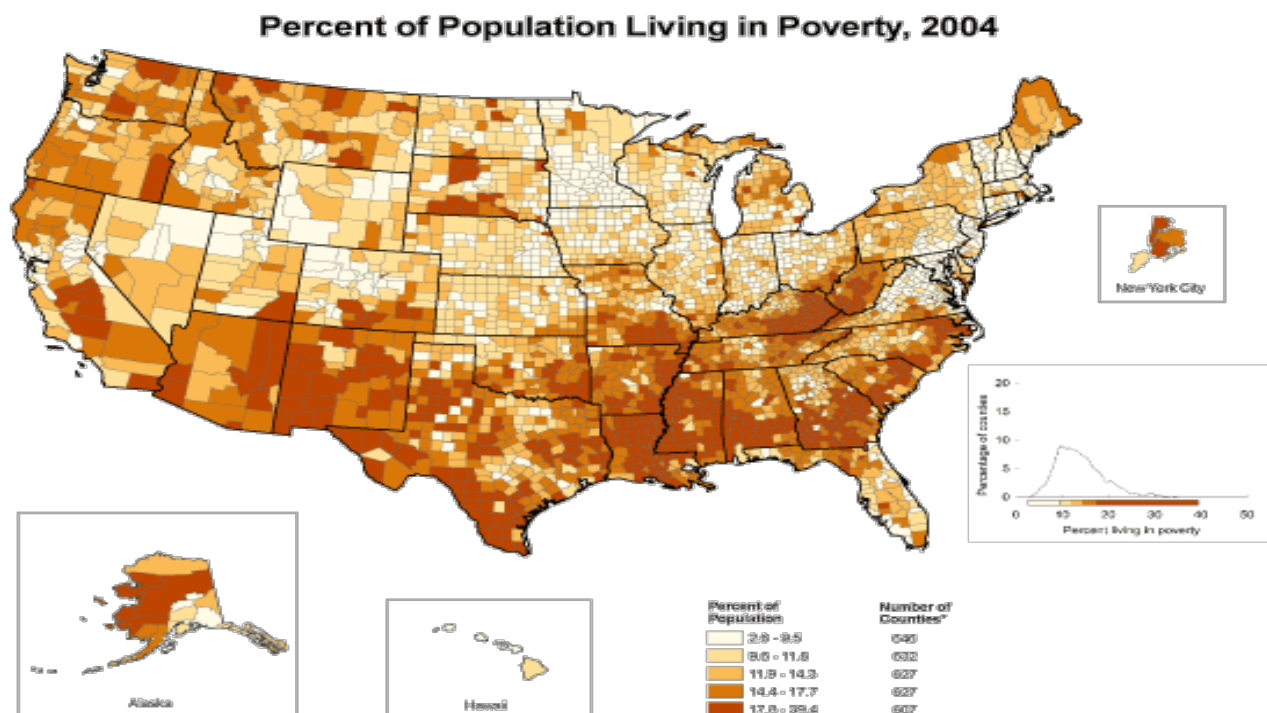
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Poverty and Education

Poverty has implications for many health outcomes including being a lead contributor to HIV infections. In 2010, a CDC survey found, “heterosexuals living below the poverty line in U.S. cities are five times as likely as the nation’s general population to be HIV-positive, regardless of their race or ethnicity...”¹⁷ HIV infection rates can be directly linked to poverty rates, but the latter also contributes to limitations on access to care. Low-income individuals are not likely to have health coverage or receive optimal treatment and care for HIV/AIDS, such as Highly Active Anti-Retroviral Therapy (HAART).¹⁸ Additionally, lower income is associated with lower treatment initiation, which often leads to lower standards of health and higher mortality rates. According to Michael Saag, M.D., Director of the AIDS Research Clinic at the University of Alabama at Birmingham:

“HIV is a disease of poverty. Those who are poor are less likely to be diagnosed, get treatment or stay in a treatment, increasing the risk not only that they’ll be sick, but that they’ll infect others. Since there’s a lot of poverty in the southern United States, there’s going to be a lot of HIV cases.”¹⁹



(Source: Centers for Disease Control and Prevention, 2010)

¹⁷ Maugh II, Thomas H. Poverty and HIV are strongly linked, CDC survey finds. (The Los Angeles Times, July 2010) Accessed April 2014. <http://articles.latimes.com/2010/jul/20/science/la-sci-aids-poverty-20100720>

¹⁸ The Deep South Project. (Southern AIDS Coalition, Southern States Manifesto, 2010)

¹⁹ Wolfson, Hannah. The Birmingham News. AIDS risk higher in the South. January 14, 2012. Accessed April 2014 http://blog.al.com/spotnews/2012/01/aids_risk_higher_in_the_south.html.

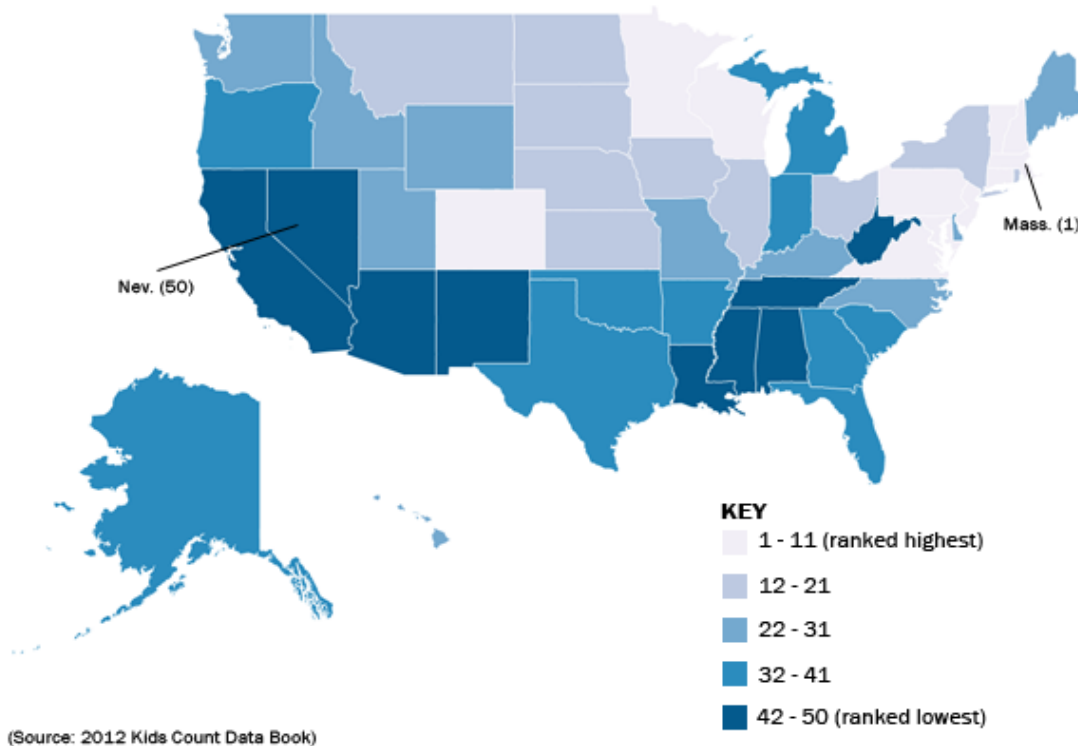
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The lack of education is another contributing factor to HIV/AIDS. Christopher Murray with the Institute for Health Metrics and Evaluation in Seattle argues, "...findings are incredibly robust..." that a lack of education may be as important an explanation as poverty for poor health in communities worldwide.²⁰ Studies have shown that people living with HIV infection who have lower literacy levels have less general knowledge about their disease and disease management.²¹ An additional concern in the South is the lack of comprehensive sex education in public schools. The "Bible-Belt" of the South has long been opposed to this curriculum, something that has had proven success in reducing sexually transmitted infections such as HIV-infection in other parts of the country.

Poverty and education level are typically negatively correlated, meaning that the higher the poverty rate in an area, the lower the education levels. These are both strong predictors of HIV rates as well as negative health outcomes associated with HIV such as treatment initiation and mortality rates. Many of the poorest areas of the country also show a large gap in education compared to the rest of the nation. These states are overwhelmingly found in the South, as seen in the diagram.

National Education Ranking



These factors, in addition to the many other social health determinates contribute to the disproportionate rate of HIV/AIDS in this region.

²⁰ Sternberg, Steve and Gillum, Jack. *Lack of education fuels HIV epidemic in the south* (USA Today, 2011). Accessed April 2014. http://usatoday30.usatoday.com/yourlife/health/2011-07-10-HIV-AIDS-south_n.htm

²¹ Southern AIDS Coalition. *Southern States Manifesto: Update 2012 policy brief and recommendations*.

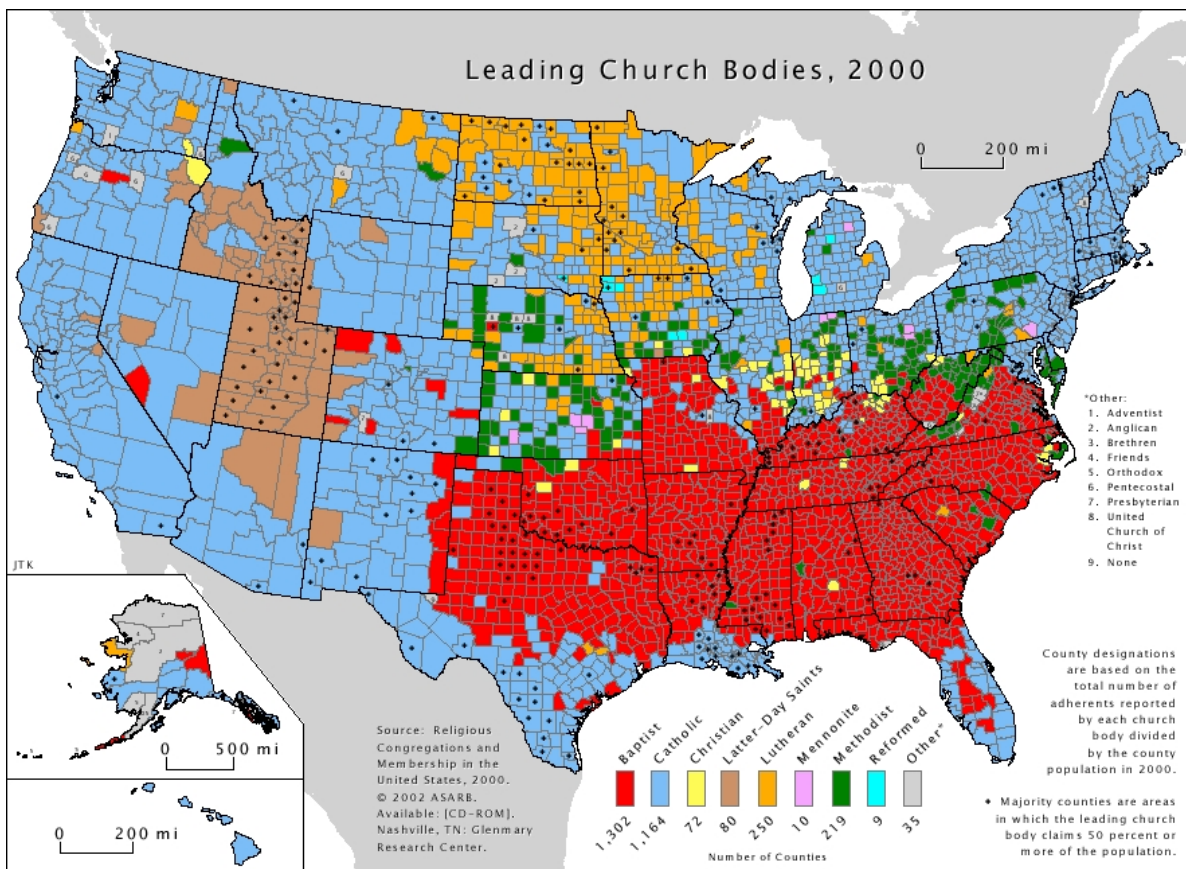
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Sexual Orientation and Stigma

Men who have sex with men (MSM) still remain the largest group affected by HIV/AIDS in the U.S. Only comprising about 4% of the U.S. population according to government reports (although some data suggests that this number could be closer to 10% of the U.S. population), this group accounts for most new HIV/AIDS infections, 63% in 2010.²² A recent study found that about one in five MSM is already living with HIV, with even higher prevalence between black MSM, and many are unaware of their status.²³ The issue with regard to this group and its relevance to HIV/AIDS is not that there is a higher prevalence in the South, but that there is more stigma attached to nontraditional sexuality in this area of the country. The stigma comes mainly from the conservative Christian values held by many in the region. The South is home to the largest Evangelical Christian population in the nation. The term “Evangelical” means to define: mainline, white Protestant Christians, typically Baptists.

Editor’s note: This is not to suggest that all Evangelical Christians, or Baptists for that matter, hold negative views toward people living with HIV/AIDS, but rather that many of the religious principles held by this group are often counter to proven public health strategies.



(Source: Glenmary Research Center, 2000)

²² “HIV Surveillance Supplemental Report”. Centers for Disease Control and Prevention. Vol. 17, No. 4; December 2012. Accessed April 19, 2014. <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>

²³ Wejnert C et al. (2013) HIV Infection and awareness among men who have sex with men – 20 cities, United States, 2008 and 2011. *PLoS ONE* 8.

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This population tends to hold very conservative beliefs and values with regard to sexuality including contraception, sex education, and sexual orientation. An article posted on the website “*Sojourners: Faith in Action for Social Justice*,” claims that Pew research shows, “nearly two-thirds (64%) of Americans agree that gay and lesbian relationships should be accepted by society, including majorities of all major religious groups **except** white evangelicals.”²⁴ This creates a climate of shame and guilt, which leads many MSM to keep their sexual relationships clandestine. Cedric Sturdevant, an HIV/AIDS activist diagnosed with HIV in 2006, says this about his home state of Mississippi:

*“Most people still think it's a gay man's disease. Mississippi, being a Bible-Belt state, is homophobic. You don't want people to know you're homosexual, if that's the case. If you're heterosexual, and you get infected, you don't want people to put you in the category of being homosexual.”*²⁵

The kind of discrimination and stigma Sturdevant is describing clearly creates a climate that makes it difficult for MSM and heterosexuals alike to face the reality of HIV/AIDS in their communities. MSM persons face so much discrimination in the South as it is that they are often hesitant to get tested for fear of being further ostracized. In addition, heterosexual persons fear being thought of as homosexual or “outed” as homosexual to the point that they are afraid of getting tested for fear of being identified as MSM and subsequently facing the same discrimination. The lack of HIV testing leaves these groups vulnerable to higher mortality rates in the South due to a lack of early detection and treatment initiation. Megan McLemore, Human Rights Watch, said in a USA Today article, “...the fact that only 50% of people have been tested and are in treatment (in Mississippi) is comparable to Botswana, Rwanda and Ethiopia. The death rate is 60% higher than the national average.”²⁶

In addition to the disproportionately high mortality rates, the lack of HIV testing (spurred by fear and shame) contributes to the spreading of the infection. Draconian HIV criminalization laws only serve to further complicate an uninviting environment for people living with HIV/AIDS in the South; combined with the lack of testing only serves to further the high rates and new infection cases in this area of the country.

Access to Healthcare

Societal factors aren't the only contributing factor to high HIV/AIDS rates in the South. Access to healthcare, or lack thereof, is a very important consideration when examining this issue. Two in five southerners are considered to be “medically disenfranchised” meaning they lack access to a medical provider.²⁷ Additionally, southerners are less likely to have health insurance than citizens in other parts of the country.²⁸ Typically there are fewer medical providers located in the South, and therefore more people in this area live in federally designated “health professional shortage areas.” Further, there is a lack of medical professionals specializing in HIV/AIDS care in the South.²⁹

²⁴ “Faith in Action for Social Justice. Evangelicals: by the numbers.” *Sojourners* .2011. Accessed May 2014. <http://sojo.net/blogs/2011/10/04/evangelicals-numbers>

²⁵ Sternberg, Steve and Gillum, Jack. Lack of education fuels HIV epidemic in the south (USA Today, 2011). Accessed April, 2014.

http://usatoday30.usatoday.com/yourlife/health/2011-07-10-HIV-AIDS-south_n.htm

²⁶ Sternberg, Steve and Gillum, Jack. Lack of education fuels HIV epidemic in the south (USA Today, 2011). Accessed April, 2014.

http://usatoday30.usatoday.com/yourlife/health/2011-07-10-HIV-AIDS-south_n.htm

²⁷ Cantor, Joel C., Schoen, Cathy, Belloff, Dina, How, Sabrina K.H., McCarthy, Douglas. “Aiming Higher: Results from a State Scorecard on Health Systems Performance.” *The Commonwealth Fund*. June 2007. Accessed April 2014. <http://www.commonwealthfund.org/Publications/Fund-Reports/2007/Jun/Aiming-Higher-Results-from-a-State-Scorecard-on-Health-System-Performance.aspx>

²⁸ “Health Coverage and Uninsured.” *Kaiser Family Foundation*. Accessed April 2014 <http://www.statehealthfacts.org/comparecat.jsp?cat=3&rgn=6&rgn=1>; Holahan J. and Blumberg L. How Would States Be Affected By Health Reform? (Urban Institute, January 2010).

²⁹ Heckman, TG et al. Barriers to Care Among Persons with HIV/AIDS in urban and rural areas (National AIDS Strategy: AIDS Care, 1998).

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Naturally this creates multiple barriers to accessing health care for all people living in this region, including people living with HIV/AIDS. These barriers are further exacerbated by the sprawling rural geography in the region. Although the South is home to several major metropolitan cities, the majority of the region is still largely rural, with limited medical facilities and treatment providers.

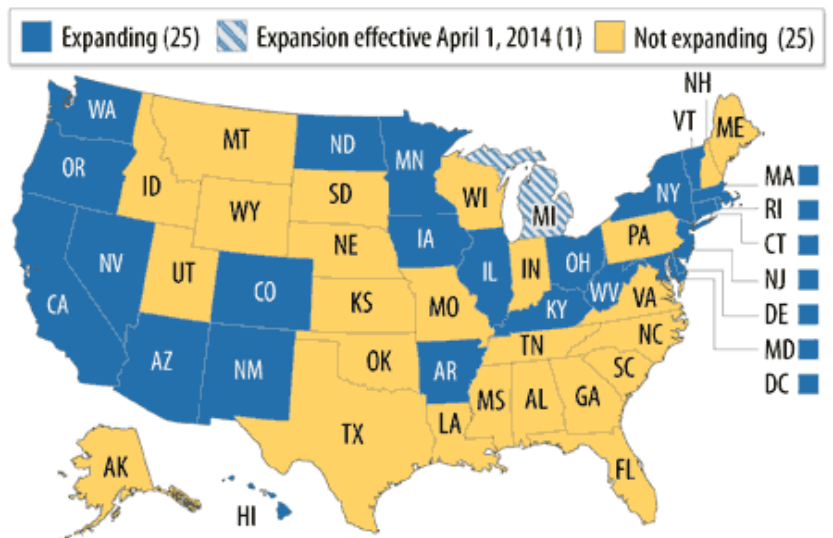
Many of the most economically disadvantaged HIV/AIDS patients in the South have only two options when seeking health care: Medicaid and Ryan White.

Medicaid is a joint state-federal government insurance program designed to assist low-income individuals without health insurance. However, states set their own rules with regard to who is eligible to receive Medicaid and what services they will provide. The southern states have some of the strictest Medicaid income eligibility requirements and some of the most limited benefits in the nation. Recent reports from the State Health Care Access Research Project (SHARP) at Harvard Law School found that Medicaid benefit limitations in North Carolina, South Carolina, Alabama, Mississippi, and Arkansas created significant barriers to medical and mental health care for people living with HIV/AIDS.³⁰ The SHARP report went on to say this about the state of HIV/AIDS in Alabama:

“A lack of sufficient investment in the Medicaid program leads to many missed opportunities to provide adequate Medicaid coverage for people living with HIV and AIDS in Alabama. The failure to adequately invest in the Alabama Medicaid program also results in a failure to maximize matching federal funding to support a comprehensive health safety net for low income people living with HIV and AIDS.”³¹

The Affordable Care Act could potentially expand eligibility for Medicaid to all persons living at or below 133 percent of the federal poverty level. This will specifically benefit people living with HIV/AIDS, particularly in the South, the region where the highest numbers of people will become newly eligible.³² However, it is important to note that Medicaid eligibility expansion will be decided on a state-by-state basis. Meaning each state will decide if they will accept the federal dollars to expand their Medicaid programs. As of May 2014, there are 24 states that are refusing to accept the federal funds to expand Medicaid eligibility. As is detailed in the graphic below, this includes every southern state with the exception of Arkansas.

25 States Have Not Adopted Health Reform’s Medicaid Expansion



Source: CBPP analysis

Center on Budget and Policy Priorities | cbpp.org

(Source: Center on Budget and Policy Priorities, 2014)

³⁰ “Alabama State Report” SHARP, “Arkansas State Report” SHARP, “North Carolina State Report” SHARP. *Health Law and Policy Clinic of Harvard Law School, State Healthcare Access Research Project (SHARP)*. July 2010.

³¹ “Alabama State Report,” SHARP, Executive Summary. July 2010.

³² Holahan J. and Blumberg L., “How Would States Be Affected By Health Reform?” *Urban Institute*, January 2010.

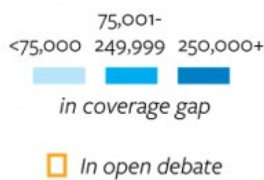
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Unfortunately for low-income individuals living with HIV/AIDS in these states, many will fall into coverage gaps, meaning they will be too poor to qualify for subsidies for insurance plans in the Marketplace exchange and not poor enough to qualify for Medicaid. These gaps will dominate the southeastern U.S. as detailed in the graphic below.

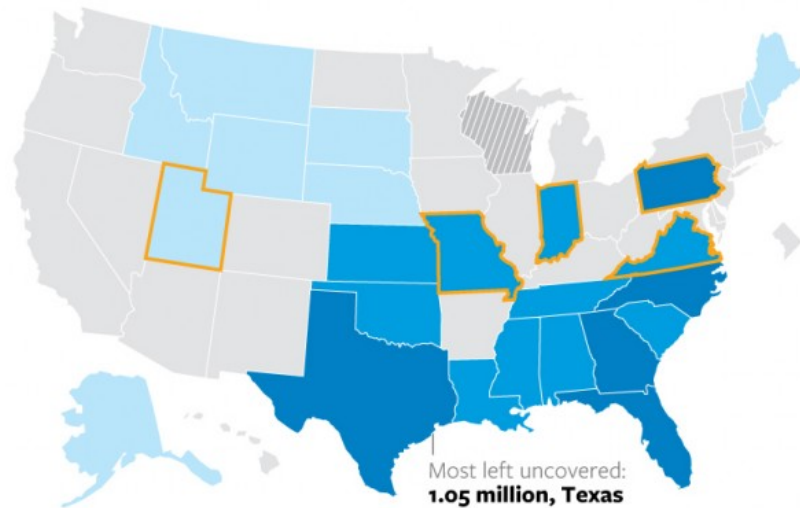
Where the Medicaid Gap Is Biggest

Twenty-five states are either in open debate or not moving forward with Medicaid expansion due to opposition to the Affordable Care Act. This leaves more than 4.8 million Americans without health insurance.



NOTE: Wisconsin has not adopted Medicaid expansion; however, the state provides Medicaid coverage to adults up to 100% federal poverty level.

Number of Poor Uninsured Nonelderly Adults in the ACA Coverage Gap, by State



Source: Kaiser Family Foundation

(Source: Kaiser Family Foundation, 2014)

The South and the AIDS Drug Assistance Program

For these uninsured southerners, Ryan White programs such as ADAPs are the only option for reliable medical coverage. ADAPs are funded with federal dollars channeled through the Ryan White CARE Act and voluntary state funding. Each state determines how much, if any, additional money they will provide to the program. Additionally, states have a large deal of discretion with regard to eligibility requirements and benefits provided.

Nationally states contribute an estimated 14% to the total ADAP budget.³³ However, southern states have historically contributed lower than average or not at all. Arkansas, Louisiana, Mississippi, and Kentucky have never contributed any state funds to the ADAP programs. In 2009, South Carolina contributed 11% and Florida contributed only 9%. The recent economic recession and subsequent rises in unemployment rates has increased the demand for ADAP services. Unfortunately the recession also has resulted in deeper budget cuts in southern states. The state of North Carolina saw their ADAP budget cut by \$8 million in the fiscal years 2014-15.³⁴ The funding cuts to ADAPs in the South have resulted in caps on enrollment and cost-containing measures.

³³ "Southern Exposure: Human rights and HIV in the southern United States." *Human Rights Watch*. November 2010. Accessed April 2014. http://www.hrw.org/news/2010/11/26/southern-exposure#_Lack_of_Access

³⁴ Equality North Carolina. "Take action: Governor's proposed budget makes cuts to state AIDS treatment program." Accessed April 23, 2014. http://equalitync.org/latest/news/governor_proposed_budget_makes_cuts_to_nc_aids_treatment_program/

State-level enrollment caps in ADAPs have led to program and medication waiting lists in multiple states. In November 2010, 3,811 people were on ADAP waiting lists, 90% of those people were in the South (Florida, North Carolina, Georgia, South Carolina, and Louisiana).³⁵ In 2009 there were 2,043 people on waiting lists in Florida alone, 53% of the waiting list nationally.³⁶ In 2006, at least two people died of complications related to AIDS while on ADAP waiting lists.³⁷ That year South Carolina contributed to their state ADAP for the first time in history. In November 2010, there were still 239 people on waiting lists in the state. The problem persists event today. According to the National Alliance of State & Territorial AIDS Directors (NASTAD), there are currently twelve people in the U.S. on ADAP waiting lists (as of April 8, 2014).³⁸ While this is welcome news for all, there is concern that waiting lists may re-emerge as a result of state budget cuts, lack of Medicaid eligibility expansion, and unintended consequences of the Affordable Care Act.

While ADAP waiting lists have been drastically reduced, other cost-saving measures are still very much in place, many in the South. Reducing medication formularies is a tactic employed by states to save money when facing budget constraints. It involves decreasing the amounts or downgrading the types of medications covered by the program. This method, though utilized nationally by many ADAPs, is very common in the South. For example, North Carolina reduced its formulary in 2009, taking many medications off the list of medications covered by their program. Mississippi has reduced their formulary to the extent that clients may only have up to five medications covered, despite the fact that many people living with HIV/AIDS are prescribed much larger medication regimens.³⁹

Enrollment caps and reduced formularies aren't the only ways in which states cut costs. Many states, especially in the South, have lowered financial eligibility requirements, which are tied to the federal poverty level. In the past, Arkansas lowered its requirements from 500% FPL to 200% FPL. South Carolina lowered its requirements from 550% to 300% FPL. Alabama has a requirement between 250-299%.⁴⁰ These represent below average financial eligibility requirements but allow for a reduced number of clients enrolled in state programs. Expenditure caps are another method of cost-containment. This is a limit on monthly or annual spending on drugs per client. Finally, client cost-sharing is sometimes used by states. This is a requirement that clients contribute a portion of their drug costs.⁴¹ These methods of cost-saving are also commonly found in the southern states.

The Future of the AIDS Drug Assistance Programs in the South

So what does this mean for the South? HIV/AIDS incidents and new cases of infections have reached an alarming rate in the South. Social factors and imprudent policies, combined with inadequate access to healthcare have created ideal conditions for this epidemic to flourish in the South. However, there are encouraging strides being made to remedy this desperate situation.

³⁵ "The ADAP Watch," NASTAD. November 11, 2010.

³⁶ ADAP Annual Report. NASTAD. 2010.

³⁷ "Southern Exposure: Human rights and HIV in the southern United States." *Human Rights Watch*. Interview with Noreen O'Donnell, Ryan White administrator for the South Carolina Department of Health and Environmental Control, Columbia, South Carolina June 17, 2010. November 2010. Accessed April 2014. http://www.hrw.org/news/2010/11/26/southern-exposure#_Lack_of_Access

³⁸ "ADAP Advocacy Association Releases 2013 Annual Report; Accomplishments tempered by return of more ADAP waiting lists." *ADAP Advocacy Association*. April 8, 2014. Accessed April 2014. <http://www.adapadvocacyassociation.org/pressroom.html>

³⁹ "Medicaid Benefits Database, Mississippi." *Kaiser Family Foundation*. Accessed April 2014. <http://medicaidbenefits.kff.org/state.jsp?nt=on&cat=0&yr=0&st=25>

⁴⁰ "2011 Annual Report." NASTAD. 2011

⁴¹ Clary, Ryan, Friedman, Michael & Lefert, Ann: AIDS Drug Assistance Programs: Utilization, Program Restrictions and Waiting Lists. (Project Inform & National Alliance of State and Territorial AIDS Directors. 2010)

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The National AIDS Strategy has committed to redirecting federal HIV funding to the region.⁴² This ambitious program, launched in 2010 by President Obama, takes a comprehensive approach to addressing HIV/AIDS in the U.S. The program's goal is to reduce HIV infections by increasing access to healthcare and reducing HIV-related disparities.⁴³ It seeks to do this through the collaboration of federal, state, and local organizations and stakeholders. The increased allocation of funds directed at the South will likely help to combat the complex problem with HIV/AIDS in the South.

Furthermore, President Obama's fiscal year 2015 budget proposal, released in March 2014, calls for an additional \$4 million in Ryan White Care program funding for a total of \$2.3 billion. This increase is optimistic, though Part B of Ryan White was flat funded at a continued amount of \$900 million.⁴⁴ While many view the proposed increase as a positive step in the right direction, there is concern that the continued flat funding of ADAPs will be detrimental. Many advocacy groups assess the need as being approximately \$189 million more than the current funding. Nowhere is that need more apparent than in the southern states.

This year's ACA rollout has seen its share of contention. While the implementation has been highly contested, this monumental piece of legislation has been mostly successful in contributing to the fight against HIV/AIDS. The ACA has been effective at enrolling many people living with HIV/AIDS in Marketplace Exchange insurance plans. Additionally, the federal funding offered to the states to expand their Medicaid programs has assisted low-income people living with HIV/AIDS in gaining insurance coverage.⁴⁵ However, there is concern over how the ACA implementation will play out and how it will affect state ADAPs. These concerns revolve around unintended consequences of the law including barriers to and gaps in coverage. In addition, many are worried as to what will be offered or covered by the ACA with regard to HIV/AIDS services. It is for these reasons that stakeholders in the fight against HIV/AIDS should exercise caution and remain vigilant as the ACA continues to unfold.

In an age of austerity where many federal assistance programs are coming under fire there is grave concern for the future of the Ryan White CARE Act. This concern is associated with the ACA and the fear that lawmakers may feel compelled to reduce, if not defund, Ryan White due to the belief that the ACA will take care of low-income people living with HIV/AIDS through Marketplace Exchange insurance plans and expanded Medicaid programs. This apprehension is warranted as many stakeholders agree that Ryan White and ADAPs are critical to ensuring access to healthcare for people living with HIV/AIDS, despite the ACA's implementation. It is likely that reducing Ryan White funding will serve only to exacerbate issues in access to care, especially in the southern states that are choosing not to expand their Medicaid programs.

These are just a few of the larger issues facing the future of ADAPs in the South. While much progress is being made in the form of redirecting funding and creating better access to care, there is also cause for trepidation related to HIV/AIDS incidents in the South. Stakeholders in this matter should keep a watchful eye on the policies and funding moving forward.

⁴² "Southern Exposure: Human rights and HIV in the southern United States." *Human Rights Watch*. November 2010. Accessed April 2014.

http://www.hrw.org/news/2010/11/26/southern-exposure#_Lack_of_Access

⁴³ "National HIV/AIDS Strategy : Implementation Progress." *AIDS.gov*. Accessed May 2014. <http://aids.gov/federal-resources/national-hiv-aids-strategy/implementation-progress/index.html>

⁴⁴ Nunn, Anna M. "President Obama's FY15 Budget Offers Promise & Dismay." Web log post. ADAP Advocacy Association. N.p. 20 Mar. 2014. Web. Apr. 2014. <http://adapadvocacyassociation.blogspot.com/2014/03/president-obamas-fy15-budget-offers>

⁴⁵ Nunn, Anna M. "Keeping a Watchful Eye on ACA Implementation, and ADAPs." Web log post. ADAP Advocacy Association. N.p. 13 Feb. 2014. Web. Apr. 2014. <http://adapadvocacyassociation.blogspot.com/2014/02/keeping-watchful-eye-on-aca.html>

12 THE SOUTHERN EPIDEMIC

Are the South's cultural, political and societal barriers making it difficult for the AIDS Drug Assistance Programs to function effectively in this region?

Summary

The South is an interesting and complex region with regard to HIV/AIDS. The region's unique social fabric, historical influences, cultural conservatism, economic disparities, and rural geography have all fueled a growing public health crisis: **a lack of access to healthcare**. These regional factors collided with the previous "Perfect Storm" that ravaged the AIDS Drug Assistance Program, all contributing to people living with HIV/AIDS in the South having to confront disproportionately unfavorable circumstances. At no point in recent years was it more evident than thousands of people living with HIV/AIDS being forced to access their life-saving medications, with nearly 95% of those patients residing in the South. Race and discrimination, poverty and failing education systems, and sexuality-oriented stigma are instrumental in the fueling the Southern HIV/AIDS epidemic. An additional underlying obstruction to reducing HIV/AIDS in the South is the overwhelming lack of access to insurance coverage and health care, specifically access to medical providers who specialize in HIV/AIDS care. There is optimism that the Affordable Care Act will ease some of barriers to healthcare, but it is still far too early to tell exactly what will be the impact of the ACA. This is especially true for the South, as the large majority of these states have chosen not to expand their Medicaid programs.

While ADAP waiting lists have drastically declined in recent years, there is apprehension that the waiting lists will return, especially in the South where ADAP funding is already low and budgets are being slashed. In addition to the anxiety surrounding waiting lists, there is concern over the rise of cost-containing measures being implemented, particularly in the South. There is reason for hope, however, as awareness about the HIV/AIDS crisis in this region is gaining national attention. President Obama's commitment to fighting disease through the National AIDS Strategy is cause for optimism. The collaboration between federal, state, and local organizations and government agencies is making strides in the HIV/AIDS community. However, much more work remains to be done because people living with HIV/AIDS continue to face significant barriers to healthcare in the South.

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