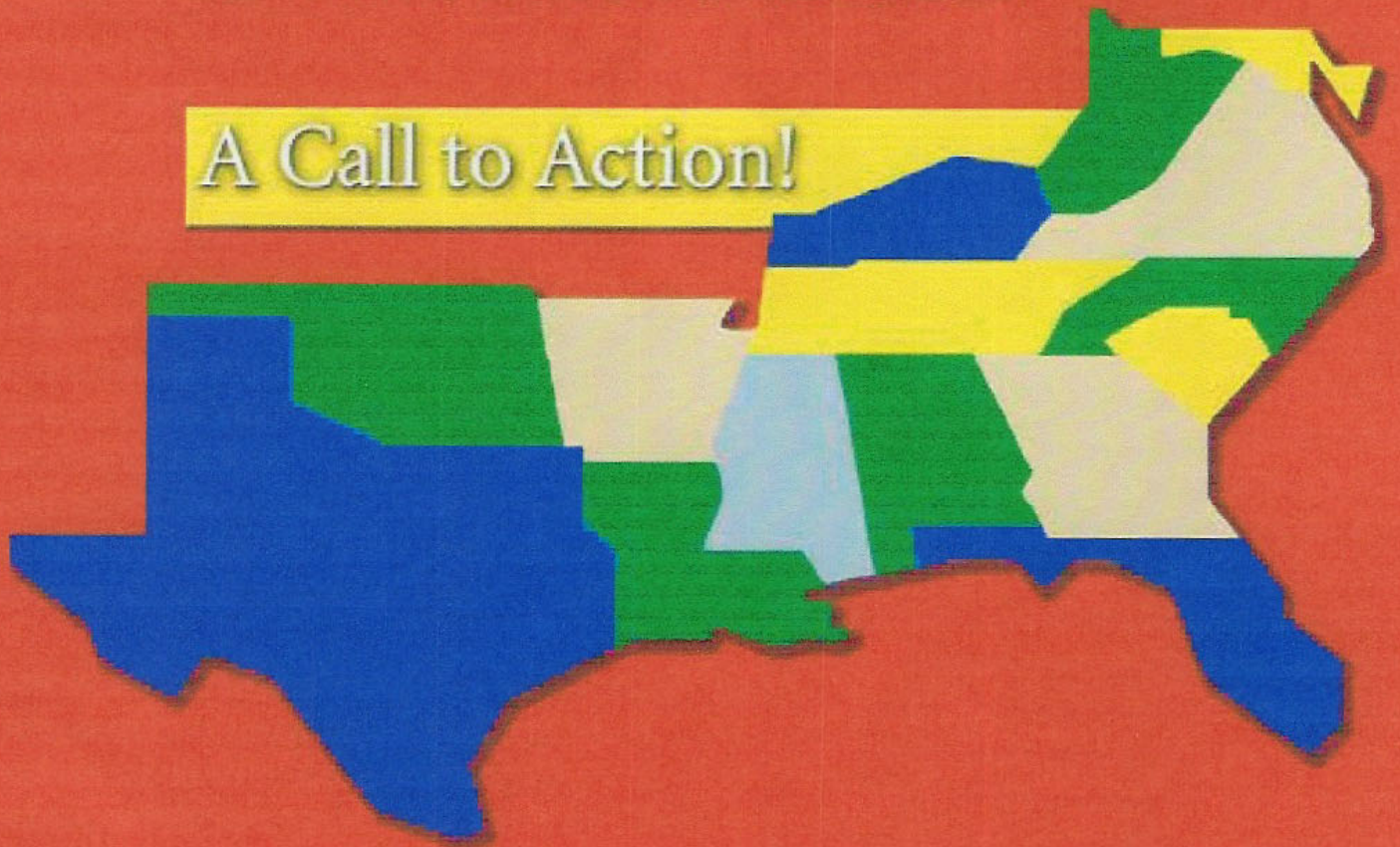


# Southern States Manifesto

HIV/AIDS & STD's in the South:

A Call to Action!



A project of the Southern State AIDS Directors Work Group in collaboration with the National Alliance of State and Territorial AIDS Directors and made possible through funding provided by CDC's Division of HIV/AIDS Prevention (DHAP) in the National Center for HIV, STD, and TB Prevention.

## SOUTHERN STATE AIDS DIRECTORS WORK GROUP



Dear Colleague;

Enclosed please find the *Southern States Manifesto, HIV/AIDS and STDs in the South: A Call to Action*. The Southern States Manifesto is the result of input based on the collective expertise and experience of each of the HIV/AIDS/STD directors and their community based partners in thirteen southern states and the District of Columbia – Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Texas, Virginia and West Virginia.

Evelyn Foust, Co-Chair  
Beth Scalco, Co-Chair  
Casey Blass  
Jane Cheeks  
Phyllis Cochran  
Brenda Crowder-Gaines  
Lisa Daniel  
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Tom Liberti  
Miguel Miranda  
Bill Pierson  
Kira Radke  
Kaleem Sayyed  
Thomas Shavor

Over the last decade, the HIV/AIDS and STD epidemics continue to increase in every southern locality, particularly among poor, disenfranchised, and minority populations. Southern state governments and localities are struggling to find resources for disease prevention, and care and treatment for the growing number of individuals living with HIV/AIDS and/or STDs. Efforts to address these epidemics are compounded by the fact that many southern states have poor health care infrastructures, large populations living in poverty, and the greatest numbers of uninsured persons in any area of the country.

The Southern States Manifesto outlines the barriers encountered in access and delivery of prevention and care services, describes Southern AIDS and STD Directors beliefs related to each issue and delineates a call to action. The document also describes each of the targeted areas of concern that must be addressed in order to provide a systematic and comprehensive approach to the emergent issues facing the South.

It is urgent that leaders in federal, state, and local governments and leaders in local communities recognize the disparate impact of HIV and STDs in the South. We ask you to review the Southern States Manifesto and to partner with us to achieve the calls to action that are necessary to improve health outcomes for southern citizens.

If you have questions, comments or would like to discuss the Southern States Manifesto, you may contact Evelyn Foust at 919-733-0490 or Beth Scalco at 504-568- 7474. You may also contact the HIV/AIDS/STD director in your state.

Respectfully,

Evelyn Foust, Branch Head  
HIV/STD Prevention & Care Branch  
North Carolina Department of Health

Beth Scalco, Administrative Director  
Louisiana DHH/OPH HIV/AIDS Program  
Louisiana Department of Health



**Southern State  
AIDS/STD Directors Work  
Group**

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# **Southern States Manifesto**

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## **HIV/AIDS and STDs in the South: A Call to Action**

Alabama Arkansas District of Columbia Florida  
Georgia Kentucky Louisiana Mississippi  
North Carolina Oklahoma South Carolina Tennessee  
Texas Virginia West Virginia

**MARCH 2, 2003**

**Manifesto:**

*A public declaration of principles, policies, or intentions, especially of a political nature.*

The American Heritage Dictionary of the English Language: Fourth Edition. 2000.

# **ACKNOWLEDGEMENTS**

The Southern State AIDS/STD Directors Work Group especially thanks:

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## National Organization Endorsements:

“The *National Alliance of State and Territorial AIDS Directors* (NASTAD) and the *National Coalition of STD Directors* (NCSD) endorse the Southern States Manifesto. We commend the Southern State AIDS/STD Directors’ collective effort to bring attention to the STD/AIDS crisis in this part of the country. NASTAD and NCSD commit to working with the Southern State AIDS/STD Directors to help achieve the calls to action outlined in this document.”

## The following participants of the “Southern States Summit on HIV/AIDS and STDs: A Call to Action” agreed to support the Beliefs and Calls to Action set forth in this Manifesto:

Ronald Brabson	Tennessee Association of People with AIDS
Hubert Brandon	Selma AIR
Michael Cassell	Mississippi Department of Health
J. Steve Cline	North Carolina Department of Health
Gene Copello	Florida AIDS Action
Pastor Gwendolyn Curry	Present Day Cares, Charlotte, NC
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Mary Ann T. Green	Florida AIDS Action
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Leslie Kooyman	Metrolina AIDS Project
Lee Langston	AR HIV/AIDS Policy Task Force
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**SOUTHERN STATES MANIFESTO**  
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## **EXECUTIVE SUMMARY**

### **SOUTHERN STATES MANIFESTO HIV/AIDS and STDs in the South: A Call to Action**

*"I am a firm believer in the people. If given the truth, they can be depended upon to meet any national crisis. The great point is to bring them the real facts."*

*Abraham Lincoln*

**There is an emergency underway in the southern states of the United States.** There is a pressing necessity to address the unique epidemics of human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS) and sexually transmitted diseases (STDs) in the South and their disparate impact on southern citizens.

As the HIV/AIDS epidemic continues to increase in every southern locality, state governments struggle to find public dollars for disease prevention interventions and care, support and treatment of people living with HIV/AIDS and/or STDs. The epidemic increasingly and disparately includes poor and disenfranchised populations.

If we are to sustain the lives of individuals currently living with HIV/AIDS and STDs, we must provide a standardized and coordinated delivery system in the southern states, encompassing a comprehensive range of services for individuals or families with HIV/AIDS and STDs to meet their health care and psychosocial service needs throughout all stages of illness. If we are to sustain the lives of individuals currently not living with HIV/AIDS and STDs, we must provide prevention interventions proven effective in the southern states, taking into consideration the cultural norms of the South which prohibit southern citizens from speaking openly about sexual issues, even age appropriate prevention messages.

The HIV/AIDS epidemic in the South will affect a significant proportion of young adults aged 20-45 during their most productive years. It was estimated early in the epidemic that for the first 10,000 AIDS cases in the United States, the average cost of years of potential life lost equaled about \$480,000 per death or \$4.6 billion total (JAMA, 1986). As AIDS deaths continued to climb among young adults, the average cost of years of work lost increased.

According to more recent research, three-drug combination therapy for AIDS, in spite of its expense, is a cost-effective use of resources. Combination therapy was associated with a near doubling in life expectancy for patients with advanced AIDS thereby reducing the average cost of potential life lost. This leads to a figure of \$23,000 per quality-adjusted year of life saved, a measure of the costs to improve and extend life. **This value is similar to that involved in the treatment of high blood pressure, and it is more cost-effective than treating high cholesterol or breast cancer in non-AIDS patients (Freedberg et al. JAMA, 2001 and New England Journal of Medicine, 2001).**

According to a study conducted in 2001, utilizing data from the Agency for Healthcare Research and Quality's (AHRQ) HIV Cost and Services Utilization Study (HCSUS), each state determines financial and medical eligibility criteria, drugs covered, and other key aspects of the programs, with some states covering as few as 20 HIV-related drugs and others covering more than 100. If states offered more instead of less generous ADAP benefits – for example, few or no limits for drug prescriptions per patient, total monthly costs would fall a significant 30%. Much of the decline in costs could be attributed to a reduction in average hospitalization costs from \$750 to \$395 (Goldman, Bhattacharya and Leibowitz et al, 2001).

Life sustaining medications related to a diagnosis of HIV disease, consistent with Public Health Service (PHS) recommendations and guidelines, must be available to everyone that is HIV positive, under 200% of the federal poverty level and residing in the United States. HIV/AIDS is both a personal and public health issue. **It is unacceptable, counter productive and contrary to the vision of a compassionate society for anyone in this country to be unable to obtain, on a regular and guaranteed basis, medications that improve and prolong their lives, facilitate their positive contributions to family and the economy and help to reduce the further spread of this pandemic.**

Southern states continue to experience problems often encountered when serving vulnerable populations in a less than adequately funded environment. Not all individuals living with HIV/AIDS are referred to a provider with expertise in treating HIV/AIDS and in some instances problems have been identified concerning the quality of care these patients receive. Provision of prevention therapy and appropriate use of anti-retrovirals are particular concerns. Creation of uniform treatment protocols developed by experts in the care of HIV/AIDS and utilized by all southern states would not only enhance services for individuals living with HIV/AIDS, but would foster enhanced management of Ryan White CARE Act programs, including the HIV Drug Assistance Program.

In addition, several studies confirm that stable housing is one of the greatest needs of persons living with HIV/AIDS. Without stable housing, individuals living with HIV/AIDS cannot access the complex treatment and care vital to survival. Research has confirmed that stable housing, coupled with supportive services responsive to their complex needs, increases the ability of persons living with HIV/AIDS, particularly those who are poor and low-income, to access and comply with life-sustaining HIV/AIDS treatment. The Housing Opportunities for Persons with AIDS (HOPWA) Program, administered by the Office of HIV/AIDS Housing at the Department of Housing and Urban Development (HUD), provides funding to eligible jurisdictions across the country to address the compelling housing needs of persons living with HIV/AIDS and their families.

AIDS is an impoverishing disease that increases the risk of homelessness and disproportionately affects very low-income persons and communities of color. Statistics reported to HUD by HOPWA grantees reflect that demographic disparity. Clients benefiting from HOPWA-supported housing were reported as: 53% Black/African-American, 21% Latino/Latino, 1% Asian/Pacific Islander, and 1% Native American /Alaskan Native. The remaining 24% were White/Caucasian; 91% of all HOPWA clients were persons/ households with monthly incomes of less than \$1,000, and more than 50% of those households earned less than \$6,000 per year (HUD, 1999).

A lack of knowledge among political leaders and the general population about HIV/AIDS and STDs combined with a lack of adequate funding, hinders HIV/STD prevention efforts, creates barriers to

care service delivery, inhibits adequate local and state support, and allows discrimination and myths to continue to impact the health outcomes of southern citizens.

### What makes the HIV/AIDS and STD epidemic unique in southern states?

**Poor Health Infrastructure:** In some states, due to limited resources, persons with HIV must become considerably ill before obtaining access to necessary care. These predominately rural states are generally poorer, have higher unemployment rates, and are less educated than more metropolitan counterparts (Rural Health in the United States, Ricketts, 1999).

**Changing Epidemic:** The epidemic is changing; the face of HIV/AIDS is becoming increasingly rural, female, black and heterosexual (Rural Health in the United States, Ricketts, 1999). Seven of the states with the ten highest AIDS case rates in the nation are located in the South (CDC, 2002).

While the South represents a little more than one-third of the U.S. population (38%), it now accounts for 40% of people estimated to be living with AIDS and 46% of the estimated number of new AIDS cases (Kaiser, 2002).

Among the 25 metropolitan areas (with a population of 500,000 or more) with AIDS case rates in 2001 above the national average for areas of this size, 18 were in the South. In addition, 6 of the metropolitan areas with the 10 highest AIDS case rates were in the South (Kaiser, 2002). **In the early days of the epidemic, the epidemiology of the disease indicated that the major U.S. cities carried the burden of increase in the number of new AIDS cases, epidemiology now shows that the epidemic is drastically and quickly increasing in the South.**

**Socioeconomic Factors:** The national percentage of population living in poverty is 12.1%. Eight of the top ten states listed as having the highest percentage of population below the Federal Poverty Level are located in the South ranging from 15% below poverty to an astounding 19.1% of the population living in poverty. Nine of the top ten states with the lowest percentage of high school graduates are in the South, with the lowest percentage of non-graduates at a staggering 25.4% compared to the National average of 17.9%. Six of the Southern states have household median incomes of less than \$35,000 annually (Census, 2000). Seven of the fifteen states with the highest rates of unemployment were southern states (Bureau of Labor Statistics, 2002).

**Lack of Affordable Housing:** HIV disease is disproportionately represented in communities of poverty where stable housing environments are sorely lacking. Without stable housing, the spread of HIV continues as individuals are disadvantaged to access healthcare and forced to prioritize food, shelter, and clothing over a stable living environment. Homelessness causes a continuation of risky behaviors for survival on the streets where sex is traded for shelter and food. Those already infected with HIV are not able to be compliant with medication or adhere to strict dosage requirements for maximum efficacy of medicines.

There is a severe and worsening shortage of low income housing in the South, including rental housing, affordable to extremely low-income renters. In 1999, for every 100 renter households

in the U.S. with incomes below 30% of area median, there were only 40 units both affordable and available for rent by them. This represents a 15% decrease from 1991. While 26% of very-low-income renters in the South received housing assistance in 1999, 45% of unassisted very-low-income renters had worst case housing problems (HUD, 1999).

**Racial Disparity:** The South includes almost 19 million African-Americans among the 100 million people living in the region, or almost 19% of the population. The region with the next largest total within their population is the Midwest, with almost 6.5 million African-Americans among their almost 65 million people (approximately 10%). (Census, 2000).

HIV/AIDS is increasingly a disease of minorities, especially African-Americans, with almost 38% of the cumulative cases and an average of 49% of newly reported (during 2000 and 2001) cases being within the African-American population.

**Rapid Increase in Reported Cases of HIV/AIDS:** The South comprises an increasing share of the estimated number of new AIDS cases (AIDS incidence) diagnosed each year, rising from 40% in 1996 to 46% in 2001. Estimated AIDS incidence in the Northwest, West, and Midwest regions, as a proportion of overall incidence, either decreased over this same period or remained constant (Kaiser, 2002).

**High Rates of Other Sexually Transmitted Diseases:** Southern states historically maintain higher rates of sexually transmitted diseases (STDs) than other regions of the country. In 2000, seven of the ten states with the highest chlamydia rates were in the South. Similarly, all of the states with the highest rates of gonorrhea and nine of the top ten states for infectious syphilis rates were located in the South. Most experts believe the reasons for these higher rates in the South include differences in the racial and ethnic distribution of the population, poverty, and availability and quality of health care services (CDC, 2001).

Sexually Transmitted Diseases (STDs) in the United States Select Data <sup>1</sup> by Region and State/Territory, 2000						
State/Territory	Chlamydia Case Rate Per 100,000 (2000)	Chlamydia Case Rate Rank <sup>2</sup>	Gonorrhea Case Rate Per 100,000 (2000)	Gonorrhea Case Rate Rank <sup>2</sup>	Primary & Secondary Syphilis case rate per 100,000 (2000)	Primary & Secondary Syphilis Case Rate Rank <sup>2</sup>
United States	257.5	--	131.6	--	2.2	--
South	296.6	1	191.8	1	3.8	1
Northeast	179.7	4	92.3	3	0.7	4
West	264.7	2	59.4	4	1.0	3
Midwest	254.5	3	142.0	2	2.0	2

Notes: 1. Data represent reported cases.

2. U.S. Territories, dependencies, possessions, associated nations not included in regional or state rankings.

Source: Centers for Disease Control and Prevention, *Sexually Transmitted Disease Surveillance, 2000, 2001*

As compiled by The Henry J. Kaiser Family Foundation, *HIV/AIDS and other Sexually Transmitted Diseases (STDs) in the Southern Region of the United States: Epidemiological Overview (Draft Document)*.

These high rates of other STDs which disproportionately impact African-Americans and other minorities, is particularly concerning as STDs increase the risk of HIV transmission and are contributing to the spread of HIV in the South.

***Lack of Health Insurance:*** The South is home to the greatest numbers of uninsured persons (an estimated 17 million). Residents of the South are more likely than average to be uninsured. A multivariate analysis of 60 communities across the United States, whose uninsured rates ranged from 5% to 29%, found that “Population characteristics, employment, and unexplained or unmeasured geographic variations account for most of the differences”. The variation in uninsured rates is attributable to a combination of differences in racial and ethnic group composition, a combination of income and education, employers’ characteristics, employment rates, and differences in Medicaid eligibility guidelines among states (Coverage Matters: Insurance and Health Care, 2001).

Lack of health insurance is linked to less access to care and more negative care experiences for all Americans according to a recent survey conducted by the Commonwealth Fund. Latinos and African-Americans are most at risk of being uninsured. Nearly one-half of working-age Latinos (46%) lacked health insurance for all or part of the year prior to the survey, as did one-third of African-Americans (Commonwealth Fund, 2002).

*It is urgent that leaders in federal, state and local governments and leaders in local communities recognize the disparate impact of HIV/AIDS and STDs in the South and commit to immediate action that will ensure improved health outcomes for southern citizens.*

The Southern States Manifesto is the result of input based on the collective expertise and experience of each of the HIV/AIDS/STD directors in fourteen southern states and the District of Columbia – Alabama, Arkansas, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia. These southern state AIDS/STD directors met in Nashville, Tennessee in June 2002 to discuss the unique and critical challenges shared among the southern states and to develop a corrective action plan. This document is a result of that meeting and subsequent work group activity.

The Southern State AIDS/STD Directors Work Group, NASTAD and the Kaiser Family Foundation held *A Southern States Summit on HIV/AIDS and STDs: A Call To Action* in Charlotte, North Carolina, November 13-15, 2002. The Summit brought together community members, state legislators and health department employees to review the HIV/AIDS and STD crisis in the South and refine discussions of future strategies. Summit participants also reviewed a draft of the Southern States Manifesto and made recommendations for improvement. The community members embraced the Manifesto and provided valuable input into the further development of the document.

In addition, this Manifesto was utilized as the foundation for discussions during the Southern AIDS Conference convened by Florida AIDS Action in Tampa, Florida, December 3-4, 2002. That conference brought together over 100 community and governmental leaders from 13 southern states and the District of Columbia representing Ryan White CARE Act Titles I, II (including AIDS Drug Assistance Programs (ADAPs), III, and IV; AIDS Education and Training Centers (AETCs); prevention; housing; and Medicaid. The participants of this meeting

endorsed the Manifesto and developed a Southern AIDS Coalition to advocate for the needs presented by the epidemics of HIV/AIDS and STDs in the southern United States.

Southern State AIDS/STD Directors Work Group members combined their collective experience with published research to develop and release the *Southern States Manifesto, HIV/AIDS and STDs in the South: A Call to Action*, a document developed by southern states AIDS directors and their staff members, with support from the National Alliance of State and Territorial AIDS Directors (NASTAD).

To organize thought around the issues, this document outlines the barriers encountered in access and delivery of prevention and care services, describes southern state AIDS directors beliefs related to each issue and delineates a call to action. This manifesto also describes each of the targeted areas of concern we believe must be addressed in order to provide a systematic and comprehensive approach to the emergent issues facing the South. Those areas are Leadership, People of Color, Partnerships, Infrastructure, Funding and the State's Role. In addition, this document includes a section specific to the role of Research and Evaluation in laying the groundwork for change.

**Southern States Manifesto**

## HIV/AIDS and STDs in the South: A Call to Action

*“It is the duty of every citizen according to his best capacities to give validity to his convictions in political affairs.”*

*Albert Einstein*

**Problem Statement**

The rural South has continued over the last decade to face unique and critical challenges in responding to the country’s HIV/AIDS and STD epidemics. Many states in the South consistently lead the nation in reported cases of syphilis, chlamydia, gonorrhea, and AIDS. The South has the greatest proportion of persons living with AIDS compared to other geographic regions of the United States. HIV and syphilis have disproportionately impacted communities of color, who are also historically, economically and socially disadvantaged. African-Americans, especially women living in southern states, have been disproportionately affected. Studies have shown that southern, rural African-American women are at increased risk of acquiring HIV and in as many as 60% of the cases, the mode of transmission was determined to be heterosexual sexual contact, often tied to syphilis outbreaks (Rural Health in the United States, Ricketts, 1999).

African-Americans are at risk for HIV infection and other sexually transmitted diseases, not because of their race/ethnicity, but because of risk behaviors that increase the likelihood for transmission of HIV and other STDs. Socio-economic and cultural factors such as access to health care, education and prevention services add to the risk for transmission. In addition, African-Americans are more likely to have STDs because they are less likely to seek treatment. Lack of health insurance, lack of trust in care and limited positive experiences with care providers are just a few of the reasons African-Americans fail to seek treatment. Untreated STDs increase the risk of HIV transmission from an infected person not in care for substantially greater periods of time than for persons engaged in care.

In the South, unemployment, poverty and lack of health insurance are significant co-factors that lead to higher rates of risk behaviors for HIV and STD transmission. Poverty is also linked to higher use of illicit drugs. Many African-Americans are more likely to have little or no health insurance because they have low incomes. This limits their access to health care or prevents some from seeking health services at all, as they are less able and willing to navigate the very complex system for obtaining government insurance.

More African-Americans live in communities with high rates of sexually transmitted diseases. Having an STD increases the risk for transmission of HIV. Stigmatization of HIV risk behaviors within African-American communities also inhibits many at risk from accessing testing or care. All these factors contribute to alarming infection rates. This is unacceptable. The South's rural environment, inequities in health care resources and the increased stigma associated with HIV/AIDS and STDs contribute to the increased risk of individuals acquiring HIV and STDs and if infected, not seeking or acquiring essential care and treatment services.

Currently, Medicaid is the largest single payer of direct medical services for People Living with AIDS (PLWA) in the United States, serving approximately 55% of all PLWAs and up to 90% of all children with AIDS. Most adults with HIV disease who qualify for Medicaid do so because they are disabled, have low income, and limited assets. Others in families with dependent children may become eligible for Medicaid by meeting certain income and resource standards. In many States individuals who would be ineligible due to income or resources may become Medicaid eligible based on their medical expenses (CMS, 2002).

States must provide the full range of Medicaid services covered in the State plan to eligible persons with HIV disease, and they may also provide optional services that are often appropriate for people with HIV/AIDS, such as targeted case management, prevention services, and hospice care. Currently, all States cover FDA-approved drugs, including various drugs for prophylactic treatment of AIDS-related opportunistic infections, and drugs for treatment of primary HIV disease, such as protease inhibitors and nucleoside and non nucleoside reverse transcriptase inhibitors (CMS, 2002). However, some states are currently considering prescription limitations within their Medicaid programs. There is an inequity in federal funding for HIV/AIDS prevention and care services, particularly in the southern region of the country compared to the burden of disease.

Adequacy of coverage and eligibility for Medicaid is the key. Many individuals living below the federal poverty level are unable to access Medicaid benefits. The solution is that there must be Medicaid expansion in which State Medicaid Programs can better negotiate for enhanced federal match dollars. The bottom line is that there must be essential basic access to primary medical care and life sustaining drugs. Along with Medicaid expansion, HRSA must provide additional funding to the South. To compliment Medicaid expansion, HRSA must fully fund AIDS Drug Assistance Programs to allow eligibility at 200% of the federal poverty level, regardless of the geographical location of the State. Every individual living with HIV/AIDS in the United States deserves equal access to care and treatment.

According to the Health Resources and Services Administration (HRSA) 2002-2003 Annual Report, federal and state expenditures for people living with HIV disease are estimated to be \$7.7 billion in FY 2002, almost 4 times that of the CARE Act (\$1.9 billion in FY 2002). Yet the CARE Act reaches more than twice as many people—estimated 533,000 people, compared with 212,000 for Medicaid. This illustrates that the overall CARE Act program is significantly under funded.

In addition, evidence exists that patients who are diagnosed in major urban centers often return home to rural areas for family support. However, much of the federal funding is distributed based on where a person was diagnosed. This has a tremendous impact on communities already stressed by lack of access to basic health care needs (Rural Health in the United States, Ricketts, 1999).



## Current Federal Resources

- Federal Ryan White Title II funds are distributed to states by a formula based on each jurisdiction's non-EMA reported living AIDS cases over the most recent ten-year period. States with fewer than 90 living cases receive a minimum Title II base grant of \$200,000, and states with over 90 living AIDS cases receive a minimum of \$500,000. U.S. territories receive a minimum of \$50,000. States with more than one percent of total AIDS cases reported in the U.S. during the previous two years must contribute a match with their own resources. AIDS Drug Assistance Program (ADAP) earmark awards are based on a formula using each jurisdiction's reported living AIDS cases (EMA and non-EMA) over the most recent ten-year period. HRSA utilizes a formula that determines the amount each state is allocated. The more AIDS cases a state has reported, the more funds allocated. There does not appear to be any comparable formula for the distribution of CDC prevention funds to states.
- Federal Ryan White Title II funds, distributed based on a formula, appear to be reasonably distributed across states – variations in the funding allocations and numbers of People Living with AIDS are relatively small. However, when Title I funds are added to the funding allocation/PLWA calculation, the variations increase significantly. This results in extreme differences in the funds available and the amount and types of services that can be provided to PLWAs in states with Title I grantees versus Title II-only states.
- Overall the southern states have historically received less federal dollars for HIV/AIDS care as compared to the rest of the nation. The federal (HRSA) appropriation per (estimated) AIDS case for HIV care activities in 2001 was:
  - \$5,625/AIDS case for the United States as a whole; and
  - \$5,184/AIDS case for the southern states (average of states)
- Overall the southern states have historically received fewer federal dollars for HIV/AIDS Prevention as compared to the rest of the nation. The federal (CDC) appropriation per (estimated) AIDS cases for HIV prevention activities in 2001 was:
  - \$1,766/AIDS case for the United States as a whole; and
  - \$1,579/AIDS case for the southern states (average of states)

*Source: CDC/HRSA data prepared by North Carolina Dept. of Health*

*Note: This is preliminary data and will require further study.*

There are now epidemiological, biological, and intervention trial data linking HIV and other STDs. Well designed studies from four continents, including North America, have confirmed at least a three- to five-fold increase in risk of new HIV infection associated with other STDs. Researchers have now documented not only that STDs facilitate sexual transmission and acquisition of HIV, but also that treatment of STDs reduces the spread of HIV (CDC, 1998).

Most of the health districts with the highest rates of syphilis and gonorrhea are concentrated in the South, where HIV prevalence among childbearing women is also highest in the country. While the heterosexual spread of HIV among young women in the United States is strongly associated with the epidemic among injecting drug users, it also is associated with the spread of HIV infection

among women in the United States through heterosexual transmission closely paralleling other STD epidemics. In addition, about one-fifth (22% at the end of 1999) of people estimated to be living with AIDS in the South are women (CDC, 2001).

The epidemic of other STDs which disproportionately impacts African-Americans is also contributing to the spread of HIV. In a recent study, CDC researcher William Kassler, M.D. examined data from 1990-1997 to identify areas dually impacted by the STD and HIV epidemics. Kassler found that the impact of HIV, syphilis and gonorrhea is highest in the southern region of the United States. A national review found that only 50 percent of local health departments provide any STD treatment services and many lack evening or weekend services. An estimated 90% of clinics in areas with high rates of STDs turn clients away due to limited resources. The lack of STD treatment services in highly impacted areas is contributing to the spread of HIV. The rates of these treatable and curable STDs are skyrocketing among African-Americans and contributing to the further spread of HIV/AIDS (Maldonado, 1998).

The purpose of this document is to make recommendations to increase public awareness of the barriers to the provision of prevention and care services for individuals living with HIV/ AIDS and STDs in the South and to provide a plan to alleviate the barriers. Working together, state AIDS/STD directors, elected officials and community partners can dramatically improve prevention interventions and treatment services to improve public health outcomes in southern states.

## **Contributing Factors**

There are many factors that contribute to barriers in the provision of prevention and care services in the South. The South has fewer large metropolitan centers than other parts of the country, with a larger proportion of its population living in rural areas. This results in a shortage of high quality health care personnel because professionals often choose to practice in large cities. The scarcity of qualified providers is especially acute in rural areas, where transportation to care can be a major service barrier. A limited number of dental providers are frequently cited by Ryan White Care Act Grantees as a major barrier, especially for people with HIV infection.

Helene D. Gayle, MD, MPH, formerly with the CDC and currently working with the Bill & Melinda Gates Foundation, stated that "In many of our rural areas, the health infrastructure is not as extensive as it is in urban areas". Unlike cities, which often have a number of physicians who specialize in treating HIV/AIDS and other infectious diseases, rural areas tend to have practitioners with little experience in treating HIV infected patients (Stephenson, 2000)

Syphilis epidemics in parts of the rural South during the late 1980's and early 1990's, coupled with epidemic rates of crack/cocaine use, have frequently been cited as leading co-factors of HIV infection in both rural and urban areas of the United States (Forney & Holloway, 1990). In 1998, half of all syphilis cases were confined to 1 percent of United States counties. These cases of syphilis were found in 28 counties, primarily located in the South. In addition to higher rates of syphilis in the 28 counties, higher rates of syphilis were also reported in three independent cities – Baltimore, St. Louis and the District of Columbia (CDC, 1999).

In 2000, the South had the highest case rates for chlamydia, gonorrhea and primary and secondary syphilis in the nation. Rates of gonorrhea and primary/secondary syphilis have been higher in the

South, compared to other regions throughout the last two decades. Chlamydia rates have been higher in the South since 1997 (CDC, 2001).

Combination therapy with protease inhibitors and changing demographics of the AIDS epidemic have cast a spotlight on rural health care professionals' abilities to keep pace with the disease. For example, in some rural areas of Georgia, Mississippi, and South Carolina, women make up one fourth of cumulative reported AIDS cases, well beyond the national figure of 15%. Yet, in those rural areas, few efforts are aimed at providing women with education about HIV or testing to detect HIV infection (JAMA, 1998).

In addition, without sufficient qualified staff within the local health department system, there is limited ability to collect data on behavior and develop appropriate evidence-based interventions. For example, there are no demonstrated evidence-based interventions for non-identifying African-American men who have sex with men (MSM), especially in rural areas.

There are many medical co-factors that complicate care and treatment for individuals living with HIV/AIDS. An increase in medical providers in the rural South, use of national standardized medical guidelines and patient adherence to prescribed medications would ensure that all individuals living with HIV have access to treatment, including co-infections.

About one quarter of HIV-infected persons in the United States are also infected with hepatitis C virus (HCV). HCV is one of the most important causes of chronic liver disease in the United States and HCV infection progresses more rapidly to liver damage in HIV-infected persons (CDC, 2001).

HCV infection may also impact the course and management of HIV infection. Prevention of HCV infection for those not already infected and reducing chronic liver disease in those who are infected are important concerns for individuals living with HIV and their health care providers. HIV/HCV co-infected patients should receive hepatitis A and hepatitis B (HBV) vaccinations because the risk for hepatitis A is increased in persons with chronic liver disease and most HIV positive individuals are at risk for HBV infection (CDC, 2001).

Another co-infection that is a contributing factor to increased barriers to care in the South is Tuberculosis (TB). An estimated 10-15 million Americans are infected with TB bacteria and about 10% of these infected individuals will develop TB at some point in their lives. However, the risk of developing TB disease is much greater for those infected with HIV and living with AIDS. Because HIV infection so severely weakens the immune system, people dually infected with HIV and TB, are at a 100 times greater risk of developing active TB disease and becoming infectious compared to people not infected with HIV. CDC estimates that nearly 30 percent of cases among people ages 25 to 44 are occurring in HIV positive individuals (CDC, 1999)

This high level of risk underscores the critical need for targeted TB screening and preventive treatment programs for HIV-infected people and those at greatest risk for HIV infection.

Another barrier to care in the South is the need for substance abuse and mental health treatment. According to CDC, in the United States, drug use and dependence are widespread in the general population. Experts generally agree that there are about 1 million active Injecting Drug Users (IDU) in this country, as well as many others who use non-injection drugs or abuse alcohol. Clearly, the need for substance abuse treatment and mental health treatment vastly exceeds our capacity to provide it. Effective substance abuse treatment, coupled with sufficient mental health treatment that helps people stop using drugs, not only eliminates the risk of HIV transmission from sharing

contaminated syringes, but for many, reduces the risk of engaging in risky behaviors that might result in sexual transmission of disease. **For injection drug users who cannot or will not stop injecting drugs, using sterile needles and syringes only once remains the safest, most effective approach for limiting HIV transmission** (CDC, 2002).

Unfortunately, the correlation between mental illness and chemical dependency are extremely strong with unstably housed southern citizens struggling with these co-factor diseases. There are no effective means of treatment for this large population without dedicated housing units to serve as the stabilizing force for someone facing these challenges. It is also well known that this population is more likely to participate in behaviors that continue the transmission of HIV in order to have food, shelter, and clothing. Housing with supportive services available on an “as needed” basis has proven to yield the best long term result for those living with HIV who are mentally ill and/or suffer from chemical dependence.

These contributing factors result in an overburdened care system, where individuals experience limited access to life-prolonging basic AIDS drugs, early STD screening and treatment, HCV and TB screening and treatment, substance abuse and mental health services and housing. These factors, coupled with the social norms of the South, create barriers unique to the South although other areas of the country experience some of the same factors in the provision of care and services to individuals living with HIV/AIDS.

### **HIV/AIDS Related Stigma**

HIV/AIDS/STD related stigma, and associated discrimination, is known to negatively affect all aspects of HIV/STD prevention, diagnosis, treatment and care (Brown et al 2001). Stigma includes prejudice and active discrimination directed toward persons either perceived to be or actually infected with HIV and the social groups and persons with whom they are associated (Herek, 1999).

HIV/AIDS first affected groups of people who were already socially marginalized (men who have sex with men, sex workers and drug users). Therefore, stigma attached to HIV/AIDS is often layered upon pre-existing stigmas of sexual behavior and drug use (Herek & Glunt 1988, Maluwa et al 2001). Many individuals still believe that all people living with HIV/AIDS are members of these socially marginalized groups.

Southern AIDS/STD directors have verified that stigma associated with the HIV/AIDS epidemic is still a reality and know that it is a deterrent to the provision of quality medical care, prevention interventions and social support services. It is difficult to provide a service if individuals in need do not access the service for fear of the social repercussions associated with HIV/AIDS. Many individuals living with HIV/AIDS are not only faced with a chronic disease and related family issues, but also the need to access food, clothing, shelter and treatment assistance. HIV/AIDS related stigma adds an additional layer to their already seemingly insurmountable challenges.

According to a study reported in the March, 2002 issue of the *American Journal of Public Health*, many Americans still express fear and discomfort about people with AIDS. In 1999, 30% of those polled would feel uncomfortable having their children attend school with another

child who has AIDS, and 22% would feel uncomfortable around an office coworker with AIDS. In addition one in five people surveyed felt afraid of individuals living with AIDS.

The Centers for Disease Control and Prevention (CDC) states that “stigma hampers prevention” and lists research and programmatic strategies to minimize the impact of stigma on HIV prevention efforts in their 5 year HIV Prevention Strategic Plan (January 2001).

Amy Lansky, PhD, MPH, of the CDC, led a study of *Rural HIV/AIDS in the United States*. Results of the study showed that people in rural areas appear to perceive that their risk of HIV infection is low because they think only gay men and injection drug users are infected. Ms. Lansky stated, “But more of the people in the rural areas are being infected through heterosexual contact” (JAMA, 2000).

The CDC study showed that people in rural areas are also more likely to be worried about stigma and confidentiality issues, making them reluctant to be tested for HIV or seek care in their own communities. “People in small towns who are concerned about people knowing they’re HIV infected may be more reluctant to go somewhere that is identified as being linked to HIV,” stated Helene Gayle, MD, MPH, formerly with the CDC and currently working with the Bill & Melinda Gates Foundation (Stephenson, 2000).

According to a recently published book by Kathryn Whetten-Goldstein, *You’re the First One I’ve Told, New Faces of HIV in the South*, although basic care may be offered by the local health department, the fear of encountering a relative’s neighbor who works there may hinder the person from seeking care locally. In addition, the fear of HIV status disclosure is higher in rural than in urban areas. “Issues of isolation and fears of disclosure must be addressed if we are to provide good care to rural-living, HIV positive persons,” stated Whetten-Goldstein (2002).

We urge policy makers and community organizations to partner with us to address HIV/AIDS and STD related stigma in terms of gender, race, ethnicity, class, sexuality and culture to ensure that initiatives aimed at reducing stigma are an integral part of HIV/AIDS program planning.

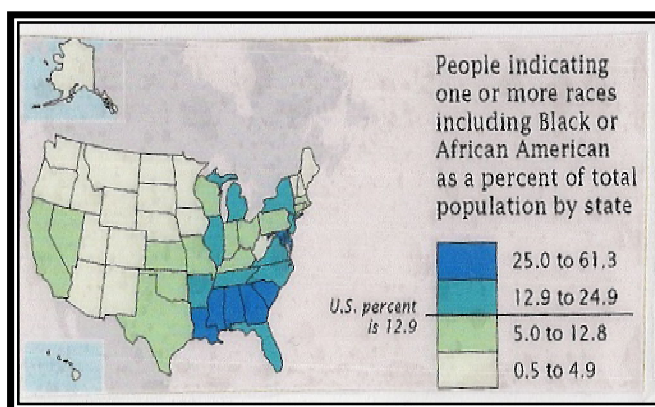
### **Unique Issues of the African-American Population**

African-Americans are disproportionately affected by the HIV/AIDS epidemic in the U.S. (Smith & Friday, 2001), and are infected with HIV at a greater rate than any other racial/ethnic group. HIV continues to be the leading cause of death for African-Americans 25-44 years of age. Among injection drug users (IDU), African-American IDUs who contract HIV are at a higher risk of receiving inadequate care. Because of this, African-Americans use more costly emergency care and fewer out patient services and are more likely to be hospitalized than white counterparts.

According to the Kaiser Commission, African-Americans’ access to health services is compromised by an uninsured rate that is one and a half times that of whites. With half of all African-Americans living in families with incomes below 200% of poverty, this rate would be much higher were it not for Medicaid coverage.

Medicaid provides an important safety net for one in five African-Americans, underscoring the role that Medicaid plays for low-income families with children. Medicaid covers half of African-Americans with incomes below poverty and 17% of those between 100 and 199% of poverty. However, Medicaid's protection is incomplete leaving 30% of African-Americans below 200% of poverty uninsured (Kaiser Commission, 2000).

### Percent of Population, 2000 One or More Races Including Black or African-American



Data Source: U.S. Census Bureau, Census 2000 Redistricting Data (PL 94-171) Summary File.  
Cartography: Population Division, U.S. Census Bureau

### One Race: Black or African-American Mapping Census 2000: The Geography of U.S. Diversity

Source: U.S. Census Bureau  
Internet Release Date: December 7, 2001

STATE	PERCENT CHANGE 1990-2000	PERCENT TOTAL POPULATION 2000	PERCENT UNDER AGE 18 2000	NUMBER 2000	NUMBER UNDER AGE 18 2000	PERCENT ONE RACE 2000
USA	15.6	12.3	31.4	34,658,190	10,885,696	95.2
ALABAMA	13.2	26.0	31.1	1,155,930	359,588	98.9
ARKANSAS	12.0	15.7	33.6	418,950	140,943	98.1
FLORIDA	32.7	14.6	33.2	2,335,505	774,577	94.5
GEORGIA	34.5	28.7	31.8	2,349,542	746,557	98.2
KENTUCKY	12.6	7.3	30.1	295,994	89,136	94.9
LOUISIANA	11.7	32.5	33.5	1,451,944	486,892	98.9
MISSISSIPPI	13.0	36.3	33.7	1,033,809	348,550	99.2
NORTH CAROLINA	19.3	21.6	29.9	1,737,545	519,075	97.8
SOUTH CAROLINA	14.0	29.5	31.2	1,185,216	369,514	98.7
TENNESSEE	19.9	16.4	31.8	932,809	296,509	97.8
TEXAS	18.9	11.5	31.2	2,404,566	751,189	96.5
VIRGINIA	19.5	19.6	29.2	1,390,293	406,208	96.5
WASH. DC	14.1	60.0	25.1	343,312	86,300	98.0
WEST VIRGINIA	1.7	3.2	25.9	57,232	14,809	91.1

Many African-Americans are hesitant to access care through the public health system. One reason for that reluctance is government activities that have impacted the relationship between African-Americans and the public health system. For example, the Tuskegee Syphilis Study which now has come to symbolize racism in medicine, ethical misconduct in human research, paternalism by physicians, and government abuse of vulnerable people. From 1932 through 1972, under the auspices of the U.S. Public Health Service, researchers subjected 400 African-American men in rural Alabama to an experiment on the effects of untreated syphilis. Researchers withheld treatment and forbade the men from seeking help elsewhere, even though penicillin became available in the 1940s (NASTAD African-American Monograph, 2001).

The HIV/AIDS epidemic in the South is greatly impacting the African-American population. One reason for this is that according to Census 2000, more African-American's reside in the South than in any other region of the country. According to CDC, looking at select seroprevalence studies among high-risk populations gives an even clearer picture of why the epidemic continues to spread in communities of color. The data suggest that three interrelated issues play a role – the continued health disparities between economic classes, the challenges related to controlling substance abuse, and the intersection of substance abuse with the epidemic of HIV and other sexually transmitted diseases (CDC, 2002)

African-Americans have higher rates of HIV-related morbidity and mortality as a result of poor healthcare access patterns. There is growing evidence that the HIV/AIDS epidemic is increasingly concentrated in low-income communities in which people of color are often disproportionately represented. African-American men who have sex with men (MSM) continue to have the highest incidence of any risk group in African-American communities.

In 2000, more African-Americans were reported with AIDS than any other racial/ethnic group. Almost 20,000 cases were reported among African-Americans, representing nearly half of the total AIDS cases reported that year. Also, in 2000, almost two-thirds of all women reported with AIDS were African-American. In addition, in 2000, African-American children also represented almost two-thirds of all reported pediatric cases (CDC, African-American fact sheet, 2002).

HIV/AIDS is only one of many health disparities that exist in African-American communities:

- African-Americans experience poorer access to general healthcare compared to white counterparts (including oral health and mental health care).
- African-Americans with HIV have a poorer survival rate than whites as well as higher rates of preventable disease complications.
- Provider prescribing patterns that differ based on patient race/ethnicity attribute to poor access to care and disparities.
- African-Americans are significantly more likely than whites to get tested later after developing HIV-related systems rather than while asymptomatic.
- Over a quarter of African-American adults and 18% of children are uninsured.
- Within African-American communities, adults are dying of diabetes, heart disease and HIV at a rate three times that of white counterparts.

Reasons for these disparities include: lack of health insurance, stigma, mistrust, provider bias, racism, homophobia, sexism, poor access, and woeful lack of minority physicians and physicians

with expertise (and the willingness) to treat people living with HIV/AIDS. Limited social and economic resources have traditionally put members of the African-American community at a disadvantage in obtaining needed healthcare (Surgeon General's Report, 2001).

Other socioeconomic factors, such as lack of adequate job-based insurance, income and education, have been shown to explain some of the racial differential in access to HIV healthcare (Surgeon General's Report, 2001). The disparities in health insurance coverage that ethnic minorities experience therefore translate into disparities in access to health care services (Racial and Ethnic Disparities in Access to Health Insurance and Health Care, 2000). For many African-Americans, primarily women, efforts to meet basic needs—food, shelter, clothing—may further delay seeking healthcare. Approximately 85% of African-Americans with HIV are lacking private health insurance, making them more likely than whites to use public sector providers and services (Kaiser, 2002). In addition, African-Americans fear and distrust the public health system (NASTAD African-American monograph, 2001).

According to the HIV Cost and Services Utilization Survey (HCSUS), African-Americans living with HIV are particularly dependent on the public sector: 43% of African-Americans with HIV are on Medicaid; 20% on Medicare, and 16% uninsured (Levi & Hidalgo, 2001). In short, 85% of African-Americans living with HIV who are in care are dependant on the public sector (Medicaid, Medicare, or other safety net programs like the Ryan White CARE Act (Levi & Hidalgo, 2001)).

In FY 2000, nearly half of clients served under the Ryan White CARE Act (RWCA) reported to be African-American (HRSA Annual Report, 2001).

In consideration of these circumstances, **it is likely that without significant intervention or change in the current state and national response, the HIV/AIDS and STD epidemics will continue to cause great harm to the health of southern citizens especially citizens of color.** Therefore, in the spirit of social justice, the southern state AIDS directors find it a moral imperative to outline action steps to eliminate the disparities currently existing in the South.



## Southern States Manifesto

### HIV/AIDS and STDs in the South: A Call to Action

*“Nothing can be more important to a state than its public health; the state’s paramount concern should be the health of its people.”*

*Franklin Roosevelt*

### Leadership

#### BARRIERS

Relative to Leadership there exists in the South:

- Inconsistent understanding by individuals and agencies in leadership roles of the policies that govern unique issues related to HIV/AIDS and STD epidemics and programming in southern states.
- Complacency and apathy regarding the acceptance of AIDS as a life-threatening disease.
- A lack of understanding that efforts to support the elimination of HIV/AIDS and STDs will free future public funds, rather than burden the system with ongoing prevention and care costs associated with the HIV/AIDS and STD epidemics.
- A lack of adequate funding to ensure equal access to care and treatment of HIV/AIDS and STDs for all individuals, regardless of geographical location.
- A lack of adequate funding to support core STD control activities.
- A lack of adequate funding to ensure citizens engaging in high risk behavior have access to appropriate and effective prevention strategies and technologies.

#### WE BELIEVE:

1. All people with or at risk of infection with HIV/AIDS or STDs must be guaranteed access to comprehensive prevention, care and treatment programs.
2. Our first responsibility as federal, state and local partners is to immediately provide prevention and care services that are available, adequate, accessible, accommodating, appropriate and responsive to the individuals living with HIV/AIDS and infected with STDs. In meeting these needs, everything we do must be of high quality.

3. There must be a standardized treatment protocol available to all HIV/AIDS and STD patients throughout the country that provides equal access to HIV/AIDS treatment medications and access to quality medical care, including basic core services, regardless of geographic location.
4. Until the burden of STDs can be reduced HIV cases will continue to increase. STDs are also a marker of one of the most vulnerable populations in need of services and interventions.
5. Responsible and courageous leadership from the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) is required to address the unique health care disparities in the southern states through development of policies and strategic planning to increase funding allocations.

### **CALL TO ACTION**

- We call upon the political leadership and policy makers to be courageous and responsible in addressing the unique health care disparities in the southern states.
- We call upon President Bush and the Congress to assure that federal Ryan White CARE Act funding is increased and provided to states in the amount required to assure that all persons living with HIV/AIDS in this country have access to life-sustaining medications and other essential medical care related to their diagnosis of HIV disease. New funds must be targeted to the South, as well as to other areas of severe need, in order to meet the vision, intent and commitment of the original Ryan White CARE Act legislation.
- We call upon President Bush and Congress to assure that federal HIV/STD prevention funding is increased and provided to states in the amount required to assure that all communities and populations and individuals, especially those at the greatest risk of developing HIV disease, have access to appropriate and effective prevention strategies and technologies. New funds must be targeted to the South, as well as to other areas of severe need, in order to meet the challenges of an epidemic that increasingly impacts minority groups, especially African-Americans, heterosexuals, women, and the poor.
- We call upon President Bush, Congress and CDC to ensure the continued funding of syphilis prevention and care activities targeting the South. Syphilis Elimination dollars have proven to be much needed and well utilized as is evidenced by the decrease in syphilis infections in the South.
- We call upon President Bush and Congress to ensure that STD prevention funding is increased to ensure core STD control strategies can be implemented in the South.
- We call upon CDC and HRSA to provide leadership through policy development and strategic planning in partnership with southern state AIDS/STD directors in addressing the unique health care disparities in the southern states.
- We call upon southern state AIDS/STD directors to ensure the meaningful involvement of historical partners as well as non-traditional organizations and individuals in decision making and resource allocations concerning HIV/AIDS and STDs.

- We call upon legislative, health department and community partners to advocate for the needs of individuals living with HIV/AIDS and STDs and to ensure provision of quality care and services.

## **People of Color**

### **BARRIERS**

Relative to People of Color there exists in the South:

- Insufficient service delivery systems for African-American and Latino men who have sex with men (MSM) due to no demonstrated evidence-based interventions for non-identifying African-American and Latino MSM, especially in rural areas.
- Distrust of the health care system and its ability to protect confidentiality of individuals infected with HIV or STDs.
- Inadequate community-level programming to address the stigma associated with HIV and STD disease.
- Scarcity of faith-based initiatives providing prevention and care services in the conservative and religious climate of the South.
- Need for culturally competent and culturally sensitive programming.
- Limited organized community-based advocacy in order to promote capacity building among African-American and Latino focused agencies.
- Continued denial of HIV status by infected individuals until symptoms are evident.
- Limited access to health care facilities due to inadequate transportation, insufficient child care, under insurance or no insurance, overburdened care system and poverty.

### **WE BELIEVE:**

1. Issues of stigma and denial must be addressed by all state, federal and local partners to increase the efficacy of prevention and care programs.
2. Communities of color that have been historically and disproportionately infected/affected by HIV/AIDS and STDs must have equal access to culturally appropriate, sensitive, and relevant prevention, care and treatment services without regard to geographical location and/or ability to pay.
3. It is the responsibility of southern state AIDS/STD directors, legislators and community leaders to work in partnership to recognize that racism, homophobia and sexism also place African-Americans and Latinos at high risk for HIV/AIDS and STDs in the South.

4. There must be increased effort to address the unique needs of African-Americans because they shoulder a greater burden of HIV/AIDS and STD infection.

### **CALL TO ACTION**

- We call upon African-American legislators, African-American religious affiliates, and African-American national organizations to partner with AIDS/STD directors and southern communities to embrace the information provided in this document and realize that we are in a state of emergency as it relates to the disproportionate rate of infection of HIV/AIDS and STDs and to ensure that HIV/AIDS and STDs are at the forefront of national agendas, with the same urgency as diabetes, hypertension, cardiovascular, and other diseases that disproportionately affect African-American communities.
- We call upon state AIDS/STD directors and community-based organizations to develop formal linkages and mentoring relationships to facilitate implementation of strategies and accessing of resources that can assist to build the capacity of African-American focused agencies to provide quality services, ensure access to services and ensure viability of agencies providing services to the African-American community (NASTAD Monograph, *HIV/AIDS: African-American Perspectives and Recommendations for State and Local AIDS Directors and Health Departments*, 2001).
- We call upon AIDS/STD directors to develop formal linkages with African-American and other minority medical societies, primary care physicians and minority medical schools to ensure the availability of quality services and care according to national standards.
- We call upon state AIDS/STD directors, health care providers and community-based organizations to create a service environment that is non-threatening, friendly and understanding of the need for diverse staff and programming in order to remove stigma associated with living with HIV/AIDS in the African-American and Latino culture.
- We call upon CDC, HRSA and state and federal legislators to work with AIDS/STD directors to provide expanded medical and supportive service capacity in communities of color that is both culturally and linguistically appropriate to individuals living with HIV/AIDS and STDs.

### **Partnerships**

### **BARRIERS**

Relative to Partnerships there exists in the South:

- Lack of partnering to share resources among service agencies resulting from cultural norms and lack of trust of the state and federal government.
- Inadequate federal technical and monetary support to encourage development of integrated programs.
- Inadequate funding for community based organizations.

- Lack of access to compassionate care programs offered by pharmaceutical companies.
- Lack of coordination between federal funding agencies and state AIDS/STD directors regarding federal activities occurring within each state.

### **WE BELIEVE:**

1. Partnerships between federal, state and local agencies must be developed as they are critical to mobilize an effective response to the HIV/AIDS and STD crisis and to ensure the delivery of equitable services in the South.

### **CALL TO ACTION**

- We call upon state AIDS/STD directors to develop and maintain relationships with organizations and entities that are links to their local health care system.
- We call upon federal funding agencies to encourage development of integrated programs ([HIV prevention/AIDS care], [HIV/STD], [hepatitis C/HIV prevention], [mental health/substance abuse/HIV/AIDS]) by providing technical and monetary support to assist states in developing needed linkages and by looking at existing successful models in the South for technology transfer.
- We call upon pharmaceutical companies to simplify the application process for compassionate care programs serving the HIV/AIDS population.
- We call upon federal funding agencies to inform state HIV/AIDS/STD directors regarding activities occurring within the state to better facilitate partnerships on the state level and to avoid duplication of services.

## **Infrastructure**

### **BARRIERS**

Relative to Infrastructure there exists in the South:

- In some states, persons with HIV become very ill before obtaining necessary primary care services. These predominately rural states are generally poorer, have higher unemployment rates, and are less educated than more metropolitan counterparts (Rural Health in the United States, Ricketts, 1999).
- Evidence showing that patients who are diagnosed in major urban centers often return home to rural areas for family support. However, much of the federal funding is distributed based on where a person was diagnosed. This has a tremendous impact on communities already stressed by lack of access to basic health care needs (Rural Health in the United States, Ricketts, 1999).

- Lack of Medicaid coverage for low-income individuals with HIV who do not meet all of the requirements for disability.
- Limited capacity to collect and analyze a wide variety of epidemiological, behavioral and programmatic data to adequately define the scope of the HIV/AIDS and STD epidemics, related unmet needs, and measure the impact of care and prevention services. Failure of a few states to collect HIV reporting data seriously affects funding allocations in **all** states.
- Limited HIV/AIDS and STD awareness and education regarding prevention and care among the health care and allied services community.
- Lack of core STD prevention infrastructure and services, including screening and treatment programs and partner services.
- Limited transportation to and from health care appointments in rural areas due to little or no personal or public transit.
- Considerable distances between the health care facilities and the patients.
- Limited pool of health care providers in rural areas.
- Overuse of existing health care providers who are stressed in their ability to see more patients.
- Insufficient strategies or models to get individuals tested and treated although studies show African-Americans are significantly more likely than whites to get tested later after developing HIV-related symptoms rather than while asymptomatic.
- Lack of permanent affordable housing for individuals living with HIV/AIDS.
- Lack of requirement for housing plans for all persons receiving medical treatment through any federally funded system.

### **WE BELIEVE:**

1. The health care infrastructure in the South must be strengthened and adequately funded to effectively respond to the HIV/AIDS and STD epidemic.
2. Core STD infrastructure must be strengthened.
3. There must be efforts to foster greater collaboration to reduce fragmentation of care.

### **CALL TO ACTION**

- We call upon the federal government, within one year of the date of this document, to work in collaboration with state AIDS/STD directors to outline the minimum HIV/AIDS and STD core services that must be guaranteed to all individuals.

- We call upon the federal government to develop program policies to ensure greater equity in the provision of minimum state and federal core HIV/AIDS/STD prevention and care services within all states and to ensure that the same standard of care and prevention services are available in all areas of the South.
- We call upon the U.S. Congress to pass the “Early Treatment of HIV Act” which would allow states to provide Medicaid coverage for low-income individuals infected with HIV.
- We call upon HRSA and CDC to ensure that STD/HIV Training Centers and AETC’s are given resources to meet the clinical, prevention and programmatic training needs in the South.
- We call upon institutes of higher education to prepare graduates in health and medical professions by means of curriculum development and incentive programs designed to ensure attainment of these standards in a culturally sensitive manner for underserved areas.
- We call upon the federal and state government to improve the system of recruitment and incentive for health care professionals to provide services in underserved rural areas.
- We call upon the federal government to utilize Ryan White CARE Act funds to establish a minimum AIDS Drug Assistance Program (ADAP) standard of care for all states and territories in order to assure that all eligible individuals (i.e. those at/below 200% of the federal poverty level, HIV+ and at/ below 350 CD4 count ) have access to a basic HIV/AIDS medication formulary including all anti-retrovirals and an adequate selection of medications for the prevention and treatment of opportunistic infections.
- We call upon federal partners to provide technical assistance to Georgia as that state moves toward implementation of HIV reporting.
- We call upon the U.S. Department of Housing and Urban Development (HUD) to permanently set-aside 10,000 Section 8 mainstream housing tenant based rental vouchers for persons living with HIV/AIDS in the Southern States.
- We call upon HUD to require housing plans for all persons receiving medical treatment through any federally funded system.
- We call upon HUD to ensure that all funding streams in all HUD categories continue to provide support to individuals with HIV/AIDS and technical assistance to help provider’s access HUD resources.

## **Funding**

### **BARRIERS**

Relative to funding there exists in the South:

- In some states, lack of access to basic AIDS drugs and other key treatments

- Limited number of dental providers due to low reimbursement rates and perceived stigma of treating individuals with HIV/AIDS
- Limited funding to target men who have sex with men (MSM) in the South, especially men in minority communities who do not self-identify.
- Scarcity of qualified health care providers in rural areas
- Deficiency in qualified personnel within the state civil service systems
- In some states, an overburdened care system
- Poor infrastructure for collection of the data which drives the formula-based funding allocations.
- Lack of funding for basic STD control activities.
- Lack of adequate funding for the Housing Opportunities for People with AIDS (HOPWA) Program.

### **WE BELIEVE:**

1. Current federal funding streams and appropriations levels for HIV/AIDS and STD Programs must be increased, as current appropriation levels do not deliver adequate funds to the South.
2. All federal resources for HIV/AIDS and STDs must be distributed in such a manner as will ensure all at-risk individuals living in southern states access to an acceptable core set of prevention, diagnostic and treatment services.
3. Financial incentives must be available to encourage healthcare professionals to practice in rural communities in the South.

### **CALL TO ACTION**

- We call upon Congress to increase appropriations of Ryan White CARE Act Title II base in FY2004 and to ensure appropriate funding is targeted to the South and other areas of the country that demonstrate severe need.
- We call upon Congress to increase funding for Ryan White CARE Act AIDS Drug Assistance Program (ADAP) earmark in FY2004.
- We call upon HRSA to continue to work with southern AIDS/STD directors to develop a plan for allocation of ADAP supplemental funds based on need, not formula.
- We call upon CDC, NASTAD and NCSD to help ensure that any new funding to address the resurgence of HIV/STDs among MSMs also go to southern states in order to help enhance



and improve existing MSM initiatives, especially among minority MSM who do not self-identify.

- We call upon Congress and CDC for increased funding for HIV/AIDS and STD prevention and surveillance activities and to ensure appropriate funding is targeted to the South and other areas of the country that demonstrate severe need.
- We call upon CDC to prioritize allocations of funding based on HIV/AIDS and STD trend data and cases in African-American communities.
- We call upon HRSA and CDC to review funding allocations for care, prevention and surveillance to ensure equitable distribution of federal resources.
- We call upon HUD to ensure that the HOPWA formula mirrors the Ryan White CARE Act distribution system of dollars instead of basing the distribution solely on the cumulative AIDS case counts.
- We call upon HUD to fully fund case management, transportation, mental health and chemical dependence treatment when linked with stabilized housing resources through a partnership program between HRSA and HUD.

## **State's Role**

### **BARRIERS**

Relative to the State's Role there exists in the South:

- Lack of incentive to encourage private physicians or other reporting agencies to report HIV/AIDS case data as recommended by the MMWR, dated December 1999.
- Lack of a standardized requirement for each state to have a mechanism in place to ensure PLWA involvement in all HIV/AIDS programming.
- Limited state capacity to collect adequate information about HIV/AIDS and STDs to gain a better understanding of patient demographics and patient access to care due to the failure of some states to collect and report HIV data.
- Insufficient funding for training to ensure that health care providers and state personnel treat HIV/AIDS and STD patients with respect, regardless of race, ethnicity, cultural norms, language, age and sexual orientation.
- Insufficient funding for training to ensure health care providers provide quality, standard of care services for HIV/AIDS and STDs.
- Lack of coordination in some states between HIV/AIDS and STD prevention and care programs perpetuates a lack of coordination among community agencies.

- In some states, although federal funds are available, there is a lack of infrastructure to support formal quality assurance monitoring systems and evaluation plans in order to conduct outcome monitoring.
- Insufficient public health workforce.

### **WE BELIEVE:**

1. State AIDS/STD directors must continue to work with federal funding agencies in coordinating an effective response to the HIV/AIDS and STD epidemics.
2. State AIDS/STD directors must take an active role in ensuring that all persons receive healthcare in a dignified manner, respectful of their race, ethnicity, cultural norms, language, age, gender and sexual orientation through open dialogue and provision of culturally specific training for health care providers.
3. The law requiring health care providers to report reportable diseases must be enforced.
4. Public health and political leaders must take a more active role in closing the gap of health disparities, especially HIV/AIDS and STDs in the South.

### **CALL TO ACTION**

#### **We call upon state HIV/AIDS and STD directors to:**

- Demonstrate responsible and courageous leadership to address unique health care disparities in the South.
- Educate physicians regarding the importance of reporting HIV/AIDS and STD cases in order to increase Ryan White CARE Act funding which is based on the number of reported cases.
- Develop a mechanism to increase the level of PLWA involvement in all HIV/AIDS program areas.
- Work with State Legislators to develop a plan to increase state funding for HIV/AIDS/STDs and improve department and program infrastructure. AIDS/STD directors must call upon state legislators and governors to increase state funding for HIV/AIDS/STD Programs.
- Seek federal action calling for emergency funding to address HIV/AIDS and STD epidemics in the South.
- Conduct a consultation with HRSA/CDC to insist on coordinated technical assistance and site visits.
- Ensure core STD prevention programs are in place in each of the southern states.
- Engage more medical groups or other new partners in addressing HIV/AIDS/STD issues.

- Work with Prevention Training Centers (PTCs) and AIDS Education and Training Centers (AETCs) to identify training needs and develop appropriate training to ensure that providers are adequately trained in HIV/AIDS and STD clinical management.
- Work with HRSA to identify reimbursement mechanisms to support providers in screening and prevention activities.
- Develop an adequate and effective public health workforce by identifying performance standards and appropriate compensation.
- Adapt known effective interventions to local needs and then evaluate these adapted prevention intervention models to determine efficacy.
- Develop statewide models to implement cross-program coordination within each southern state with a focus on planning and service delivery to empower consumers and reduce fragmentation of care.
- Use HIV/AIDS/STD and hepatitis and other related data to determine “full trend” analysis of our community needs.
- Implement the recommendations in the NASTAD African-American monograph.
- Actively engage with community groups, including people living with AIDS (PLWAs) to foster advocacy and expand community programming to address the unmet need identified in the State HIV Prevention Plan and the State CARE Act Comprehensive Plan.
- Actively develop and implement quality assurance and evaluation processes across all programs to ensure accountability and effectiveness of programs.
- Commit to stay active in the Southern State AIDS/STD Directors Work Group.

# Laying the Groundwork

## Southern States Manifesto

### HIV/AIDS and STDs in the South: A Call to Action

*“Health is not simply the absence of sickness.”*

*Hannah Green*

#### Research and Evaluation

State and federal partners must ensure the development and delivery of effective and replicable prevention interventions critical to reducing the number of new HIV/STD infections. Once the effectiveness of an intervention has been demonstrated, the intervention must be rapidly and widely replicated. Ongoing evaluation of these interventions is necessary to assure fidelity to the original model while adapting to the changing prevention needs of the target populations.

The National Institute of Health (NIH), the CDC, and other public and private institutions have funded HIV/STD prevention research for many years. Since the beginning of the epidemic, institutions conducting research tended to be located in large urban centers, primarily in East and West coast cities. As a result, most of the research to date has been focused in the early epicenters of the epidemic. Therefore, most research focuses on urban populations and areas with relatively mature epidemics.

This tendency, while understandable, has significant implications for HIV prevention, particularly in the South. Many of the interventions that have been rigorously evaluated have diminished relevance to HIV prevention efforts in many areas of the southern stat. There are significant gaps in research on effective behavioral interventions for at-risk southern populations, particularly African Americans.

Federal agencies should fund research on the design, adaptation and implementation of effective interventions for at-risk African-Americans and other at-risk populations in the South. **Federal agencies need to recognize the emergency that exists in the South, and must implement research studies immediately.**

When effective interventions are identified through these research efforts, funding must be allocated to assure speedy, successful and widespread implementation across the South. Adequate funds must be made available to implement evidence-based interventions to improve the poor health infrastructure in southern states. Additionally, funds must be allocated for ongoing technical assistance to ensure successful replication.

To sustain and improve the effectiveness of these interventions once implemented, federal agencies must design program evaluation models in consultation with southern experts to assure compatibility with the unique nature of the South and its residents. This will ensure that evaluation models will be useful and can contribute to a growing science base for HIV prevention programs.

## Southern States Manifesto

### HIV/AIDS and STDs in the South: A Call to Action

*“Injustice anywhere is a threat to justice everywhere.”*

*Dr. Martin Luther King, Jr.*

#### Conclusion

It is essential that people living with HIV/AIDS and STDs have basic access to primary medical care and life sustaining drugs. There must be expanded eligibility under Medicaid to ensure that Ryan White CARE Act funding is payer of last resort. It is imperative that a national standard of core minimum services be developed and implemented immediately. In addition, increased resources must be directed to the South in order to meet the ever increasing need. And finally, the federal government must realize that individuals in rural areas of the South, especially African-Americans, do not have the safety net available in most urban areas. In order to slow down transmission of HIV and STDs and treat individuals living with HIV/AIDS/STDs in the South, the federal government must embrace the uniqueness of these epidemics in the South and create quality HIV/STD and AIDS prevention and care programming accordingly. The time is NOW.

Unfortunately, the existing health care systems are not always sensitive to the needs of diverse populations. As a result, there are few well-developed service delivery systems for African Americans, Latinos, or men who have sex with men (MSM). Economic and cultural barriers, along with a failure to test for HIV until symptoms appear, are also factors. (AEGIS, 2000). In addition, for Latinos who are less acculturated or less familiar with the health care system, access to care and services is enhanced if the individuals have a core service provider who is trusted to act in the individual's best interest (Multhoma County Health Department, Latino PLWH, 2001).

According to the Rural Center for AIDS/STD Prevention (2002), HIV infection has diffused from large metropolitan areas to smaller cities and rural areas. This rise of HIV/AIDS in rural areas creates new challenges for an already overburdened rural health care system. Historically, funding has been directed to the needs of large urban areas. With the growing epidemic in rural areas, this now leaves HIV prevention and health care in rural communities under funded.

Based on the scientific studies cited in this Manifesto, the epidemiological trends in the South as compared to the rest of the nation and the collective years of experience directing HIV/AIDS and STD programs, we conclude the HIV/AIDS and STD epidemics in the South that continue to affect and infect southern citizens must be addressed immediately. The southern state AIDS/STD directors further conclude that we are passionate about the health outcomes of our citizens and if the increase in disparity among states is not considered an emergency and corrected immediately, the public health disaster in the South will worsen. We are confident that by working together with a shared vision for change, we can make a difference.

Therefore, we collectively call upon the political leadership and policy makers to join us in being courageous and responsible in addressing the unique HIV/AIDS and STD healthcare disparities in the South.

## Southern States Manifesto

### HIV/AIDS and STDs in the South: A Call to Action

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