



Southern AIDS Coalition

Southern States Manifesto: Update 2012
Policy Brief and Recommendations

Southern AIDS Coalition
P.O. Box 55703
Birmingham, AL 35255
www.SouthernAIDSCoalition.org



Letter from SAC

The Southern States Manifesto: Update 2012 is released during a unique time in our country. Since the release of the *Southern States Manifesto: Update 2008*, the Southern AIDS Coalition (SAC) has witnessed historic progress in addressing the HIV/AIDS epidemic in the South and in the nation. Examples of this historic movement include the enactment of the Patient Protection and Affordable Care Act, the implementation of the first ever National HIV/AIDS Strategy (NHAS), the HIV Prevention Trials Network 052 that indicated the importance of adherence as a means of stopping transmission, and a historic change in the HIV prevention funding formula so that funds are based on living HIV cases rather than AIDS data. In recent months, the South has experienced continued progress with the announcement that \$14 million annually will be allocated to focus on health disparities and outcomes in the South and other highly impacted areas. This Funding Opportunity Announcement from the Department of Health and Human Services is directed to state health departments with at least 25% of the funding going to community-based organizations. Through this initiative, SAC feels that our voice and the voices of our many partners and other advocates have finally been heard.

Despite historic progress, the southern United States continues to face great challenges. The South has the most people living with HIV and AIDS, the greatest poverty, the highest rates of sexually transmitted infections (STIs), the greatest number of people without health insurance, the least access to health care, the highest mortality rates, and the fastest growing epidemic in the nation. These statistics are fueled by a number of underlying factors, including stigma, discrimination, racial and ethnic disparities, aggressive homophobia, and poor social determinants. The need in the South is apparent. The numbers are clear. We must take the next steps in identifying opportunities, creating interventions, and coordinating our efforts so that funds and other resources are used in the best ways possible.

Targeting the HIV/AIDS epidemic in the South is a vital component to winning the national fight against AIDS and achieving the goals of NHAS. The Southern AIDS Coalition is dedicated to this cause, and there is still a great deal of work to be done. SAC must continue to educate and mobilize stakeholders across the South to respond to the many changes occurring in HIV health care. SAC also wishes to offer our partnership and collaboration in determining how new southern funds can be equitably and fairly distributed. We need your continued support in these efforts and ask that you join us in this quest. Through collective efforts, we can stem the growing HIV epidemic in the South.

-----*Southern AIDS Coalition Board of Directors*

Manifesto: a public declaration of principles, policies, or intentions, especially of a political nature.

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Jared Barras, Acadiana C.A.R.E.S.

Nic Carlisle, JD, AIDS Alabama, Inc.

Kathie Hiers, AIDS Alabama, Inc.

Sigga Jagne, MPA, Kentucky Department of Public Health

Amy Killelea, JD, Harvard Law School Center for Health Law and Policy
Innovation/Treatment Access Expansion Project

Robin Lewy, MA, Rural Women's Health Project/Voices of Immigrants in
Action

Butch McKay, Okaloosa AIDS Support & Informational Services, Inc.

Fran Ricardo, Rural Women's Health Project/Voices of Immigrants in Action

Skip Rosenthal, International AIDS Empowerment

Carl Schmid, The AIDS Institute

Cathalene Teahan, RN, MSN, CNS, Georgia AIDS Coalition, Inc.

Robin Webb, PhD, A Brave New Day

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I. Introduction

A. Overview of HIV/AIDS in the U.S.

Over thirty years ago, the first cases of human immunodeficiency virus (HIV) were found and reported by the U.S. Centers for Disease Control and Prevention (CDC). Since then, over 1.7 million people in the U.S. are estimated to have been infected with HIV, including over 600,000 who have already died and more than 1.1 million are estimated to be currently living with the disease.¹ While the response to the U.S. epidemic has yielded numerous successes, great challenges still remain. One monumental success was the announcement of the first *National HIV/AIDS Strategy* (NHAS) in July 2010. The strategy outlines three goals: (1) reduce the number of people who become infected with HIV, (2) increase access to care and improve outcomes for people living with HIV, and (3) reduce HIV-related health disparities. Although the *National HIV/AIDS Strategy* is the first national strategic plan to stem the HIV/AIDS epidemic, many gaps and challenges still exist, especially as it pertains to HIV/AIDS in the southern United States. With the southern region of the United States experiencing the highest HIV infection and mortality rates in country, targeting the disease in the South is a vital component in achieving the goals of NHAS.

B. HIV/AIDS in the South

Newly Diagnosed HIV and AIDS Cases

According to surveillance data by the CDC, the southern region of the United States has a significant disproportionate impact of the incidence and prevalence of HIV.² While the southern region of the United States accounts for only 37% of the population, it accounts for approximately 50% of new HIV infections. The incidence, or rate of new HIV infections per 100,000, in the South is the highest of any region at 22.3. The South is followed by the Northeast with a rate of 19.6/100,000 and double that of the West (10.9/100,000) and Midwest (10.0/100,000).³ Additionally, out of the ten states with the highest rates of HIV infections, eight were in the South (Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas).

The CDC also tracks new diagnoses of AIDS. HIV-positive individuals are diagnosed with AIDS if their disease meets certain diagnostic criteria set by the CDC, determined either by a CD4 test or the presence of specific AIDS-defining medical conditions. The South accounted for approximately 46% of new AIDS diagnoses in 2010,⁴ and has the second highest AIDS diagnoses rate per 100,000 (13.0). The Northeast has the highest rate at 14.2; the West and Midwest were nearly half that rate at 8.8 and 6.3 respectively. AIDS diagnoses, which

| Top Ten States by HIV Diagnosis Rate per 100,000 | |
|---|----------------------------|
| State | HIV Diagnosis Rate 2010 |
| Florida | 33.0 |
| Georgia | 32.9 |
| New York | 29.5 |
| Louisiana | 28.8 |
| New Jersey | 22.8 |
| Mississippi | 21.3 |
| South Carolina | 19.9 |
| North Carolina | 19.7 |
| Texas | 18.4 |
| Tennessee | 17.2 |
| U.S. Diagnosis Rate | 17.4 |

Source: CDC HIV Surveillance Data, 2010.

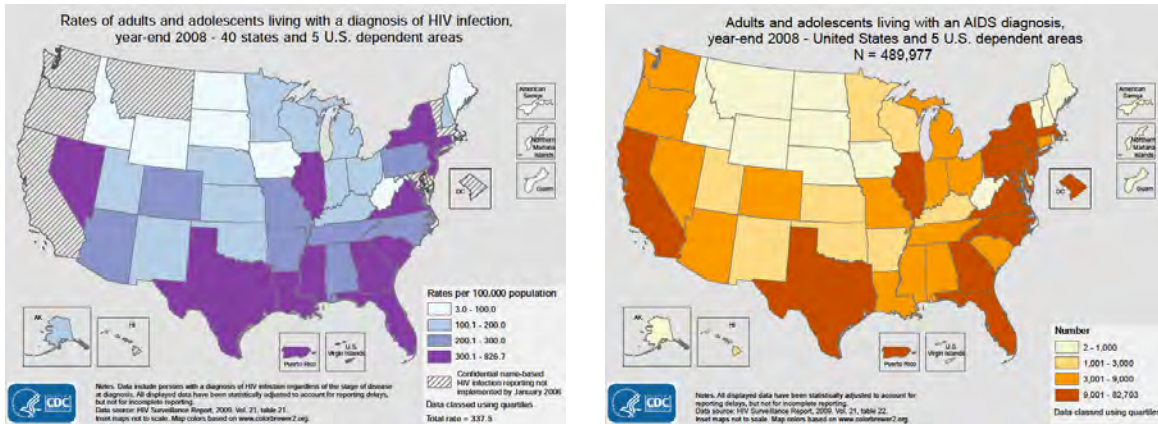
¹ The Kaiser Family Foundation, Fact Sheet. *The HIV/AIDS Epidemic in the United States*. www.kff.org/hivaids/upload/3029-13.pdf. Published March 2012. Accessed April 2012.

² Centers for Disease Control and Prevention. *HIV Surveillance Report, 2010*; vol. 22 at 14. www.cdc.gov/hiv/surveillance/resources/reports/2010report/pdf/2010_HIV_Surveillance_Report_vol_22.pdf. Published March 2012. Accessed April 2012.

³ Duke Center for Health Policy and Inequalities Research (CHPIR), Duke University, Southern HIV/AIDS Strategy Initiative. *HIV/AIDS Epidemic in the South Reaches Crisis Proportions in Last Decade* at 7. <http://globalhealth.duke.edu/news/2011/ResearchReportFinal3-12.pdf>. Published 2011. Accessed April 2012.

⁴ Kaiser, *HIV/AIDS in the U.S.* at para. 3.

provide a different measure of the epidemic's impact, reflect the concentration of diagnoses after adjusting for differences in population size across jurisdictions.⁵ Seven of the ten areas with the highest rates of AIDS diagnoses are in the South (Delaware, District of Columbia, Florida, Louisiana, Maryland, Mississippi, and South Carolina).⁶

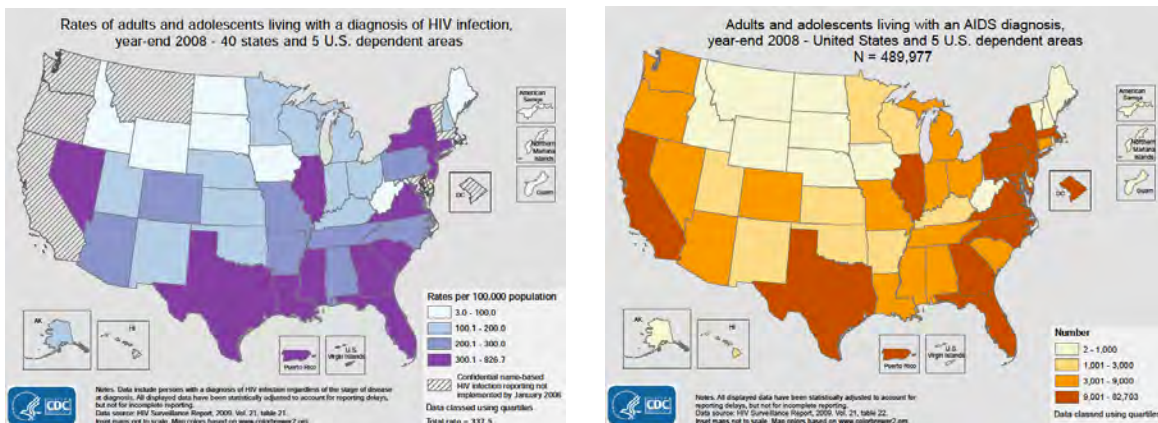


Source: CDC, Maps Based on Data from 2009 HIV Surveillance Report.

People Living with HIV/AIDS

The southern U.S. has some of the highest numbers of people estimated to be living with HIV and AIDS.⁷ The Northeastern region historically has the highest HIV prevalence rates (501/100,000) largely attributable to the high prevalence rates in New York and New Jersey, areas "...where the epidemic began and where people have been living with the disease for long periods of time."⁸ According to CDC HIV prevalence data, 43% of people living with HIV reside in the southern U.S.,⁹ while the South only comprises 37% of the U.S. population. Of the forty states that have CDC HIV prevalence estimates, seven of the ten states with the highest HIV prevalence rates are located in the southern region (Florida, Georgia, Louisiana, Mississippi, South Carolina, Texas, and Virginia).¹⁰

The southern states and the District of Columbia represent six of the ten jurisdictions with the highest AIDS prevalence rates.¹¹ While AIDS prevalence is highest in the Northeastern region, approximately 40% of people with AIDS live in the southern United States.



Source: CDC, Maps Based on Data from 2009 HIV Surveillance Report.

⁵ Kaiser, *HIV/AIDS in the U.S.* at para. 3.

⁶ *HIV Surveillance Report* at 65.

⁷ Kaiser, *HIV/AIDS in the U.S.* at para. 3.

⁸ *HIV/AIDS Epidemic in the South Reaches Crisis Proportions* at 9.

⁹ *HIV/AIDS Surveillance Report* at 66,67.

¹⁰ *HIV/AIDS Epidemic in the South Reaches Crisis Proportions* at 9

¹¹ *Id.* at 2.

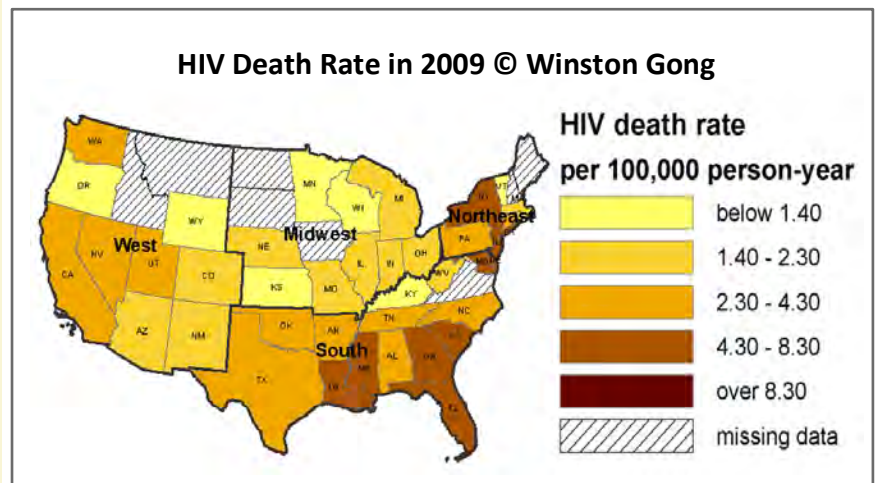
Key Snapshot of the Southern Epidemic:

The South has 37% of the country's population but:

- 50% of new HIV diagnoses (the highest proportion of any region);
- 46% of new AIDS diagnoses;
- 43% of all people with HIV;
- 8 of the 10 states with the highest HIV infection rates;
- 8 of the 10 states with the highest new AIDS diagnoses;
- 8 of the 10 states with the highest HIV death rates per 100,000;
- 9 of the 10 states with the highest HIV fatality rates;
- A greater HIV and AIDS prevalence by nearly 50% compared to the next closest region;
- 9 of the top 10 Metropolitan Statistical Area AIDS case rates.

HIV/AIDS Disease Outcomes

The southern region is also plagued by some of the highest mortality rates for HIV/AIDS. According to the Duke Center for Health and Inequalities Research, data on deaths among individuals with HIV that occurred from 2001-2007 indicated that nine of the ten states with the highest age-adjusted HIV case fatality rates (the number of deaths due to HIV among individuals with HIV) were located in the South (Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, and Tennessee).¹² These findings suggest that many southerners do not discover their HIV status until they are too sick to benefit fully from available treatments.



Source: Duke Center for Health Policy and Inequalities Research (CHPIR), Southern HIV/AIDS Strategy Initiative, 2011.

Demographics

Racial and ethnic minorities represent the majority of new HIV infections, AIDS diagnoses, AIDS deaths, and people living with HIV/AIDS.¹³ According to CDC data, Blacks comprise

approximately 56% of people living with HIV/AIDS (PLWHA) in the South.¹⁴ Ten states account for 71% of Blacks estimated to be living with AIDS and 66% of new AIDS diagnoses. These states are concentrated in the South with Georgia and Florida in the top three.¹⁵ In 2010, the rate of new HIV infections in Blacks was about eight times that of whites, and the AIDS diagnoses rate was even more disparate as it was ten times greater among Blacks than that of whites.¹⁶ In 2008, Blacks comprised 56% of deaths due to HIV and 13% of HIV deaths were Latinos.¹⁷ Blacks also have the lowest survival rate and the highest age-adjusted death rate due to HIV disease.¹⁸ For Black men and women between the ages of twenty-five

¹² Reif, S, et al. Southern HIV/AIDS strategy Initiative (SASI), Duke Center for Health Policy and Inequality Research. *HIV/AIDS Epidemic in the South Reaches Crisis Proportions in the Last decade*. (December 2011).

¹³ Kaiser, *HIV/AIDS in the U.S.* at para. 4.

¹⁴ *HIV Surveillance Report* at 66-69.

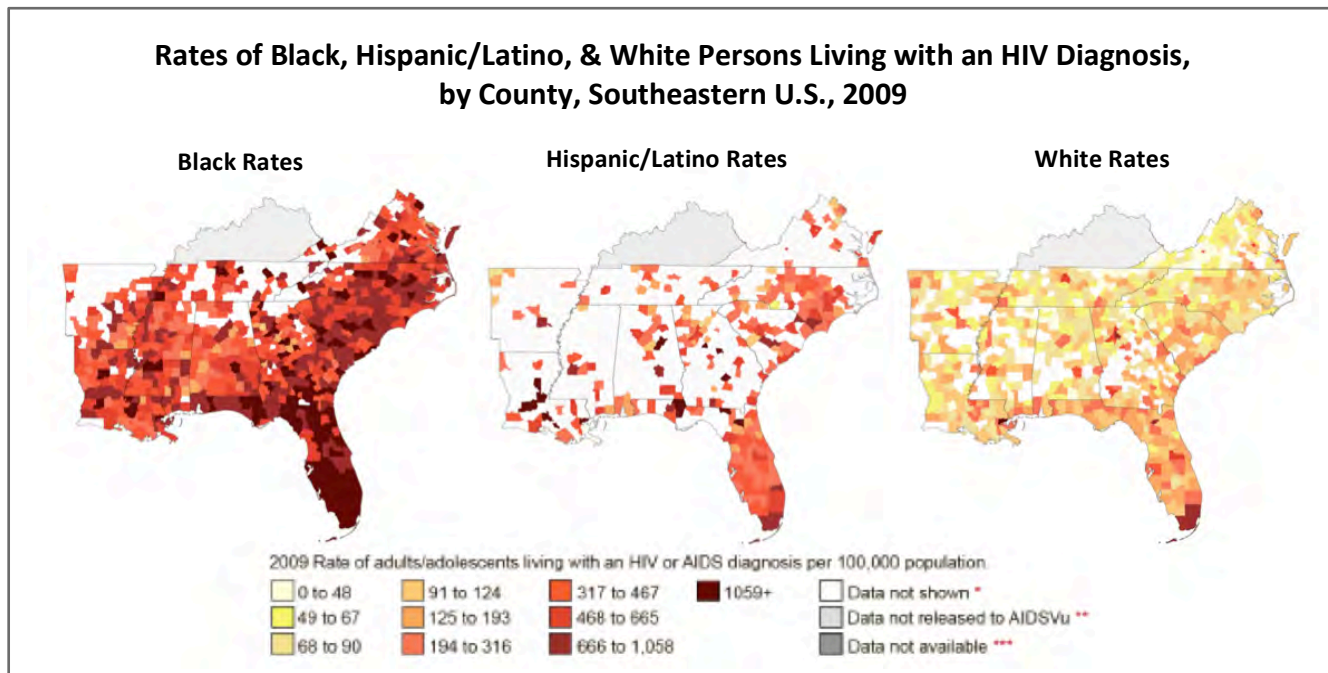
¹⁵ The Kaiser Family Foundation, Fact Sheet. *Black Americans and HIV/AIDS*. www.kff.org/hiv/aids/upload/6089-10.pdf. Published March 2012. Accessed April 2012.

¹⁶ Kaiser, *HIV/AIDS in the U.S.* at para. 4.

¹⁷ *Id.* at para. 4.

¹⁸ *Id.* at para. 4.

and forty-four, HIV was the fourth-leading cause of death in 2008.¹⁹ Additionally, the South accounts for more overall Latino population growth than any other region. Of new HIV diagnoses among Latinos in the United States, 50% were in the South.²⁰



Source: AIDSvu, Illustrating HIV/AIDS in the United States, 2012 Update.

Men have historically represented the majority of new HIV infections and AIDS diagnoses, and they still comprise this majority; however, the impact on women has continued to grow since the beginning of the epidemic.²¹ In 2010, the southern region had more new AIDS diagnoses among women (4,100) than all the other regions combined (Midwest at 853, North at 2,221, and West at 748).²² Women of racial and ethnic minorities, particularly Black women, have been hardest hit by this trend and represent the majority of new HIV infections and AIDS diagnoses among women.²³ Black women accounted for 64% of new AIDS diagnoses among women, followed by Latinas at 17% and white women at 15% in 2010.²⁴ In the South, 71% of women diagnosed with HIV are Black. HIV and AIDS diagnoses are highest in the Northeast and the South.²⁵ The District of Columbia HIV/AIDS diagnoses rate, 79.9 per 100,000, is approximately twelve times the national rate for women.²⁶ Out of the states with the highest number of women living with AIDS, four of the ten states are in the South (Florida, Georgia, Maryland, and Texas).²⁷

HIV and AIDS also particularly affect young persons between the ages of fifteen and twenty-nine. In 2009, this age group accounted for 39% of new HIV infections (the largest share of any age group), yet

¹⁹ *Id.* at para. 4.

²⁰ McAllaster, Carolyn. *The Southern HIV/AIDS Strategy Initiative (SASI): Focusing White House Attention on the HIV Epidemic in the South*. Webinar. Farmworker's Justice. June 13, 2012. Accessed June 13, 2012. www.farmworkers-justice-webinar-presentation1.pdf

²¹ The Kaiser Family Foundation, Fact Sheet. *Women and HIV in the United States*. www.kff.org/hiv/aids/upload/6092-10.pdf. Published March 2012. Accessed May 2012.

²² CDC, *HIV Surveillance in Women* at slide 15 (2010). www.cdc.gov/hiv/topics/surveillance/resources/slides/women/slides/Women.pdf. Accessed July 2012.

²³ *Id.* At para. 1.

²⁴ Kaiser, *HIV/AIDS in the U.S.* at para. 5.

²⁵ *HIV and Women* at para. 6.

²⁶ *Id.* at para. 6.

²⁷ *Id.* at Figure 3.

this group only accounted for 21% of the U.S. population.²⁸ “Undiagnosed HIV cases are also thought to be highest among young people.”²⁹ The CDC estimates that over half of all undiagnosed HIV infections are among youth ages thirteen to twenty-four.³⁰ Among young people, minorities have been largely affected as Black teens represent 70% of new AIDS diagnoses followed by Latinos at 19%.³¹ Additionally, almost 80% of all adolescent HIV infections are among males with nine out of ten male HIV infections resulting from male-to-male sexual contact.³² The same proportion of youth females are infected from heterosexual contact. Of adolescent HIV diagnoses, the highest concentrations are found in the southeastern United States, specifically in Florida, Louisiana, and South Carolina.³³

Gay and bisexual men and other men who have sex with men (MSM) “...continue to be the risk group most severely affected by HIV.”³⁴ The most recent CDC data show an increase in the number of new infections that occur each year among youth MSM, driven largely by an alarming 48% increase among young, Black MSM between the ages of thirteen and twenty-nine.³⁵ While MSM account for only about 2% of the population and 4% of men in the U.S., they account for nearly half of people living with HIV, more than half of all new HIV infections in the U.S. each year (61%), and a rate of HIV infection forty-four times that of other men.³⁶

Injection drug users (IDUs) also continue to be affected by HIV. In 2009, IDUs represented 9% of new HIV infections and 17% of those living with HIV in 2008.³⁷ Since the beginning of the epidemic, more than 175,000 IDUs with AIDS have died, including 4,759 in 2009.³⁸ Among males, approximately 8% of diagnosed HIV infections are attributed to injection drug use and 4% are attributed to male-to-male sexual contact and injection drug use.³⁹ Among females, 15% of diagnosed HIV infections are attributed to injection drug use.⁴⁰ Among male injection drug users, approximately 50% are Black, 30% Latino, and 17% white. For female IDUs, an estimated 54% are Black, 26% white, and 18% Latina.⁴¹

Contributing Factors to HIV/AIDS Health Disparities in the South

Despite prevention efforts, HIV/AIDS, viral hepatitis, STIs, and tuberculosis (TB) affect some groups of people more than others. The occurrence of these diseases at higher levels among certain population segments more than other groups is often referred to as a “health disparity.”⁴² Disparities may occur by

²⁸ Centers for Disease Control and Prevention, National Center for HIV/AIDS, Fact Sheet. *HIV among Youth*. <http://www.cdc.gov/hiv/youth/>. Published December 2011. Accessed April 2012.

²⁹ U.S. Department of Health & Human Services, Office of Adolescent Health. *Adolescent Health Insider: Teens and the HIV/AIDS Epidemic*. <http://www.hhs.gov/ash/oah/news/e-updates/june-2012.html>. Published June 2012. Accessed June 2012.

³⁰ Centers for Disease Control and Prevention. *HIV Surveillance – United States – 1981 – 2008*. MMWR 2011, 689-693. www.cdc.gov/mmwr/pdf/wk/mm6021.pdf. Accessed May 2012.

³¹ Kaiser, *HIV/AIDS in the U.S.* at para. 5.

³² *Teens and the HIV/AIDS Epidemic* at para. 2.

³³ Centers for Disease Control and Prevention. (2012) *Slideshow: HIV surveillance in adolescents and young adults*. www.cdc.gov/hiv/topics/surveillance/resources/slides/adolescents/slides/Adolescents.pdf. Accessed May 2012.

³⁴ Centers for Disease Control and Prevention, CDC Fact Sheet. *HIV and AIDS among Gay and Bisexual Men*. www.cdc.gov/nchhstp/newsroom/.../fastfacts-msm-final508comp.pdf. Published September 2011. Accessed May 2012.

³⁵ *Id.* at para. 1.

³⁶ *Id.* at para. 2.

³⁷ Centers for Disease Control and Prevention, *HIV in the United States: At A Glance*.

www.cdc.gov/hiv/resources/factsheets/PDF/HIV_at_a_glance.pdf. Published March 2012. Accessed May 2012.

³⁸ *Id.* at 2.

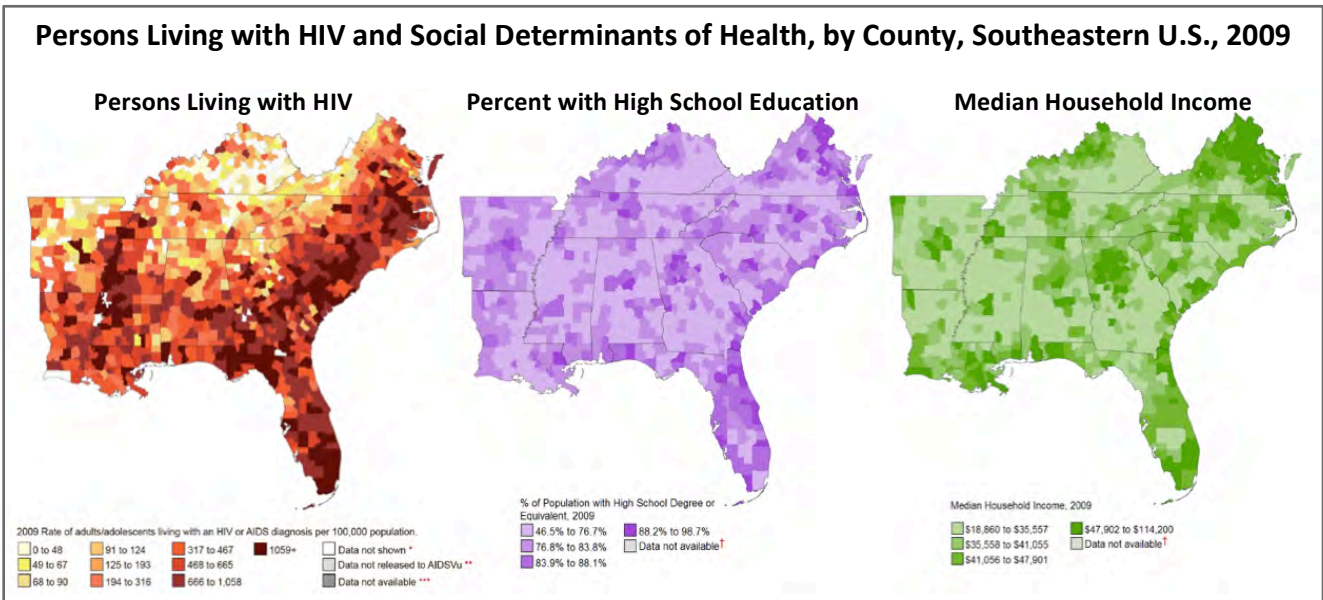
³⁹ Centers for Disease Control and Prevention, *HIV Surveillance in Injection Drug Users (through 2009)* at slide 3. www.cdc.gov/hiv/idu/resources/slides/slides/idu.pdf. Accessed June 2012.

⁴⁰ *Id.* at slide 3.

⁴¹ *Id.* at slide 4.

⁴² Centers for Disease Control and Prevention, (2011). *Disparities in HIV/AIDS, Viral Hepatitis, STDs, and TB*. <http://www.cdc.gov/nchhstp/healthdisparities/>. Accessed May 2012.

gender, race or ethnicity, income, education, sexual orientation, or geographic location among others. Such disparities pose significant costs to society in terms of health care needs and lost productivity.⁴³ Social determinants of health, such as poverty, lack of education, unequal access to health care, stigma, and racism, are linked to health disparities.⁴⁴ For instance, studies show that an HIV-infected person with lower literacy levels typically has less general knowledge about his/her disease and disease management. Additionally, studies show that social determinants of health, such as homelessness, unemployment, and low education level, are interdependently associated with HIV infection.⁴⁵



Source: AIDSvU, Southeastern United States, 2012 Update.

There are numerous environmental factors contributing to the disparate impact of HIV in the South. The legacy of racial segregation and residual racial prejudice combined with homophobia create disparities in HIV and AIDS incidence and prevalence. Additionally, unequal economic and social opportunities for racial, ethnic, and sexual minorities contribute to their disenfranchisement and limited access to opportunities for equitable access to health care and for social change. Racial prejudice, homophobia, poverty, homelessness, unemployment, lack of insurance and access to affordable health care, and substance abuse and mental health challenges are all factors that exceed the national average in the South. The combination of these complex, integrated, and overlapping social and economic factors are linked to a “...lack of opportunity and to a lack of resources to protect, improve, and maintain health.”⁴⁶ According to the Southern HIV/AIDS Strategy Initiative (SASI), the southern states has “...some of the worst overall health rankings in the U.S., as nine of the ten states with the worst health ratings are the in the South.”⁴⁷ Additionally, poverty is consistently found to be a lead contributor to HIV infections.

⁴³ Centers for Disease Control and Prevention. *Establishing a Holistic Framework to Reduce Inequities in HIV, Viral Hepatitis, STDs, and Tuberculosis in the United States*; October 2010. www.cdc.gov/socialdeterminants/docs/SDH-White-Paper-2010.pdf. Accessed May 2012.

⁴⁴ *Id.* at 3.

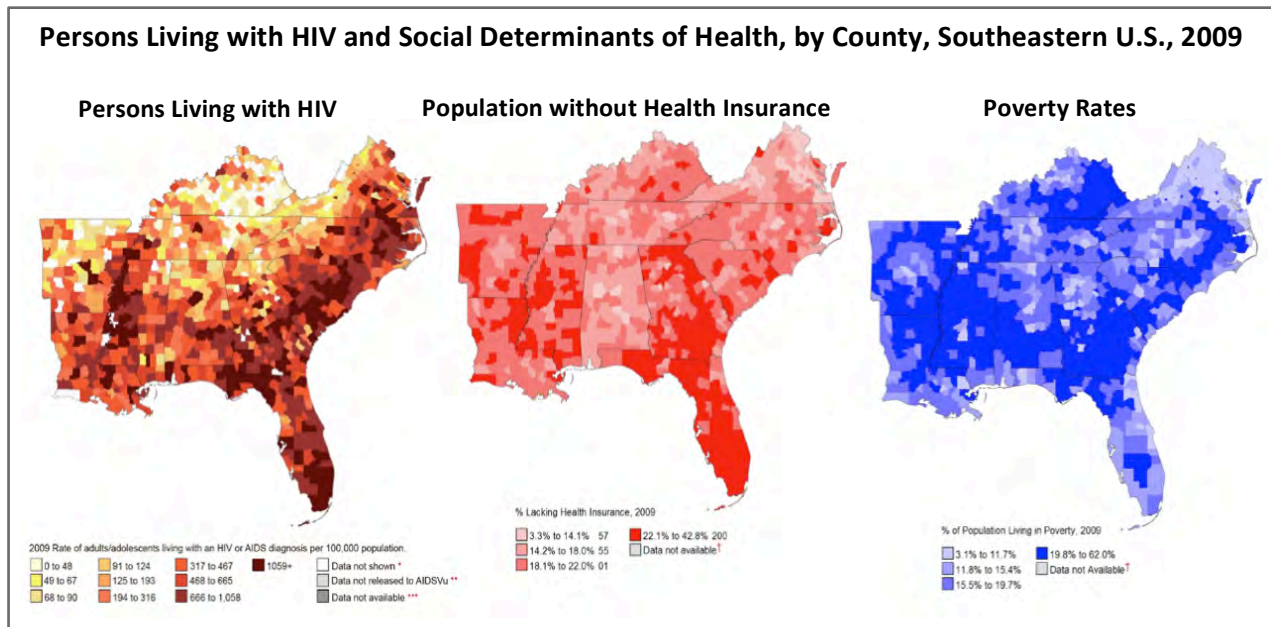
⁴⁵ Denning P, DiNenno E. *Communities in crisis: Is there a generalized HIV epidemic in impoverished urban areas of the United States?* Abstract WEPDD101. XVIII International AIDS Conference, July 18-23, 2010.

⁴⁶ *Establishing a Holistic Framework to Reduce Inequities in HIV* at 3.

⁴⁷ *HIV/AIDS Epidemic in the South Reaches Crisis Proportions* at 4.

Michael Saag, MD, Director of the AIDS Research Clinic at the University of Alabama at Birmingham, told the *Birmingham News*:

*HIV is a disease of poverty. Those who are poor are less likely to be diagnosed, get treatment or stay in 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.*⁴⁸



Source: AIDSvu, Southeastern United States, 2012 Update.

HIV epidemiological and outcomes data clearly indicate a disproportionate impact of HIV in the South. A combination of characteristics, including high poverty rates, lack of access to health care, high rates of uninsured individuals, HIV-related stigma and discrimination, and rural geography, provide partial explanation of the disparate impact of HIV in the southern region. Considering these complex, interrelated social and economic factors is vital to understanding the epidemic in the southern United States and in further formulating strategies to address the crisis of HIV disease in the South.

⁴⁸ Wolfson, Hannah. The Birmingham News. *AIDS risk higher in the South*. http://blog.al.com/spotnews/2012/01/aids_risk_higher_in_the_south.html Published January 14, 2012. Accessed May 2012.

II. Policy Implications for HIV/AIDS in the South

While HIV infection and mortality rates are relatively stable across the United States, they continue to increase in the southern region. Efforts to stem the tide of the U.S. HIV/AIDS epidemic increasingly depend on addressing the driving underlying factors in the southern region. These factors include poverty, homophobia, stigma, discrimination, racial and ethnic disparities, poor social determinants, limited resources, and lack of access to quality care. The Southern AIDS Coalition (SAC) believes that without targeting efforts and directing resources to the root of the epidemic in the southern region, we cannot win the national fight against HIV and AIDS. Through this document, *The Southern States Manifesto: Update 2012*, SAC hopes to bring light and understanding of the current and complex issues associated with HIV in the South by providing an analysis of the following topic areas: Health Care Infrastructure, Ryan White Care Act, Immigration, Housing, Prevention, and Stigma and Criminalization.

A. Health Care Infrastructure (Health Reform)

Systemic challenges involving access to care and health insurance coverage remain a public health crisis for people living with HIV/AIDS (PLWHA) and other chronic conditions in the South. This crisis is characterized by high rates of the uninsured, restrictive Medicaid eligibility rules, and barriers to accessing routine health care. The Ryan White Act has provided an essential lifeline for PLWHA, but funding for the program is not keeping pace with growing need, resulting in AIDS Drug Assistance Program (ADAP) waiting lists and AIDS Service Organization (ASO) funding cuts and closures. These financial losses to the ASOs reduce the supportive services necessary to keep HIV-positive persons in care.

The Patient Protection and Affordable Care Act of 2010 (ACA) includes a number of provisions that will greatly expand access for PLWHA that are uninsured and underinsured. The provisions that will have the most significant impact include Medicaid expansion, establishment of state-based health insurance exchanges, private insurance reforms, and investments in health care workforce and safety net providers.

Medicaid Expansion

The most notable change for HIV systems of care under the Affordable Care Act is the potential expansion of Medicaid to cover tens of thousands of currently uninsured PLWHA. Under the current structure, it is not enough to be poor to be eligible for Medicaid; a person must also fall into a particular category (e.g., being disabled). In 2014, states will have the opportunity to expand their Medicaid programs by removing this disability requirement. As a result, most people living with HIV who are not disabled and live at or below 133% Federal Poverty Level (FPL) (~\$15,000 year for an individual and ~\$30,000/year for a family of four) will be eligible for Medicaid based on income alone. Data indicate that the majority of Ryan White clients have incomes below 133% FPL and will meet the income criteria for the Medicaid expansion. Medicaid expansion could potentially have the largest impact in the South, where eligibility rules are most restrictive.

In June 2012, the U.S. Supreme Court ruled that the mandatory expansion of Medicaid to cover all individuals living at or under 133% FPL exceeds federal power to require states to comply with federal regulations. Consequently, the federal government cannot withdraw all Medicaid funding from those states that do not participate in the expansion. However, the ACA provides substantial incentives for states to expand their Medicaid programs. For instance, the federal government will pay for the overwhelming majority of the costs of the expansion including 100% of the funding for those people

who are newly eligible for Medicaid in years 2014 to 2016, gradually reducing to 90% in 2020 and beyond.

Additionally, the ACA requires that newly eligible Medicaid beneficiaries (those ineligible under current Medicaid law but who will be eligible under the expansion) have access to a “benchmark” plan that includes, at a minimum, a set of “essential health benefits” (EHB). The law includes ten broad categories for the EHB: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services; chronic disease management; and pediatric services, including oral and vision care. However, states will have flexibility in implementing the EHB and designing their Medicaid benefits packages for the expansion population.

Lastly, the ACA establishes a Medicaid Health Home Program. This program, which is already in effect, allows states to amend their Medicaid state plans to receive enhanced federal funding (90% federal match for two years) for providing coordinated care to individuals with chronic conditions such as HIV. Services available through the Medicaid Health Home Program include case management, care coordination and health promotion, transitional care from inpatient to other settings, individual and family support, referral to community and social support services, and the use of health information technology to coordinate service and link individuals to multiple service providers.

Private Insurance Reforms

For people living with HIV, prohibitions on discriminatory insurance practices, such as denying someone coverage based on a pre-existing condition, imposing lifetime or annual limits on coverage, or charging high premiums based on health status, will make it easier to purchase private insurance. In 2014, states are required to have “exchanges,” which will act as regulated marketplaces for the purchase of this private insurance. In states that opt not to run their own exchanges, the federal government will run the exchange. Plans sold through exchanges must include the ten EHB categories discussed above. As is true for the Medicaid expansion, states will have significant flexibility in defining the EHB for private insurance sold through exchanges. States must choose a “benchmark” plan from ten options in the private insurance market, which will serve as the standard for coverage. The benchmark must include the ten EHB categories, but the scope of coverage within categories will largely depend on the benchmark plan chosen. In addition, the federal government will provide financial assistance for people between 133% and 400% FPL to help people pay for premiums and cost-sharing obligations. Data indicate that a significant number of current Ryan White clients will qualify for subsidies to purchase private insurance in the exchanges.

Even before 2014, the health reform law establishes Pre-existing Condition Insurance Plans (PCIPs) to provide coverage for people with pre-existing conditions, like HIV, who are unable to get insurance through the private market.⁴⁹ Every state must have a PCIP, and in many states ADAPs are able to pay for premiums and cost-sharing to help people living with HIV enroll in comprehensive coverage.

Investments in Health Care Workforce and Safety Net Providers, and Prevention

Health care reform includes \$11 billion in funding for the operation, expansion, and construction of community health centers throughout the nation over the next five years. The law also contains numerous workforce expansion and training initiatives, including increased National Health Service

⁴⁹ NASTAD, *ADAP Coordination with Pre-existing Condition Insurance Plans (PCIPs)*, December 2011. <http://www.hivhealthreform.org/wp-content/uploads/2012/03/NASTAD-ADAP-and-PCIPs.pdf>. Accessed July 2012.

Corps funding, grants to develop and expand primary care residency programs, student loan repayment incentives, and grants for preventive medicine and public health training. Finally, the law includes significant investments in prevention and wellness, including establishing a Prevention and Public Health Fund, which is already funding a range of community prevention initiatives across the country.

SAC Call to Action

Health care reform presents an unprecedented opportunity to address some of the systemic barriers to care for PLWHA in the South, but only if the federal and state implementation decisions incorporate the needs of the HIV community. HIV providers, advocates, and PLWHA must work to ensure that the federal government does not abrogate its responsibility, as mandated under the health care reform law, to address the needs of vulnerable populations. Recent federal guidance, however, indicates that many implementation decisions, including the content of the essential health benefits for plans sold through the exchanges and for newly eligible Medicaid beneficiaries, will fall to the states. As a result, advocates must also be prepared to work collaboratively with state agencies, health officials, and state legislators to ensure implementation decisions meet the care and treatment needs of PLWHA.

To ensure that critical components of the Affordable Care Act are implemented in ways that meet the care and treatment needs of persons living with HIV/AIDS, SAC calls upon:

- The Department of Health and Human Services (HHS) to enforce the anti-discrimination provisions of the ACA and ensure that implementation of the essential health benefits requirement includes protections for people living with chronic conditions.
- The Health Resources and Services Administration (HRSA) to develop technical assistance to help AIDS Service Organizations and Ryan White providers manage ACA transition and preserve valuable HIV treatment and care expertise.
- States to expand their Medicaid programs to include most people with incomes up to 133% of the Federal Poverty Level.
- States to define their Essential Health Benefits (EHB) to include comprehensive access to prescription medications, chronic disease management, prevention services, specialists, and other benefits needed for PLWHA to be healthy and ensure that outreach and enrollment services are able to reach the many PLWHA who will be entering the care system in 2014.
- State Medicaid agencies to apply for the Medicaid Health Home Program and designate HIV as an eligible condition and Ryan White providers as eligible participants.
- AIDS Service Organizations and Ryan White clinics to prepare for the changing health care landscape by either becoming Federally Qualified Health Centers (FQHCs) or partnering with community health centers and other safety net providers to provide vital HIV services and care.
- HIV providers, advocates, public health officials, and people living with HIV to be active participants in state health reform implementation, including participating in planning bodies and exchange boards.

B. Ryan White Care Act

The Ryan White CARE (Comprehensive AIDS Resources Emergency) Act (“The Act”) was first enacted in 1990 to provide critical services for PLWHA who do not have resources to access the healthcare and supportive services necessary to effectively treat HIV disease.⁵⁰ The Act was re-enacted in 2006 as the Ryan White Treatment Modernization Act. The 2006 reauthorization mandated that the Health Resources and Services Administration (HRSA) include both HIV and AIDS cases in the funding formula for Ryan White programs, assuring for the first time that funding would follow the shift of the epidemic to the southern United States. The Act was again reauthorized in 2009 and is slated to be reauthorized September 30, 2013.

Nationally between 2009 and 2010, real median household incomes declined and poverty increased.⁵¹ The South was the only region with increased poverty rates, as well as the highest poverty rate (16.9%).⁵² Mississippi has the highest poverty rate in the country (28%).⁵³ Ryan White programs serve over half a million clients annually that are the poorest of the poor; 72% of participants report incomes below the Federal Poverty Level (FPL). The programs in the South serve the most indigent clients in the country yet have been funded below other regions—especially in the six-state “Deep South” (Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina).⁵⁴ The United Health Foundation reports that every state in the Southeast except for two are below the national average health ranking; the eight lowest scores are states in the Southeast.⁵⁵ There have been almost twice as many AIDS deaths in the South as the next most affected region, the Northeast.⁵⁶ The South has the lowest proportion of PLWHA that survive the 12, 24, and 36 month marks after diagnosis⁵⁷ and the greatest absolute number of people living with an AIDS diagnosis.⁵⁸

There are almost 550 Ryan White grantees and more than 2,100 service providers.⁵⁹ In 2008, 73% of Ryan White clients receiving services reported being of a racial or ethnic minority.⁶⁰ Blacks were 46% and Latinos were 22% of the minority population. Ryan White pays for 13% percent of HIV healthcare and social services in the United States.⁶¹ In 2008, 70% of Ryan White clients reported living at or below the FPL.⁶² Southern Ryan White programs are often the last safety net under entitlement programs such as Medicaid and Medicare. Poverty, lack of access to quality healthcare services and providers, lack of insurance, and enhanced stigma and discrimination render Southerners more vulnerable to HIV-related disparities and poor health outcomes, and thus deeply dependent on Ryan White Services. In addition to having nine of the ten states with the worst health rankings, the South

⁵⁰ Killelea, A., et al. Texas State Report: Analysis of the Successes, Challenges, and Opportunities for improving Healthcare access with a Focus on the Texas Medicaid Program. State Healthcare Access Research Report (SHARP) 2011 ; pp. 29 -32.

⁵¹ DeNavas-Walt, Carmen, Bernadette D. Proctor, and Jessica C. Smith, U.S. Census Bureau, Current Population Reports, P60-239, *Income, Poverty, and Health Insurance Coverage in the United States: 2010*, U.S. Government Printing Office, Washington, DC, 2011; 1.

⁵² *Id.* at 18.

⁵³ *HIV/AIDS Epidemic in the South* at 4.

⁵⁴ *Id.* at 14.

⁵⁵ *America’s Health Rankings: A Call to Action for Individuals & Their Communities 2011 Edition* at 16.

⁵⁶ Centers for Disease Control and Prevention. *HIV Surveillance Report, 2010*; vol. 22 at 43.

<http://www.cdc.gov/hiv/topics/surveillance/resources/reports/>. Published March 2012. Accessed April 2012.

⁵⁷ *Id.* at 48.

⁵⁸ *Id.* at 55.

⁵⁹ U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. *Going the Distance: The Ryan White HIV/AIDS Program 20 Years of Leadership, A Legacy of Care (Going the Distance)*. 2010; p. 39. Note: This is the most current biennial report.

⁶⁰ *Id.* at 42-3.

⁶¹ Kaiser Family Foundation. *Medicaid and HIV: A National Analysis*. 2011; p. 1. <http://www.kff.org/hiv/aids/upload/8218.pdf>. Last viewed April 18, 2012.

⁶² *Going the Distance* at 45.

also has six of the ten states with the highest poverty rates and nine of the ten states with the lowest incomes.⁶³

Given the dependency of PLWHA, especially those living in the South, on Ryan White services, the Ryan White Treatment Modernization Act must be extended indefinitely. In the short-term, Ryan White must be extended for another three years (through 2016) in order to ensure services during the transition and implementation of the ACA. PLWHA need stability in their lives above all else, and extending Ryan White funding during the early years of the ACA will preserve stability in three areas: (1) PLWHA rely on the current network of Ryan White Programs for frequent health care visits for critical services with an established long-term provider. Integrating the Ryan White system into a larger ACA system will require clients and providers to slowly learn a new system. Missing services because of confusion is dangerous for medically fragile Ryan White clients. (2) Aggressive stigma and discrimination and the threat to confidentiality in small, close-knit communities make PLWHA reluctant to establish new medical relationships. Patient-centered medical homes within Ryan White programs have established trust in their safety and confidentiality. (3) Medicaid services critical to PLWHA are often left out of legislation or the first to be cut in budgetary crises. To lose stability for PLWHA is to sacrifice many of the gains in HIV care and treatment.

Ryan White is also needed long-term. After full implementation of health care reform gaps in coverage and affordability will still exist for PLWHA. For instance, many of the essential support and wrap-around services that Ryan White currently provides fall outside of the scope of both current Medicaid-covered services, as well as the broad categories of required services that will make up the EHB package, including dental and vision coverage, transportation, peer support services, and insurance assistance. In addition, because of the degree of state flexibility, gaps may occur in scope of coverage for case management and mental health services. Finally, the insurance expansion will not include undocumented immigrants and some legal immigrants, who will depend on safety net care systems for access to care. The HIV community must continue to work diligently to ensure sufficient levels of federal funding for the Ryan White Act. Discussions around using Ryan White for cost offsets are premature in the absence of successful implementation of the ACA. HIV care, treatment, and service models must be integrated into the newly created health care systems without destabilizing access to current care and services.

In addition, even with the full implementation of the health care reform law, the Ryan White Act will clearly be needed to fill gaps in care, treatment, and essential support services for people living with HIV, as well as to close gaps in affordability. At the same time, the HIV community must be prepared to work with state health departments, state Medicaid offices, and state departments of insurance to ensure that the vital services provided through the Ryan White Act are integrated into health care reform implementation.

Ryan White funds are allocated in five parts.⁶⁴ Part A provides funding to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs), which are the most

| Ryan White Program, Funding in Millions | | |
|---|----------------|-------------|
| Part | FY 2012 | |
| | \$ | % |
| Part A | \$679.1 | 28% |
| Part B | \$1,358.2 | 57% |
| <i>ADAP (non-add)</i> | \$933.3 | - |
| Part C | \$211.5 | 9% |
| Part D | \$77.8 | 3% |
| Part F AFTC | \$34.8 | 1% |
| Part F Dental | \$13.6 | 1% |
| Part F SPNS | \$25 | 1% |
| Total | \$2,400 | 100% |

Source: Dept. of Health and Human Services, Budget Justification, 2012.

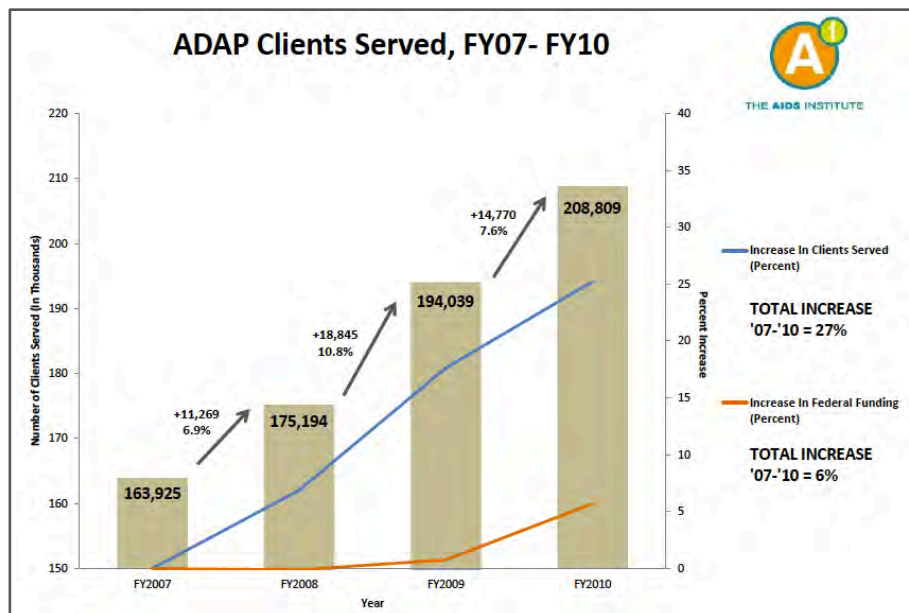
⁶³ HIV/AIDS Epidemic in the South Reaches Crisis Proportions at 4.

⁶⁴ HIV/AIDS Bureau, Health Resources and Services Administration: *About The Ryan White HIV/AIDS Program*. <http://hab.hrsa.gov/abouttab/aboutprogram.html> Accessed April 2012.

impacted cities and jurisdictions. Part B programs are funded through grants to states and territories and include a base grant, the AIDS Drug Assistance Program (ADAP) earmark, ADAP supplemental grants, grants to states for Emerging Communities (EC), and an award for Minority AIDS Initiative (MAI) activities. Part C funds public and private organizations to provide core medical treatment, outpatient early intervention, and ambulatory care services. Part D funds healthcare providers for family-centered primary medical care for women, infants, children, and youth (WICY) living with HIV/AIDS. Part F funds various programs, including the Special Projects of National Significance (SPNS) (innovative projects for health and support services for underserved groups living with HIV), the AIDS Education and Training Centers (AETCs), and the Dental Programs.

Crisis among ADAPs (AIDS Drug Assistance Programs)

The 2012 federal budget funded the Ryan White program at \$2.4 billion with 39% of the budget earmarked for ADAP.⁶⁵ The FY 2012 budget was a 2% funding increase for Ryan White programs and 5.5% increase for ADAPs in FY 2011.⁶⁶ Based on HRSA data, ADAP clients served grew from 164,000 in FY07 to 209,000 in FY10, an increase of 27%. At the same time federal funding for ADAP rose by only 6%. ADAP provides HIV-related medications to low-income PLHWA, but funding has not kept up with demand. As of July 6, 2012, 1,958 individuals in nine states were on ADAP waiting lists.⁶⁷ Approximately 92% of ADAPs are in the South. As of February 1, 2012, 445 people in six states were dis-enrolled because of eligibility changes regarding income.⁶⁸ Between April 1, 2009, and April 12, 2012, fifteen states imposed other cost containment strategies.⁶⁹



Source: The AIDS Institute, 2011.

Years of funding gaps have forced ADAPs to cut services severely. Three options are utilized to address the current fiscal crisis: (1) restrict eligibility for services; (2) limit the drugs on the formulary; and/or (3) reduce the amount paid for medication. Restricting eligibility, especially in southern ADAPs, often has limited yield as most participants are already of very low income. For example, although the

⁶⁵ Kaiser Family Foundation, HIV/AIDS Policy Fact Sheet, *U.S. Federal Funding for HIV/AIDS: The President's FY 2013 Budget Request*; p. 3. <http://www.kff.org/hiv/aids/upload/7029-08.pdf>. February 2012. Accessed April 18, 2012.

⁶⁶ *Id.*

⁶⁷ *ADAP Watch* at 1. http://www.nastad.org/Docs/024445_ADAP%20Watch%20update%20-%204.13.12.pdf. Accessed July 10, 2012.

⁶⁸ *Id.*

⁶⁹ *Id.* at 2.

Kentucky ADAP requires income to be at or below 300% of the FPL, approximately 95% of participants are at or below 200% of the FPL. If the income eligibility criteria of the Kentucky ADAP is lowered to 200% of the FPL it will exclude less than 5% of participants—people who will most likely not be eligible for the only other safety net available to them, the Patient Assistance Programs (PAPs), whose income requirements they probably will not meet either.

ADAPs face challenges reducing formularies because 89% of their budgets pay for antiretroviral (ARVs) drugs. Only a small amount is allocated to drugs for opportunistic infections and the harsh side effects of the ARVs. Despite the inefficiency, programs cut non-ARVs from their formularies jeopardizing effective treatment without substantially ameliorating funding. This cost containment measure presents a great challenge in rural southern programs, where formularies are often more limited than in other parts of the country. Programs are forced to limit costs through strategies such as reducing access points and distribution methodologies—a major barrier to timely access for resource-poor clients in rural areas without public transportation systems.

The ADAP crisis is a result of the economic downturn, consequent funding shortages, increased demand for services, and more intense program use in the face of budgets that have long lagged behind program needs. Successful ARVs have led to much longer lives; according to Emory University's Center for AIDS Research, people live an average of twenty-four years after being diagnosed with HIV, almost equal to the mainstream population. Since HIV drug therapy is normally for life, ADAPs expend resources on clients for much longer periods than earlier in the epidemic. Innovative testing programs have also increased ADAPs' rolls. A significant number of new ADAP clients in the rural South have counts at or below 350 CD4 cells—the level at which most ARV treatment is initiated and indicative of disease progression and an excessively compromised immune system, which can lead to medical complications and opportunistic infections. Additionally, in March 2012, the Panel on Antiretroviral Guidelines for Adults and Adolescents updated its guidelines on the initiation of ARVs for persons with HIV.⁷⁰ ARVs are now recommended for all persons with HIV (rather than waiting for CD4 counts) with the strength of the recommendation varying according to a person's pretreatment CD4 cell count.

To address the current ADAP funding crisis, \$40 million of the Ryan White budget is allocated to a supplemental grant specifically for jurisdictions with waiting lists and program restrictions/cost containment measures; this amount is well below the actual need. Without enough resources to meet the need, program costs will continue to rise. Research indicates that early access to medical treatment, including anti-retroviral therapy, limits total annual costs per person to \$25,000 or below. But when treatment is initiated late during the disease progression, costs can reach up to \$300,000 due to medical complications requiring high-cost, complex salvage treatment regimens due to multiple opportunistic infections and multiple hospital admissions that often result in poor treatment outcomes and death (which is one of the reasons for the high HIV mortality rates in the South).⁷¹ The price of not providing early treatment, especially drug therapy, is highly costly to society in many ways. Whether we pay now or pay later, we will pay; the later the payment, the more costly it will be.

SAC Call to Action

Ryan White provides critical services for PLWHA. The HIV community and the state health departments, Medicaid offices, and departments of insurance must be prepared to work together in

⁷⁰ Centers for Disease Control and Prevention, MMWR, June 22, 2012. *Previous HIV Testing Among Adults and Adolescents Newly Diagnosed with HIV Infection — National HIV Surveillance System, 18 Jurisdictions, United States, 2006–2009*. www.cdc.gov/mmwr/pdf/wk/mm6124.pdf. Accessed June 2012.

⁷¹ ADAP Advocacy Association (AAA), *99 Too Many! ADAP Advocacy Association Concerned Over Growing Waiting Lists*; June 9, 2009. <http://www.adapadvocacyassociation.org>. Accessed June, 2009.

ensuring that the vital services provided through Ryan White are integrated into the implementation of health care reform. Additionally, funding must be allocated to address the current ADAP crisis.

To address the care and treatment needs of PLWHA, provide unfettered access to high quality, life-extending care, and achieve cost-containment measures, SAC calls upon:

- Congress and the Health Resources and Services Administration (HRSA) to extend the Ryan White Treatment Modernization Act for three years to ensure services for PLWHA during the implementation years of the ACA.⁷²
- Congress and HRSA to extend the Ryan White Treatment Modernization Act long-term to provide a safety net to cover gaps in services and affordability for PLWHA, as well as continued services necessary to keep persons in care, even after full implementation of health care reform.
- HRSA to allocate ADAP funds to eliminate waiting lists and cost containment measures. Early access to life-saving medications is the next milestone in treatment, disease reduction, and program cost savings.
- HRSA to earmark funds for reducing HIV-related health disparities in the South. Resources must be allocated to improve the social determinants of health that are driving HIV transmission in the region.

⁷² Project Inform. Think Tank on Financing the Goals of the National HIV/AIDS Strategy in a Changing Environment. *Affordable Care Act: Overview, Gaps and Challenges*. www.ProjectInform.Org. Accessed January 2012.

C. Housing Policy

Recent findings from the National AIDS Housing Coalition (NAHC) state that 3% to 10% of all homeless persons are HIV-positive, which is ten times the rate of infection in the general population.⁷³ On the local level, annual surveys, called Point in Time counts, are conducted by most jurisdictions' Continua of Care bodies, and these results substantiate the national data.

AIDS housing experts estimate that about 72% of all HIV-positive persons will need some form of housing assistance during the course of their illness.⁷⁴ The Center for HIV Law & Policy (CHLP) surveyed PLWHA in eight southern states that all reported affordable housing to be their most pressing need.⁷⁵ CHLP also found that among HIV case managers, people most knowledgeable about resources available for PLWHA, 66.3% reported they needed help accessing affordable housing for clients.⁷⁶ At current funding levels, the federal Housing Opportunities for Persons with AIDS (HOPWA) program serves only 60,234 households per year; about 1.2 million people live with HIV/AIDS in the United States. In addition, there is not a single county in the United States where a person who relies on the maximum federal Supplemental Security Income (SSI) payment (\$674 in 2011) can afford even a studio apartment.⁷⁷ The Southern HIV/AIDS Strategy Initiative (SASI) of Duke University reports that 50% of all newly diagnosed individuals reside in the South.



Findings reported at the North American Housing Research Summit and in a special issue of *AIDS & Behavior* in November 2007 show that homelessness and unstable housing are associated with rates of HIV through sex and drug risk behaviors; that unstable housing increases HIV risk behaviors, even among those at highest HIV risk; that homelessness and unstable housing are directly related to delayed HIV-related care, poor access to care, and decreased likelihood of treatment adherence; and that the association between lack of stable housing and greater HIV risk behaviors remains even among persons who have received risk reduction services.^{78 79}

The National HIV/AIDS Strategy (NHAS) calls for both the possible reallocation of federal funding to most effectively address the domestic HIV epidemic and a shift to living HIV/AIDS cases as the foundation for funding distribution.⁸⁰ For the HOPWA legislation, the NHAS specifically calls on the U.S. Department of Housing and Urban Development (HUD) to "...work with Congress to develop a plan

⁷³ National AIDS Housing Coalition, *Breaking the Link Between Homelessness and HIV* at 1. <http://www.nationalaidshousing.org/PDF/Factsheets-Homelessness.pdf>. Accessed April 2012.

⁷⁴ Aidala, A. (2005). *Homelessness, Housing Instability and Housing Problems Among Persons Living with HIV/AIDS*. Housing and HIV/AIDS Research Summit.

⁷⁵ The Center for HIV Law & Policy, *Send Lawyers, Guides and Money: The Legal Services Needs of People Living with HIV in the Southern United States* at 4-6,9. (December 2010). <http://hivlawandpolicy.org/resources/view/575>. Accessed April 2012.

⁷⁶ *Id.* at 4.

⁷⁷ National Low Income Housing Coalition. *Out of Reach 2009: U.S. Statistics, 2009*. http://www.nlihc.org/oor/oor2009/OOR_US-Fact-Sheet.pdf. Accessed April 2012.

⁷⁸ Aidala, A.A. (2008). *Housing and HIV prevention and care: Recently published findings on the relationship of housing status and HIV risk and health outcomes*. Paper presented at the Third National Housing and HIV/AIDS Research Summit, Baltimore, Maryland.

⁷⁹ German, Danielle, Melissa A. Davey, and Carl A. Latkin. *Residential Transience and HIV Risk Behaviors Among Injection Drug Users*. *AIDS and Behavior* 11.2 (2007): 21+.

⁸⁰ White House Office of National AIDS Policy. *National HIV/AIDS Strategy for the United States*. 2010; <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>. Accessed May 2012.

(including seeking statutory changes if necessary) to shift to HIV/AIDS case reporting as a basis for formula grants for HOPWA funding.”⁸¹ Current HOPWA formula funding is distributed based on cumulative AIDS cases, including more than 600,000 deceased persons.

Additionally the current methodology provides 25% of the formula funding as a bonus to 31 urban areas with higher than the national average of AIDS incidence. Seven of these metropolitan areas receive 72% of the bonus, resulting in a per case impact at \$10,030, compared to \$202 per case for grantees receiving the cumulative AIDS case funding of the 75% formula dollars.⁸² HUD recognizes the need to better target HOPWA formula funds through distribution based of living HIV/AIDS cases, as well as consideration of poverty and Fair Market Rent, both of which impact the costs of housing.

Re-alignment of HOPWA funding is critical, as stable housing has been recognized in a substantial body of research to improve health outcomes, to reduce risk behaviors that result from inadequate housing, and to be cost effective as a structural intervention. Funding reallocation is of critical importance in the South for several reasons. Most obvious, the South has more people living with HIV than any other region of the country, resulting in more people with inadequate housing than any other area. Additionally, the pervasive poverty of the region, particularly among the HIV-positive population, results in more homelessness and less adherence to medical care. The rural nature of much of the South further complicates living arrangements, as safe, decent, and affordable housing may not exist. In a statewide needs assessment performed by AIDS Alabama in 2007, 19% of the state’s HIV-positive Black females surveyed were chronically homeless and stayed homeless longer because of a lack of available shelters and other housing options. Finally, a 2010 report from Funders Concerned about AIDS indicates that only 25% of private philanthropic dollars went to the South,⁸³ which has almost half of the nation’s epidemic.

According to research by Dr. David Holtgrave, Dean of the Bloomberg School of Public Health at Johns Hopkins University, each HIV infection averted saves approximately \$355,000, much of which is paid through public systems of health care. Dr. Holtgrave was also recorded at the North American Research Summit in 2010 as stating that housing may be the most important factor for successful health outcomes for a person living with HIV/AIDS.

SAC Call to Action

In accordance with the National HIV/AIDS Strategy (NHAS) and in order to improve health outcomes, reduce HIV risk behaviors, and decrease health care expenditures, SAC calls upon the following:

- Congress and the U.S. Department of Housing and Urban Development (HUD) to realign the HOPWA funding formula to target the current disease epidemic based on living HIV/AIDS cases, poverty rates, and local Fair Market Rent with shifts in funding to be incremental over a five-year period.
- Congress to increase allocations for HOPWA in order to mitigate losses to jurisdictions that will lose funding.
- HOPWA grantees to work with HUD technical assistance providers to establish the broadest coverage possible for low income PLWHA in jurisdictions.

⁸¹ White House Office of National AIDS Policy, *National HIV/AIDS Strategy for Federal Implementation*, 2010. www.whitehouse.gov/files/documents/nhas-implementation.pdf. Accessed May 2012.

⁸² Presentation by Office of HIV/AIDS Housing, HUD. September 2011.

⁸³ Funders Concerned About AIDS, *U.S. Philanthropic Support to Address HIV/AIDS in 2010* at 50.

http://www.fcaids.org/Portals/0/Uploads/Documents/Public/Publications/2011/FINAL%202011%20FCAA_ResourceTracking_WEB.pdf. Accessed April 2012.

D. Immigration

The number of Latinos living in the South nearly doubled between 2000 and 2010, according to the Pew Research Center's analysis of the U.S. Census.⁸⁴ In fact, twelve of the thirteen states with the highest rate of Latino population growth in the last decade were in the South (Alabama, Arkansas, Delaware, Georgia, Kentucky, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, and Virginia).⁸⁵ The Latino population more than doubled across a large swath of the region, including Alabama, Arkansas, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.⁸⁶ Currently, one in three Latinos in the United States resides in the South. Further analysis of migration trends suggest that the population of Latinos in the U.S., particularly in the South, will double to 30% by 2050.⁸⁷



"Take care of your community, Look for *Claridad!*" Farmworker peer HIV-prevention educators from North Central Florida work to break down stigma around HIV by participating at the Annual Catfish Parade in Crescent City, Florida. Photo Credit: Rural Women's Health Project.

Ethnic composition within the emerging Latino population is increasingly diverse. The diversity of national representation and legal status is a shift from previous Latino composition of the South prior to 2000. Presently, the Mexican population in the Southeast is by far the largest ethnicity represented, followed by Puerto Rican, Cuban, Salvadoran, Dominican, Guatemalan, and Colombian.

The South's emerging Latino community is at risk for HIV/AIDS. As the fastest growing minority group in the region, Latinos are already experiencing the devastating effects of the epidemic. While Latinos represent approximately 16% percent of the total U.S. population, they account for approximately 20% percent of all new HIV infections.⁸⁸ In 2009, the HIV infection rate among Latinos (26.4/100,000) was nearly three times as high as that of Caucasians (9.1/100,000).⁸⁹ The CDC estimates that one in 36 Latino men and one in 106 Latina women will be diagnosed with HIV during their lifetime.⁹⁰ Moreover, infrequent HIV screening among southern Latinos almost certainly masks an even larger, hidden epidemic.

⁸⁴ Passel, Jeffrey S., and D'Vera Cohn. *U.S. Foreign-Born Population: How mUch Change from 2009 – 2010?* Washington: Pew Research Center at 1-3. <http://pewhispanic.org/files/reports/140.pdf>. Accessed April 2012.

⁸⁵ *Id.* at 2.

⁸⁶ *Id.* at 3.

⁸⁷ Shrestha, L.B. (2006) The changing demographic profile of the United States. *Congressional Research Service Report for Congress*, Washington, D.C. Shrestha, Laura, Heisler, and Elayne J. *The Changing Demographic Profile of the United States*, March 2011. Congressional Research Service.

⁸⁸ Kaiser Family Foundation Fact Sheet, *Latinos and HIV/AIDS*, February 2012. www.kff.org/hiv/aids/upload/6007-09.pdf. Accessed April 20, 2012.

⁸⁹ *HIV/AIDS Surveillance Report*, Vol. 22.

⁹⁰ Center for Disease Control and Prevention. *HIV among Latinos*. <http://www.cdc.gov/hiv/resources/factsheets/pdf/latino.pdf>. Published November 2011. Accessed April 2012.

Many of the factors that contribute to the South's overall disproportionate HIV burden also apply to Latinos, including poverty, rural geography, cultural conservatism, and stigma. However, several additional factors greatly impact Latinos in the South and contribute to the emerging epidemic. These factors include (1) sexual risk taking behavior and sexually transmitted infections; (2) cultural barriers to healthcare and preventative services; (3) anti-immigrant policies; (4) domestic violence; and (5) incomplete demographic data.

Sexually Transmitted Infection Risk

The South has consistently higher reported rates of chlamydia, gonorrhea, and syphilis than any other region in the country.⁹¹ Unfortunately, Latinos are disproportionately infected. The prevalence for chlamydia among Latinos was three times higher than that of non-Hispanic whites, and the prevalence for syphilis was twice that of non-Hispanic whites.⁹² This disparity is particularly alarming because of the substantial biological evidence demonstrating that the presence of these sexually transmitted infections (STIs) greatly increases the likelihood of both transmitting and acquiring HIV. According to the Centers for Disease Control and Prevention, individuals who are infected with STIs are at least two to five times more likely than uninfected individuals to acquire HIV if they are exposed to the virus through sexual contact. In addition, if an HIV-positive individual is also infected with another STI, he or she is more likely to transmit HIV than other HIV-positive persons.

Further, many Latinos are engaging in sexual risk-taking behaviors. For instance, a North Carolina study found that 42% of Latino men surveyed had extramarital sex at some time in their relationship, 21% had two or more sexual partners during the past year, and 21% had twenty or more lifetime partners.⁹³ Recent studies also note that Latino men who have sex with men (MSM) have the highest rate of unprotected sex in the nation.



Cultural Barriers to Healthcare and Preventative Services
Historically, cultural barriers and a dearth of linguistically appropriate services have made it more difficult for Latinos to access testing and, if necessary, treatment for HIV in the South. Access issues are exacerbated in most Southern states where there are high rates of Health Professional Shortage areas and uninsured rates between 50% and 79%.^{94 95} Also, southern AIDS Service Organizations

The Latino population in the Deep South has nearly doubled since 2000. It is now common to see multi-generational families settling into new communities.
Photo Credit: Rural Women's Health Project.

⁹¹ CDC. *STD Surveillance 2010* at 2. <http://www.cdc.gov/std/stats10/surv2010.pdf>. Accessed April 2012.

⁹² *Id.*

⁹³ International Journal of Family Medicine, *Factors That Influence HIV Risk among Hispanic Female Immigrants and Their Implications for HIV Prevention Interventions* at 7. <http://www.hindawi.com/journals/ijfm/2012/876381/>. Accessed April 20, 2012.

⁹⁴ Ryan, Kara. Washington DC: National Council of La Raza Washington. *A Burden No Child Should Bear: How the Health Coverage System is Failing Latino Children*. Accessed March 2012.

⁹⁵ Voices of Immigrants in Action (VIA), Rural Women's Health Project. 2010 VIA Community Survey.

(ASOs) have significant shortages of bilingual service providers. As a result, “...many HIV cases among Latinos in the South are not discovered until the individual has fallen seriously ill, and so concurrent diagnoses of HIV and AIDS are common.”⁹⁶

In addition, the recent passage of the Affordable Care Act has prompted southern states to also consider health-related immigrant bills; most of these health-related bills restrict immigrant access to health benefits, including participation in state health benefit exchanges. “Two million Latinos face severe barriers to healthcare and preventive services as these southern states are further restricting Latinos’ access to HIV/AIDS prevention and care by excluding immigrants from government health-promotion efforts.”⁹⁷

Increase in Anti-Immigrant Policies

As the HIV epidemic among Latinos demands heightened attention in the South, many southern legislatures have passed measures driving Latinos further away from contact with healthcare institutions, public health services, and other community-based organizations. States should avoid measures that impede the state’s ability to treat and provide Latinos living with or at risk for HIV/AIDS. Further, state legislatures must consider public health concerns when enacting future legislation.

Domestic Violence

Domestic violence is a significant risk factor for Latina women. In fact, 25% of Latino community members in North Central Florida and East Tennessee stated that domestic violence is the greatest issue facing women in their communities.⁹⁸ The same study found that domestic violence intensifies the issues of depression, low self-esteem, and limited access to reproductive prevention and health support among women.

Incomplete Demographic Data

Although existing data on HIV seroprevalence rates for Latinos in the South provide a vision of the current status of the epidemic, the data offer a very limited perspective. Additional concern must be raised due to the undefined incidence among Latino immigrants, their sex partners, and the limited data on STI prevalence and co-occurring risk factors in rural and urban settings of the rapid-growth states in the South. Also, quantifying all Latinos as one demographic group, or an even less useful division into Latino Black and non-Hispanic Black, ignores essential cultural, economic, and immigration status differences and impedes the critical implementation of effective strategies. Similarly, the common misuse of the terms “immigrant” and “migrant” also hampers the delivery of services. Moreover, “...there is a void in HIV/AIDS incidence data that specifically focuses on Latino immigrants in the South as a unique community.”⁹⁹ Ultimately, the lack of accurate demographic data reduces the public health community’s ability to execute impactful prevention, testing, and treatment programs.

SAC Call to Action

Without a prioritized commitment to address the unique prevention, testing, and treatment needs of those currently classified as Latinos in the South, curbing the expansion of the looming HIV/AIDS epidemic into this community will be difficult to attain.

⁹⁶ Latino Commission on AIDS, *Shaping the New Response: HIV/AIDS & Latinos in the Deep South*, 2010. www.latioaids.org/docs/latinos_deep_south.pdf. Accessed April 2012.

⁹⁷ 2010 VIA Community Survey

⁹⁸ *Id.*

⁹⁹ Voices of Immigrants in Action. *Risk Factors for HIV/AIDS & the Rural Hispanic Immigrant Community* at 1. Rural Women’s Health Project, 2011. www.farmworkerjustice.org/files/hiv/Community_Fact.pdf. Accessed June 2012.

To address the growing epidemic among Latinos in the South, SAC calls upon:

- State legislators to consider the public health consequences of any legislation that impedes the community's ability to serve Latinos living with or at risk for HIV/AIDS.
- State and local health departments to incorporate the Latino community into HIV/AIDS strategies and programs for prevention, testing and care.
- Health care providers, AIDS service organizations, and other community-based organizations to review funding sources to determine which funding sources can be used to serve all immigrants.

E. Prevention

As the South continues to face alarming HIV/AIDS infection and death rates, there is a need for refocused and intensified federal, state, and local prevention efforts. The National HIV/AIDS Strategy (NHAS) clearly states targeted goals of reducing HIV incidence, improving outcomes for people living with HIV, and reducing HIV-related disparities. Accomplishing these goals will require a comprehensive approach, including expanded prevention efforts. NHAS further cites numerous prevention issues that contribute to the HIV disease burden in the South, such as abstinence-based education. In order to improve the quality and length of life for people living with HIV, reduce morbidity and mortality rates, prevent new HIV infections, and reduce health care expenditures, the southern region must expand prevention programs and services. Expanded efforts should be concentrated around the most significant prevention areas, including HIV testing, basic HIV/AIDS and sex education, syringe exchange programs, and treatment as prevention.



AIDS Alabama is one of 12 organizations selected for their outstanding work in HIV by Greater Than AIDS and will be featured at the International AIDS Conference in metro stations and on buses.

HIV Testing

Statistics indicate great progress has been made in HIV testing. According to the CDC, in 2009, 82.9 million adults between the ages of eighteen and sixty-four reported having ever been tested for HIV, an increase of 11.4 million since 2006.¹⁰⁰ Although this increase in HIV testing is certainly a success, data also indicate that continued efforts are needed, as 55% of adults have never been tested for HIV.¹⁰¹ Additionally, young persons (in the eighteen to twenty-four age bracket) had rates of HIV diagnoses similar to that of other age groups but much lower testing rates.¹⁰² According to the 2011 National Youth Risk Behavior Survey (YRBS), 47.4% of high school students reported having sex at least once, yet only 13% report ever having had an HIV test.¹⁰³ In the thirty-three states with mature HIV reporting systems, approximately one third of diagnosed HIV infections were diagnosed late (an indicator of the progress of testing efforts).¹⁰⁴ With increased HIV testing and linkage to care, more persons infected with HIV are identified, and if persons are diagnosed early in the course of infection, earlier treatment can save and increase the quality of life, reduce disease progression, prevent new infections, and reduce the cost of healthcare.

¹⁰⁰ The Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report (MMWR). *Vital Sign: HIV Testing and Diagnosis Among Adults – United States 2001 – 2009*; Vol. 59 at 1550 – 1555. Published December 2010. Accessed May 2012.

http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5947a3.htm?s_cid=mm5947a3_w

¹⁰¹ *Id.* at 1552.

¹⁰² *Id.* at 1552.

¹⁰³ Sexuality Information and Education Council of the United States, 2012. *CDC Releases 2011 YRBS Data; Fewer Youth Receiving Information about HIV and AIDS* [Press Release]. Accessed June 2012. <http://www.siecus.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=2171>.

¹⁰⁴ *HIV Testing and Diagnosis Among Adults* at 1552.



Photo Credit: Georgia AIDS Coalition, Inc.

For adults, the CDC recommends routine HIV screening in health care settings and annual or periodic testing for high-risk populations.¹⁰⁵ HIV testing expansion efforts should be focused where the disease burden is greatest. Approximately 60% of Blacks have been tested for HIV at least once in their lifetimes, a higher testing rate than any other racial or ethnic group.¹⁰⁶ Despite the higher percentage rate of Blacks being tested, the disproportionate impact of diagnoses indicate that Blacks, Latinos, and other high-risk subpopulations would benefit from more frequent testing to increase early diagnoses. The need for increased

frequency of testing also translates to gay, bisexual, and other men who have sex with men (MSM), where the HIV burden is greatest. Data show that a high percentage of MSM (58%) are getting tested, although 45% of HIV-infected MSM who were unaware of their infection reported having an HIV test in the previous year.¹⁰⁷ These findings indicate that although progress has been made in HIV testing for high-risk populations, testing is not repeated with enough frequency and has not occurred at a sufficient scale to identify all persons living with HIV.

Sex Education

In January 2012, four leading health organizations (the American Association of Health Education, the American School Health Association, the National Education Association Health Information Network, and the Society of State Leaders of Health and Physical Education) collaborated to release the first-ever national standard for sexuality education in schools.¹⁰⁸ The *National Sexuality Education Standards: Core Content and Skills, K-12* provide teachers, schools, school districts, and state education agencies with a new national standard with straightforward, clear, and consistent guidance on the essential minimum, core content for sexuality education that is developmentally and age-appropriate for students in Kindergarten through grade 12.¹⁰⁹ For many years, research has highlighted the need to provide effective, comprehensive sexuality education to young people. In addition to the need for increased testing for youth, the 2011 YRBS also showed an increased need for appropriate sex education programs. “Between 1991, when the YRBS was first conducted, and 1999 there were sharp increases in positive sexual health behaviors and decreases in negative behaviors. Since then, however, that progress has predominantly stalled or moved backward.”¹¹⁰ According to Monica Rodriguez, President and Chief Executive Officer of Sexuality Information and Education Council of the United States (SIECUS):

*The [2011 YRBS] survey tells us that even fewer young people are being reached with sex education that includes vital information youth need to delay sexual activity and prevent HIV, other STDs, and unintended pregnancies when they do become sexually active.*¹¹¹

¹⁰⁵ *Id.* at 1552.

¹⁰⁶ *Id.* at 1553.

¹⁰⁷ *Id.* at 1553.

¹⁰⁸ American Association for Health Education, 2012. *Groundbreaking National Sexuality Education Standards Set the New Gold Standard for Sexuality Education in Public Schools* [Press Release]. <http://www.aahperd.org/aahe/advocacy/pressreleases/education.cfm>. Accessed May 2012.

¹⁰⁹ *Id.* at para. 1,3.

¹¹⁰ *Fewer Youth Receiving Information about HIV and AIDS* at para. 2.

¹¹¹ *Id.* at para. 3.

For ten years, approximately “...10-15% of young people reported not being taught about HIV/AIDS in school.” The 2011 YRBS shows a worsening of this trend: for the first time, more than 15% of students reported not being taught about AIDS or HIV in school.¹¹² The lack of effective sex education is also an issue facing southern states, as many school districts are unwilling to provide constructive, comprehensive sex education programs. In eight of the southern states, sex education is not required in schools despite every southern state showing sexual activity among teens above the national average.¹¹³ Another six southern states focus on an abstinence-only curriculum for sex education, although these programs have been shown to have very little effect on teens’ sexual behavior and may contribute to a lack of knowledge about HIV/STIs.¹¹⁴ A recent report states that 47,000 young people (ages thirteen to twenty-four) are living with HIV/AIDS in the US, and the southern states ranked highest in the nation for rates of gonorrhea, chlamydia, and syphilis (STIs that double the risk of acquiring an HIV infection).¹¹⁵ The South also ranks high in teen pregnancy rates, as Mississippi and Arkansas are ranked number one and number three in the nation, Kentucky, Louisiana, and Tennessee are among the top ten, and Alabama, Florida, Georgia, North Carolina, and South Carolina are among the top twenty.¹¹⁶ Despite indicators of the highest sexual activity in the nation, southern states continue to strongly emphasize abstinence-only education and limit sex education discussions altogether.

Programs that stress abstinence-only while restricting discussion of condoms withhold important HIV prevention evidence and further endanger students, who are undoubtedly sexually active. Abstinence-only or abstinence-based sex education is not recommended by the CDC; rather the CDC recommends comprehensive sex education that discusses and demonstrates HIV prevention and contraceptive methods (such as condoms).¹¹⁷ In addition to the lack of general sex and HIV/AIDS education about contraception and prevention, these programs carry, and in some cases mandate, negative messages about homosexuality. Most states mandate that where sex is discussed, abstinence before marriage be “stressed”, and further, many states include messages stating that heterosexual marriage is the only acceptable place for sex.¹¹⁸ These programs create a stigmatized environment, discriminate, and restrict necessary health information for gay and bisexual youth, further discouraging HIV and STI testing for this group.

Lack of Syringe Exchange Programs

Syringe exchange programs (SEP) have been consistently proven to reduce the risk of HIV and are recommended by the CDC to reduce HIV transmission among injection drug users (IDU).¹¹⁹ SEPs, like other harm reduction initiatives, “...meet people where they are by exchanging clean syringes for used ones,” as the sharing of used syringes significantly increases the risk of HIV/AIDS transmission.¹²⁰ In the United States, injection drug users represented 9% (4,172) of new HIV infections in 2009 and 17% of

¹¹² *Id.* at para. 4.

¹¹³ *HIV/AIDS Epidemic in the South* at 24.

¹¹⁴ *Id.* at 23, 24.

¹¹⁵ Human Rights Watch. *Southern Exposure: Human Rights and HIV in the Southern United States*. Published November 2010. Accessed April 2012. <http://www.hrw.org/news/2010/11/26/southern-exposure>.

¹¹⁶ *Id.* at 13, 14.

¹¹⁷ The Centers for Disease Control and Prevention. *Teen Pregnancy: Improving the Lives of Young People and Strengthening Communities by Reducing Teen Pregnancy*. Published 2011. Accessed April 2012. http://www.cdc.gov/chronicdisease/resources/publications/aag/pdf/2011/Teen-Pregnancy-AAG-2011_508.pdf.

¹¹⁸ *Southern Exposure* at 14-16.

¹¹⁹ *HIV/AIDS Epidemic in the South* at 24.

¹²⁰ *Southern Exposure* at 20.

those living with HIV in 2008.¹²¹ However, because IDUs are a difficult population to reach, many believe the numbers to be underreported. Since the beginning of the epidemic, more than 175,000 IDUs with AIDS have died, including approximately 4,759 in 2009.¹²² Approximately 2,652 injection drug users diagnosed with HIV were male and approximately 1,520 were female.¹²³ For both men and women, 50% or more of HIV diagnoses for IDUs were among Blacks, 25% were among Latinos, and the remaining cases were mostly among whites (20%). In the South, the percentage of PLWHA who were exposed due to injection drug use varies greatly by state. In Louisiana, the rate is high as 21%, yet syringe exchange programs are nearly non-existent in the southern region.¹²⁴

Thirty-three states and the District of Columbia have syringe exchange programs. However, only a handful of syringe exchange programs operate in the South. Eight states in the South do not have syringe exchange programs at all (Alabama, Arkansas, Kentucky, Mississippi, South Carolina, Tennessee, Virginia, and West Virginia),¹²⁵ and the SEPs that do exist are concentrated in four states (Florida, Georgia, Louisiana, and North Carolina); in all of these states except North Carolina, only one program is reported.¹²⁶ Although the effectiveness of syringe exchange programs is well documented, and federally endorsed as part of a comprehensive harm reduction plan, there continues to be pervasive misunderstanding with policy makers and law officials and a lack of clear legal mandates, even within the states that do have SEPs. While the federal ban on funding for syringe exchange programs was lifted in 2009, many states still have laws “...prohibiting possession and transfer of drug paraphernalia.”¹²⁷ These laws regulate the ability of pharmacists and medical providers to prescribe or sell clean syringes, further limiting public health and HIV prevention efforts. State laws need clarification (that they do not apply to distribution of clean syringes for health purposes and are not intended to inhibit public health efforts) in order to increase access and relieve apprehension for both injection drug users and medical workers.¹²⁸ Additionally, federal leadership is needed to model legislation and provide guidance to the states regarding access to sterile syringes, the need for evidence-based methods, and rewards for states with federal support.¹²⁹

Treatment as Prevention

In recent years, important research supporting the value of treatment as prevention has occurred. Clinical trials have been conducted since 2007 to explore the option of medication not only being used to hinder HIV replication for HIV-positive persons but also to potentially stop HIV acquisition for HIV-negative individuals; this intervention is known as a Pre-Exposure Prophylaxis (PrEP).¹³⁰ In May 2012, an advisory panel to the U.S. Food and Drug Administration (FDA) recommended that the FDA approve the antiretroviral drug, Truvada, as an option for HIV prevention. Although regulators have delayed the FDA’s decision on expanding the use of Truvada as a preventative therapy until September 2012, the recommendation is a critical step toward developing a comprehensive approach to reduce HIV

¹²¹ CDC, *HIV in the United States* at 2.

¹²² *Id.* at 2.

¹²³ Centers for Disease Control and Prevention, *HIV Surveillance in Injection Drug Users (through 2009)*. June 2011. Accessed May 2012. www.cdc.gov/hiv/idu/resources/slides/slides/idu.pdf.

¹²⁴ *Southern Exposure* at 21.

¹²⁵ Kaiser Family Foundation, *Sterile Syringe Exchange Programs, 2011*. Accessed May 2012.

<http://www.statehealthfacts.org/comparetable.jsp?ind=566&cat=11&sub=185&yr=200&typ=5>.

¹²⁶ *HIV/AIDS Epidemic in the South* at 24.

¹²⁷ *Southern Exposure* at 20.

¹²⁸ *Id.* at 20, 21.

¹²⁹ *Id.* at 23.

¹³⁰ Stone, Krishna. *GMHC Commends FDA’s Recommendation on HIV Drug to Prevent New Infections*. Published May 2012. Accessed May 2012. <http://gmhc.org/news-and-events/press-releases/gmhc-commends-fdas-recommendation-on-hiv-drug-to-prevent-new-infections>.

infection rates in the U.S. With HIV infection rates soaring in the southern region, this intervention could provide a vital tool in slowing the epidemic. However, southern PLWHA are often the last to access life-saving technology due to a lack of resources to implement proven and innovative techniques. Increasing access is necessary to reduce HIV transmission and program costs through early, effective treatment. Additionally, financial challenges exist. With many HIV-positive southerners on AIDS Drug Assistance Program (ADAP) waiting lists, the prospect for uninfected individuals to have affordable access to these drugs is unlikely.

SAC Call to Action

The National HIV/AIDS Strategy (NHAS) provides an opportunity for refocusing and strengthening federal, state, and local HIV prevention efforts. As the goals of NHAS are interdependent, reducing HIV incidence and improving health outcomes will require a concerted effort of federal, state, and local organizations working together. Only success at each step of the HIV continuum of care (e.g. identifying those with HIV through testing, linking and retaining them in care and ensuring prevention services such as sex and HIV/AIDS education, clean syringes, and innovative prevention options) can lead to the ultimate goals of improving health, extending healthy lives, and preventing further HIV transmission. To achieve these goals, SAC calls upon the following:

- Congress to provide adequate funding to implement new, innovative preventative interventions, such as PrEP.
- Federal leaders (such as the CDC and the FDA), state insurance companies, and state Medicaid agencies to increase access to evidenced-based, comprehensive prevention, treatment, and care, including PrEP and non-occupational Post-Exposure Prophylaxis (nPEP).
- Federal leadership to provide guidance to states regarding access to sterile needles and syringes, encouraging evidence-based methods, and rewarding states with federal support.
- The CDC, state, and local health departments to promote routine HIV testing for all populations with more frequent testing among high-risk populations.
- State and local health department programs to expand and monitor HIV testing and linkage to care, especially in high prevalence areas.
- Schools and school districts to implement the *National Sexuality Education Standards* to provide comprehensive, evidence-based sex education that includes medically accurate information about HIV.

F. Stigma and Criminalization

During the earliest days of the HIV/AIDS epidemic, ignorance, fear, and denial led to harsh, ugly treatment of people living with HIV/AIDS, as well as their friends, families, and allies. People were denied hospital care, thrown out of jobs, churches and families, and even denied dignified deaths. Some Americans even called for forced quarantine of all PLWHA.¹³¹ Stigma and discrimination faced by PLWHA was extremely high. This discrimination manifested in one of the greatest empowerment movements in our nation's history. However, even today PLWHA continue to face discrimination in numerous areas of life, including employment, housing, provision of health care, and access to public accommodations.¹³² Stigma attached to HIV infection directly undermines efforts to encourage individuals to learn their HIV status, causing individuals to both delay testing and to forego medical attention until their health deteriorates beyond denial. Additionally, disclosure of HIV-positive status to sexual partners and to other members of the community from whom understanding and support are needed becomes increasingly difficult.

The *American with Disabilities Act*, the landmark civil rights law that has proven vital in protecting people with disabilities including HIV, was enacted over twenty years ago. However, thirty-four states and two U.S. territories currently "...have laws that criminalize HIV exposure and/or nondisclosure of HIV status for sexual contact, needle-sharing, and/or contact with 'body fluids' such as saliva."¹³³ In addition, even in states that do not have specific laws on HIV exposure and/or disclosure requirements, PLWHA have been prosecuted under general criminal laws, such as attempted murder or assault. Between 2008 and 2010, at least eighty such prosecutions occurred.¹³⁴ In many jurisdictions, even when an HIV-positive person discloses his/her HIV status to a partner, takes precautions to prevent transmission (such as condom use during sex), or engages in conduct that presents no real risk of transmission, that person can be prosecuted and/or imprisoned. Examples of recent prosecutions shared by the Center of HIV Law & Policy include:

- A man with HIV in Texas is serving thirty-five years for spitting at a police officer;¹³⁵
- A man with HIV in Iowa, who had an undetectable viral load, received a twenty-five year sentence after a one-time sexual encounter during which he used a condom; his sentence was suspended, but he had to register as a sex-offender and is not allowed unsupervised contact with his nieces, nephews, and other young children;¹³⁶
- A woman with HIV in Georgia received an eight-year sentence for failing to disclose her HIV status, despite the trial testimony of two witnesses that her sexual partner was aware of her HIV positive status;¹³⁷ and
- A man with HIV in Michigan was charged under the state's anti-terrorism statute with possession of a "biological weapon" after he allegedly bit his neighbor.¹³⁸

¹³¹ *National HIV/AIDS Strategy for the United States* at 35.

¹³² *Id.* at 35.

¹³³ The Center for HIV Law & Policy, Positive Justice Project. *Guidance for People Living with HIV Who Are At Risk of, or Are Facing, Criminal Prosecution for HIV Nondisclosure or Exposure*, January 2011. <http://hivlawandpolicy.org/resources/download/580>. Accessed June 2012.

¹³⁴ The Center for HIV Law & Policy, Positive Justice Project, *Ending and Defending Against HIV Criminalization: State and Federal Laws and Prosecutions*, November 2010. <http://www.hivlawandpolicy.org/resources/view/564>. Accessed June 2012.

¹³⁵ *Ending and Defending Against HIV Criminalization* at 162.

¹³⁶ *Id.* at 61-62.

¹³⁷ *Id.* at 36-37.

¹³⁸ *Id.* at 85-86.

While HIV-related stigma, discrimination, and criminalization is a national issue, the trend is particularly pervasive in the South. Stigma and discrimination associated with HIV/AIDS are often enshrined in the laws in the southern United States. While some laws were initially enacted at a time when there was less knowledge about HIV transmission, research now clearly indicates that spitting and biting pose virtually no risk of HIV transmission, that condom use during sex prevents most transmissions, and that anti-retroviral treatment dramatically reduces HIV viral load and the risk of HIV transmission. However, prosecutions are not based on the facts of HIV infection or risks of transmission, but on the proof that a person knew that she/he had HIV at the time of contact.¹³⁹

Empirical trials and studies show that criminal laws as they are now written and enforced do not have a disease control function.¹⁴⁰ They are not effective in “...preventing the transmission of HIV or encouraging behaviors known to reduce the risk of exposing others to HIV.”¹⁴¹ Rather, these laws and policies complicate public health efforts by highlighting the distinctions between persons with HIV and uninfected persons.¹⁴² They reinforce misperceptions about the routes and risks of HIV transmission, further legitimizing the ignorance, homophobia, and racism that fuel inflated fears of HIV and those who are living with the disease.¹⁴³ These misperceptions promote stigma and, when acted upon, result in the unfair treatment of people living with HIV. For example:

- An Black woman in Mississippi is told that she and her children are banned from ever attending their church again;
- An HIV-positive retired schoolteacher, parent of four, and grandmother to fourteen, is denied access to a nursing facility on the Gulf Coast;
- An HIV-positive man is denied treatment at a Chiropractic Clinic in Tennessee because the doctor could not treat people “like him.”

The examples of HIV-related stigma are vast. However, if any hope exists to end the HIV/AIDS epidemic, working to end the stigma and discrimination experienced by PLWHA will be a vital component. “The success of public health policy depends upon the cooperation of the affected populations. People at high risk for HIV cannot be expected to, nor will they seek testing or treatment services if they fear that it would result in adverse consequences of discrimination.”¹⁴⁴ Establishing an environment where people feel safe getting tested and seeking treatment will require vigorous enforcement of the *Americans with Disabilities Act*, the *Fair Housing Act*, the *Rehabilitation Act*, and other civil rights laws, as well as reconsidering whether existing laws continue to promote public health goals.

¹³⁹ The Center for HIV Law & Policy, Positive Justice Project. *A New Strategy to End Civil and Criminal Punishment and Discrimination on the Basis of HIV Status: The Positive Justice Project*. Published November 2010. <http://www.hivlawandpolicy.org/resources/view/563>. Accessed June 2012.

¹⁴⁰ Burris, Scott; Beletsky, Leo; Bursleson, Joseph; Case, Patricia; Lazzarini, Zita. *Arizona State Law Journal. Do Criminal Laws Influence HIV Risk Behavior? An Empirical Trial* (2007). http://papers.ssrn.com/sol3/Delivery.cfm/SSRN_ID981428_code497260.pdf?abstractid=977274&mirid=1. Accessed June 2012.

¹⁴¹ Burris, Scott; Bray, Sarah; Zita Lazzarini. Center for Law and the Public’s Health at John Hopkins and Georgetown Universities. *Evaluating the Impact of Criminal Laws on HIV Risk Behavior* (June 2002). www.publichealthlaw.net/Research/PDF/HIV_Crim.pdf. Accessed June 2012.

¹⁴² Galletly, Carol L.; Pinkerton, Steven D. Department of Psychiatry and Behavioral Medicine, Center for AIDS Intervention Research (CAIR), Medical College of Wisconsin. *Conflicting Messages: How Criminal HIV Disclosure Laws Undermine Public Health Efforts to Control the Spread of HIV* (June 2006). www.ncbi.nlm.nih.gov/pubmed/16804750. Accessed June 2012.

¹⁴³ UNAIDS, Policy Brief: *Criminalization of HIV Transmission*, (2008).

www.unaids.org/en/media/unaids/contentassets/dataimport/pub/manual/2008/jc1601_policy_brief_criminalization_long_en.pdf. Accessed June 2012.

¹⁴⁴ *National HIV/AIDS Strategy for the United States* at 36.

SAC Call to Action

To be free from stigma and discrimination on the basis of HIV status is both a human and civil right.

To reduce stigma and discrimination experienced by people living with HIV, and further promote the public health goals stated in NHAS, SAC calls upon the following:

- The Department of Justice and federal agencies to continue and strengthen the enforcement of federal anti-discrimination and other civil rights laws.
- State legislatures to review and reconsider existing laws to ensure they are consistent with current knowledge of HIV transmission and proven public health approaches to prevent and treat HIV. Legislatures must remove punitive laws that single out people living with HIV or other STIs.
- Community-based organizations, businesses, schools, faith-based organizations, and society to take responsibility for affirming, non-discriminatory support for PLWHA.
- Communities to abolish racism, homophobia, misogyny, domestic violence, and disability discrimination. All efforts must be made not only to bring compassion to the front of the fight against AIDS, balanced by non-discriminating, science-based interventions and strategies.
- Doctors' offices, medical clinics, hospitals, health care providers, and social workers to participate in cultural sensitivity trainings.

III. Conclusion

HIV surveillance data from the CDC clearly indicate a disproportionate impact of HIV in the southern United States. The South has both the highest new HIV infection rates and the highest rates of individuals living with HIV. Additionally, HIV case fatality rates are particularly striking as people living with HIV in the South are dying faster than in any other region of the country. The exact causes of the disparate impact in the South are difficult to pinpoint, but numerous factors ranging from the greatest number of people on ADAP waiting lists to the least access to health care to inadequate prevention strategies all contribute. These issues are fueled by a wealth of structural barriers that plague the South, including poverty, high rates of STIs, shortage of health care professionals, rural geography, stigma, limited resources, health inequality, racial and ethnic disparities, and poor social determinants. Because HIV is a communicable disease, there are serious consequences for not adequately responding to the epidemic. As stated in the President's National HIV/AIDS Strategy, stemming this comprehensive and complex epidemic will require a holistic approach to HIV prevention and care that must extend beyond individual risk behaviors to also address mental health as well as contextual factors including, "...sexual and drug use networks, joblessness or homelessness and other [factors] that increase risk for infection."¹⁴⁵

Only through partnership and collaboration can we address the HIV epidemic in the South. Communities and states must work together to define the need, identify resources and opportunities, send messages to policy makers, and create coordinated, effective interventions. The Southern AIDS Coalition (SAC) would like to encourage all individuals to participate in HIV advocacy efforts in your state and in your community. Advocating in southern legislatures is often more difficult than in other regions of the country due to cultural differences among affected populations.

Additionally, advocating for funding in the South is made extremely difficult by

economic plight of states facing job loss, manufacturing closures, and the mortgage/housing crisis. However, there are several solutions for success, and we encourage you to use the *Southern States Manifesto: Update 2012*, and the advocacy page of our website (www.southernaidscoalition.org/advocacy) for your local, state, and national efforts.

Role of Advocates in Forming a Statewide Action Plan

To be heard, a message must resonate with its intended audience. Messages must be appropriate for the legislators, policy makers, and opinion leaders in each state. Before formulating a Statewide Action Plan for AIDS, advocates should first do an individual state assessment by taking the following factors into account:



South Carolina HIV/AIDS Crisis Task Force, "Your Voice Matters" Advocacy Training and "Visit Your Legislator" Activity, March 29, 2011. Pictured: 16-year-old, Caleb Brown, advocating with the administrative assistant of his Senator John Courson, who serves on the Medical Affairs Committee.

¹⁴⁵ National HIV/AIDS Strategy for the United States at 35.

- The commitment of the legislature, state agencies, and the executive branch.
- How funding decisions are made by each level of state government – the health agency, the Governor’s office, and the legislative process.
- The ability of HIV/AIDS agencies and grassroots groups to work together.

Understanding the political power in each state, and knowing the decision makers for funding and health care issues are essential. Advocating with the right people at the right time is an advocate’s key to success.

Role of SAC in Facilitating the Statewide Action Plan

One focus of SAC is to work as a facilitator in bringing community organizations and state agencies together. Through our unique partnership of government representatives, community organizations, advocates, PLWHA, and business entities, we are able to help state AIDS organizations meet their goals and use grassroots mobilization to activate stakeholders. Through ongoing forums, SAC is able to share best practices, provide needed technical assistance, and utilize strategic planning opportunities focused specifically on the needs of the South. The SAC Advocacy Leadership Council serves as the conduit for bringing grassroots advocates together for briefing on issues and concerns for PLWHA, developing policies, messages, and identifying strategic solutions.



Photo Credit: South Carolina HIV/AIDS Care Crisis Task Force

After completing a state assessment and developing an action plan, advocates must turn to their grassroots support to contact legislators and other policy makers to deliver the messages. Events such as “AIDS Day at the Capitol,” “Rally Around HIV,” and “Hill Visits at the State House,” bring faces and voices to the message. Legislators are most effectively persuaded by their own constituents. When

advocates develop relationships with local legislators and stay on message, grassroots efforts can have a profound impact. Coordinated efforts and careful preparations are keys to effective action.

The Southern AIDS Coalition (SAC) hopes that advocates will use the supportive data and information provided in *Southern States Manifesto: Update 2012* to become knowledgeable and skilled advocates for persons living with HIV/AIDS. Building public policy and advocacy skills, identifying community HIV prevention needs and solutions, effectively communicating issues to decision makers, and mobilizing members and leaders to action are all critical actions necessary for achieving SAC’s health outcome goals and reducing the HIV disease burden in the South.

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Oklahoma State Department of Health
South Carolina HIV/AIDS Council
Louisiana Office of Public Health
Maryland Dept. of Health & Mental Hygiene
Careteam, Inc.
Sisters Together and Reaching, Inc., MD
AIDS Alabama
Families First, GA
Nashville CARES, TN
Kentucky Department of Public Health
Virginia Department of Health
Acadiana C.A.R.E.S., LA
Florida Department of Health
Okaloosa AIDS Support and Informational
Services, Inc. (OASIS), FL
UAMS College of Public Health, AR
Texas Department of Health
International AIDS Empowerment, TX
Tennessee Department of Health
SC Dept. of Health & Environmental Control
NO/AIDS Task Force, LA
A Brave New Day, MS

Southern AIDS Coalition Staff

Michael Murphree, MSW, LCSW
Rainey Campbell, MPH, MBA

Executive Director
Program Director



The Southern AIDS Coalition (SAC) is a membership organization comprised of government representatives, community organizations, advocates, people living with HIV disease, and business entities. This unique partnership is a result of the burgeoning numbers of people in the South with infection rates much higher than the rest of the U.S. population, particularly for newly diagnosed cases. SAC promotes and supports highly effective advocacy coalitions and activities at the state and federal levels in sixteen states and the District of Columbia. We are committed to the development of accessible and high quality systems of HIV and STI prevention, care, treatment, support services, and housing throughout the South. SAC's direct actions to promote accessible and high quality systems related to HIV disease are achieved through targeted and broad-based, community-driven, effective advocacy efforts with state and local policy makers, federal policy decision makers, and national HIV/AIDS advocacy groups. SAC provides advocacy coaching for southern state advocacy leaders and meeting facilitation for growing advocacy coalitions in these states. The coalition framework of SAC enhances the utilization of our policy position statements used by federal and state policy decision makers.

The Southern AIDS Coalition

P.O. Box 55703

Birmingham, AL 35255

www.SouthernAIDSCoalition.org

email: membership@SouthernAIDSCoalition.org



Meet Michael Murphree...

SAC is pleased to announce the appointment of Michael Murphree as its new Executive Director. A lifelong resident of Alabama, Michael is a graduate of Auburn University at Montgomery and the University of Alabama. He received his Master of Social Work degree in 1989, and is licensed at the LCSW level. Michael brings with him more than ten years of senior level HIV/AIDS, mental health, and public health experience including agency development, professional and administrative supervision, grant project management, and professional speaking. In addition to his administrative service, he has direct care experience in Social Work, mental health counseling, and HIV prevention education. The majority of Michael's life has been spent living and serving in rural areas of Alabama. Having grown up in that environment led him to an extra sensitivity to the specific needs and cultural differences that rural communities present. This background was particularly helpful during his leadership at Montgomery AIDS Outreach in Montgomery, Alabama as the agency expanded its HIV specific medical care to rural communities in Southeast and West Alabama. He is a frequently requested speaker on Social Work, Case Management, Mental Health, and HIV/AIDS issues at state and local conferences and programs. Always seeking balance in his life, a major goal has been to find a strong mission and purpose on which to focus his professional energy. The Southern AIDS Coalition is the home to which he has been called for just that purpose in mind.



JOIN TODAY!

Sign up for SAC email alerts to stay informed about HIV/AIDS in the South

We welcome people living with HIV, advocates, social workers, medical providers, employees of AIDS Service Organizations, the pharmaceutical industry, educators, legislators, and anyone interested in the mission to ensure that all people with HIV disease receive care, treatment, housing, and prevention services necessary to maximize their ability to live healthy, independent, and stable lives.

Please provide all contact information possible.

Name: _____

Organization: _____ Position: _____ Phone: _____

Current Address: _____

City: _____ State: _____ Zip: _____

Email Address: _____

Cell phone: _____ Fax: _____ Alternate phone: _____

Please Print Mail, Email, or Fax To:

Southern AIDS Coalition

P.O. Box 55703

Birmingham, AL 35255

Fax: (205) 324-9311

Email: admin@SouthernAIDSCoalition.org

Southern States Manifesto: Update 2012
A Policy Analysis and Recommendations for HIV in the South

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