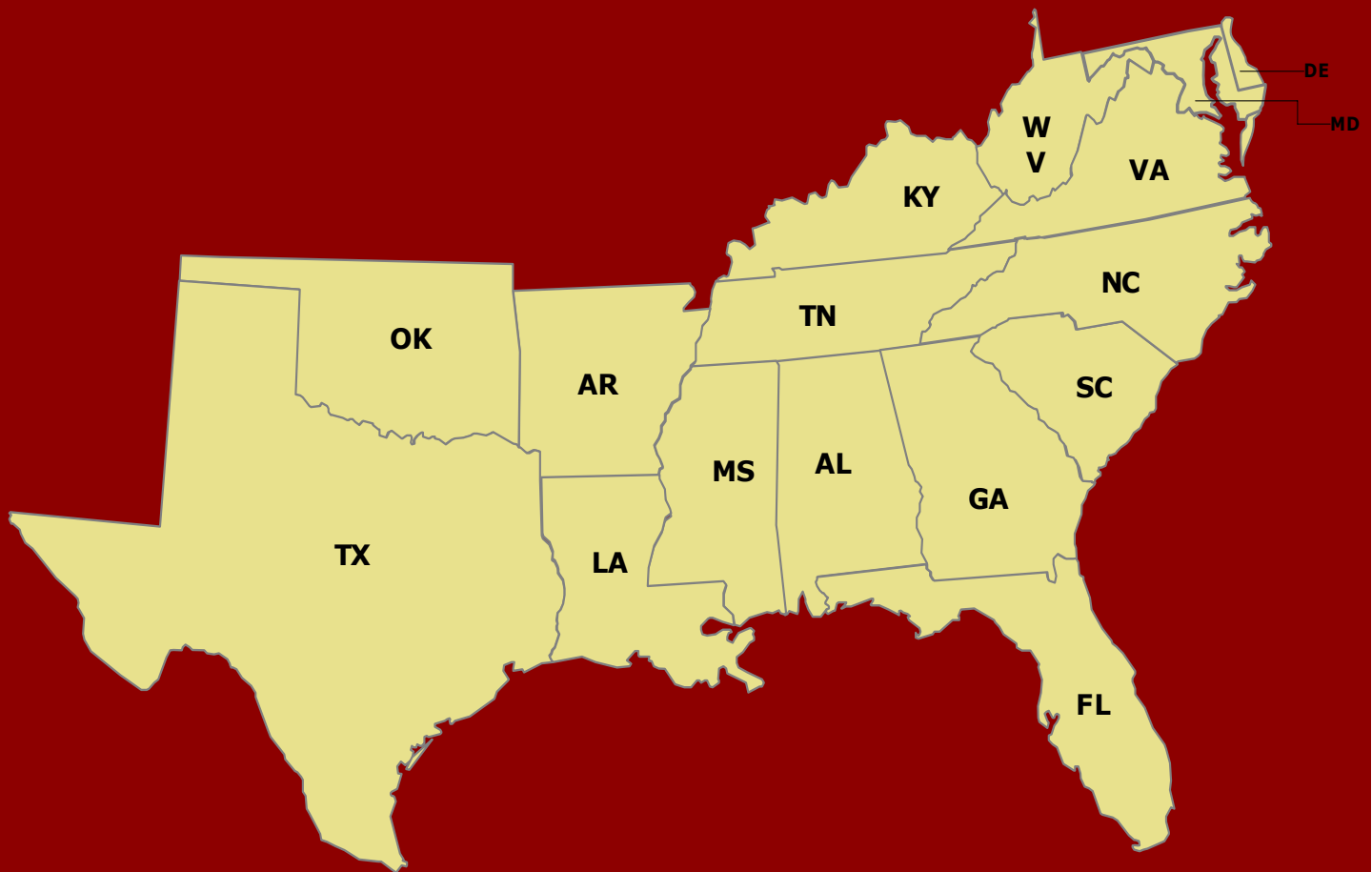




SOUTHERN STATES MANIFESTO: UPDATE 2008

HIV/AIDS and Sexually Transmitted Diseases in the South
July 21, 2008





Southern States Manifesto: Update 2008
HIV/AIDS and Sexually Transmitted Diseases
in the South

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The Southern AIDS Coalition (SAC) is 501 (c) 3 nonprofit membership organization comprised of community-based organizations and advocates, HIV/AIDS government experts, and private industry. SAC members at this time are from Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia and the District of Columbia. Data in this report include the southern region as defined by the Centers for Disease Control and Prevention with statistics from Delaware and Maryland added to the SAC jurisdictions.

For questions please contact Kathie Hiers at kathie@aidsalabama.org or Evelyn Foust at evelyn.foust@ncmail.net.

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MANIFESTO
MEMORIAL
DEDICATION

Stephen G. Sherman
North Carolina
Original SAC Co-Chair
Esteemed Colleague
Advocate



The Southern AIDS Coalition lost a dedicated, talented, and revered colleague in March 2008, Stephen G. Sherman. To celebrate his life, the *Southern States Manifesto: Update 2008* is dedicated to Steve and to the values he held dear. Primary among those values was access to care and treatment for people with HIV disease who had limited alternatives. Steve's dedication and know-how fueled many a great debate and discussion as he fearlessly spoke the truth about disparities. We were honored with his presence, and now we continue the work he began with a new-found earnestness and authenticity out of respect for the way Steve lived his life.

SOUTHERN STATES MANIFESTO: UPDATE 2008

HIV/AIDS and Sexually Transmitted Diseases in the South

Introduction

The March 2002 release of the original *Southern States Manifesto* described the disproportionate impact of the rapidly growing interrelated epidemics of HIV/AIDS and STDs on communities in the southern United States and the shared challenges those of us living in the South faced in working to address them. These shared challenges led to the creation of the Southern AIDS Coalition (SAC), a unique partnership of state AIDS directors and staff, community advocates, national nonprofit entities, people living with HIV, and private industry, to better meet the needs of those at risk and those living with HIV and other sexually transmitted diseases.

Despite progress, many challenges remain for us in the South as well as the United States as a whole. We present this *Update 2008* to describe what HIV looks like now in the South, six years after our first efforts brought us together in a dynamic way to achieve mutually desired public health outcomes through what has become a solid collaboration.

This report is released after the conclusion of the first year of the Ryan White HIV/AIDS Treatment Modernization Act of 2006 (RWHATMA) and of the Centers for Disease Control and Prevention (CDC) testing guidelines, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health Care Settings*. These two important policy events, along with the continued burgeoning need in the South, present an opportunity to co-

alesce these critical and new advances to focus on very accomplishable goals.

A major focus of SAC has been to advocate for increased federal funding for prevention, treatment, care, and housing to rectify the historical inequities embedded in the federal HIV and STD funding portfolios. To that end, SAC was involved intensively in the discussions and negotiations that resulted in the passage of RWHATMA. Changes in the Ryan White Act, implementation of the new CDC testing guidelines, and new CDC funding have improved in important ways how we are able to address the needs created by HIV/AIDS in the South. SAC's focus also includes ongoing forums to share best practices, provide technical assistance, and utilize strategic planning opportunities focused on the specific needs of the South.

The *Update 2008* provides the rationale for our continuing commitment to the following goals:

- 1) Reduce new HIV infections by 25% in five years while increasing the outreach and access to HIV counseling, testing, and screening in every State and Territory;
- 2) Reduce all late-term AIDS diagnoses by 25% within five years;
- 3) Implement the CDC opt-out testing recommendations across each of the SAC jurisdictions within three years;
- 4) Increase the number of persons aware of their HIV, STD, or hepatitis infections who enter and make optimal and sustained use of care and treatment;
- 5) Improve health outcomes for people with HIV/AIDS as indicated by clinical and other indicators (CD4, viral load, etc.);
- 6) Increase age-appropriate, science-driven education for prevention of all sexually transmitted diseases; and
- 7) Advocate for increased state funding for prevention, treatment, care, housing, and services for people living with or at risk of HIV/AIDS, STDs and hepatitis.
- 8) Continue to advocate for increased federal funding for prevention, treatment, care, housing, and services for people living with or at risk of HIV/AIDS, STDs, and hepatitis that is based on and allocated by the growth of the epidemics and the needs of people living with these diseases throughout the U.S.

As our community prepares for the inevitable changes ahead, the Southern AIDS Coalition extends our dedicated support and strong interest in all efforts that bring the people of our nation together to achieve our collective goals. We offer this view into the South as a way to substantiate the dire needs of people in our region. We will champion the needs of any person with or at risk of HIV, hepatitis, or other STDs wherever they live in the United States or around the world and will collaborate with any willing partners. We are united in the desire to meet these goals and to live in a South, a nation, and a world without STDs, HIV, and AIDS. We invite you to join us in this quest.

— Southern AIDS Coalition Board of Directors

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

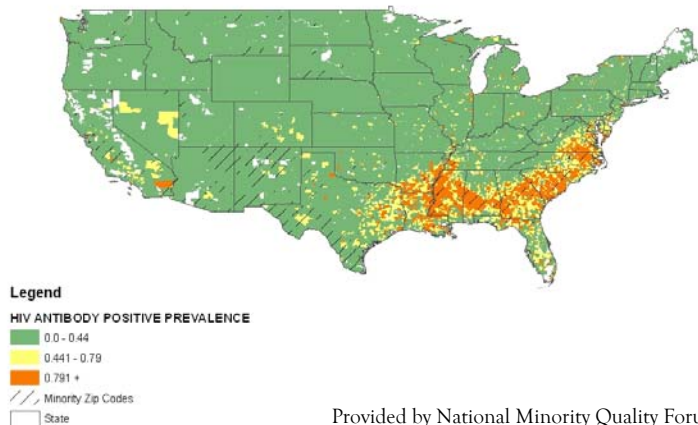
Why a *Manifesto* Update Now? To Save Lives!

The Problem

Rising infection rates coupled with inadequate funding, resources, and infrastructures have resulted in a disparate and catastrophic situation in our public health care systems in the South. The impact of HIV/AIDS on populations that also disproportionately reflect vast poverty and inadequate support continues to fuel the challenges of 1) reducing new infections; 2) identifying infections as early as possible; and 3) providing adequate care, treatment, and housing.

While studies show that early diagnosis and treatment of HIV infection to prevent or delay the transition to an AIDS diagnosis is more cost-effective,³ lack of funding for early treatment for those most vulnerable to HIV/AIDS has systematically led to greater rates of AIDS diagnoses in these groups. Unless we act to correct funding and treatment disparities, we endanger not just isolated communities, but our states and our nation.

**HIV PREVALENCE AMONG YOUNG ADULTS (18-49)
1999-2002**



Provided by National Minority Quality Forum

Throughout the rest of the country from 2001 through 2005, the number of deaths from AIDS decreased, but continued to increase in the South.^{1,13} The South has the highest number of adults and adolescents living with and dying from AIDS in the United States.^{1,29}

Systems of care have become increasingly overburdened as HIV/AIDS devastates vulnerable populations of the South.^{8,13,27} Characterized by pervasive poverty, lack of adequate services and infrastructures, unemployment, and uninsured individuals,⁴⁵ the South is faced with a crisis of having to provide medical and support care for increasing numbers of infected individuals without adequate funding.

The slide above documents known HIV cases throughout the U. S. among young adults from 1999 through 2002 with obvious disproportionate representation from the South. Since the release of the first *Manifesto* (March 2002), more than 36,000 people have died of AIDS in the South as estimated by the CDC. In 2005 the South was burdened with half of all deaths from AIDS in the United States.⁵⁶

Deaths estimated from AIDS according to the CDC - Numbers							
Region	2001	2002	2003	2004	2005	2006	Cumulative ^a
Northeast	5,091	5,047	5,376	4,904	3,948	4,074	180,623
Midwest	1,682	1,675	1,655	1,619	1,541	1,325	54,468
South	7,469	7,361	7,776	8,353	8,240	6,475	197,209
West	2,738	2,559	2,597	2,577	2,588	2,141	113,506
Totals	16,980	16,642	17,404	17,453	16,317	14,015	545,806
^a Since the beginning of the epidemic							
Deaths estimated from AIDS according to the CDC - Percents							
Region	2001	2002	2003	2004	2005	2006	Cumulative ^a
Northeast	30%	30%	31%	28%	24%	29%	33%
Midwest	10%	10%	10%	9%	9%	9%	10%
South	44%	44%	45%	48%	50%	46%	36%
West	16%	15%	15%	15%	16%	15%	21%
Totals	100%	100%	100%	100%	100%	100%	100%

Introduction

The South has the highest number of new AIDS diagnoses in the United States as a region and sadly has for years.⁴ The levels of HIV transmission coupled with initial diagnoses of AIDS continue to complicate the prevention, care, and treatment systems. The later people are diagnosed, the greater the likelihood that increased transmissions occur.⁵² Care is more complicated when entry into care occurs with concurrent opportunistic infections. Treatment options and systems are also burdened with increasing numbers of drug-resistant strains of the virus, given the number of people infected by those not in care.^{1,4,12}

In addition, many areas of the South continue to face ongoing poverty and discrimination, placing individuals and communities at elevated risk of infection. Unlike the early days of the epidemic, when outbreaks were concentrated in urban areas, a greater proportion of the southern population, including those with HIV/AIDS, live in rural areas.¹¹ This shift further complicates efforts to deliver appropriate care.

Four out of ten (40%) of Americans living with AIDS reside in the South.

HIV/AIDS has had a greater impact on blacks in the South than in any other area of the country, especially among men who have sex with both men and women.¹³ Compared to other regions of the country, HIV/AIDS in the South also disproportionately affects more heterosexuals and those who live in rural areas.^{11,13,14}

The South also reports higher rates of syphilis and gonorrhea than other regions of the country, which increase the risk of HIV transmission.^{3,4,9} Additionally, stigma due to social conservatism

AIDS in the South^{1,4,13,15,17,56,57}

Note: The South comprises 36.4% of the population of the U.S. through 2006.⁵⁹

- Of the top 20 areas (includes 18 states, Washington, DC, and Puerto Rico) with the highest AIDS case rates in 2006, 11 (55%) are in the South.
- The South has the highest number of adults/adolescents living with AIDS in the U.S.
- The number of persons living with AIDS has increased from 1993 to 2005 at a greater rate in the South than in the other regions of the U.S.
- The South has the highest number of people dying from AIDS in the U.S. The number of persons who died from AIDS-related deaths increased from 2001 to 2005 at a greater rate in the South than in other region of the country.
- Of the 20 metropolitan areas with the highest AIDS case rates in 2006, 16 (80%) are in the South.
- The southern states have a higher percentage of new AIDS cases among persons living in non-metropolitan areas than other regions of the U.S.
- Of the 20 states with the highest rates of persons living with HIV (not AIDS) in 2006, 11 (55%) are in the South.
- Of the 15 states with the highest rates of new HIV diagnoses, nine (60%) are in the South.
- Prevention and treatment of HIV/AIDS are further complicated in the South by the high prevalence of HIV-infected individuals living in rural areas. Southern states comprise 65% of all AIDS cases among rural populations.

is more pronounced in the South as compared to the rest of the nation.

Geographic Concerns

Rural populations tend to be dispersed over extremely large areas dotted with small communities and are often compared to higher density urban areas. Yet in rural areas of the Southeast, people with HIV/AIDS often travel for several hours to see an infectious disease specialist in a medical care setting.

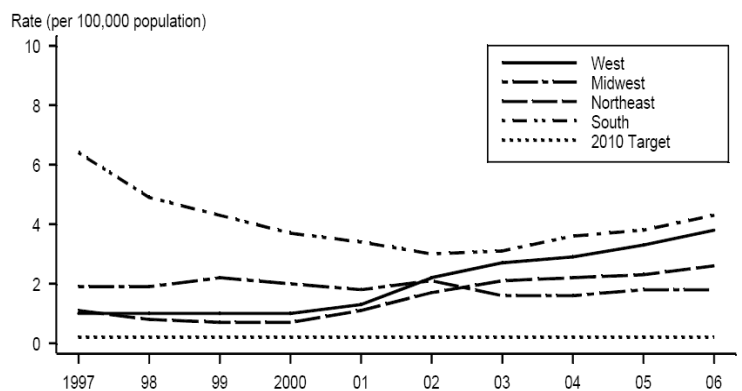
Sexually Transmitted Diseases (STDs)

Individuals with STDs, especially syphilis, are at a significantly higher risk for HIV transmission.¹⁹ Throughout the last two

decades, STD rates have been higher in the South, compared to other regions.

- The South ranked first among the four regions of the U.S. in rates of primary/secondary syphilis and rates of gonorrhea in 2006.⁵⁸
- Of the ten states that had the highest primary/secondary syphilis rates in 2006, seven (70%) were southern states.
- Of the 20 states that had the highest gonorrhea rates in 2006, 13 (65%) were Southern states.

Figure 9. Primary and secondary syphilis — Rates by region: United States, 1997–2006 and the Healthy People 2010 target



Note: The Healthy People 2010 target for P&S syphilis is 0.2 case per 100,000 population.

THE NEED AND THE NUMBERS, continued

Overall Health

Southern states perform poorly on most health indicators in comparison to other states, as noted in *The Commonwealth Fund Commission on Aiming Higher*, released in June 2007. The 14 states and Washington, DC, considered by the U.S. Department of Health and Human Services as the South Region, hold 15 of the bottom 21 rankings and 11 of the 12 lowest-ranked states. The indicators can be seen in *Illustration 1.1*.

- The ten states (100%) with the lowest ranking in overall health by the United Health Foundation were all in the South (see p. 17).
- Lack of health insurance: ten out of 20 (50%) were in the South.
- Premature death: 12 out of 22 (60%) were in the South.
- Infectious disease: eight out of 20 (40%) were in the South.
- Children in poverty: 12 out of 22 (55%) were in the South.
- Nearly two in five residents in the South were considered medically disenfranchised, meaning they had little or no access to primary medical care in 2005.³³

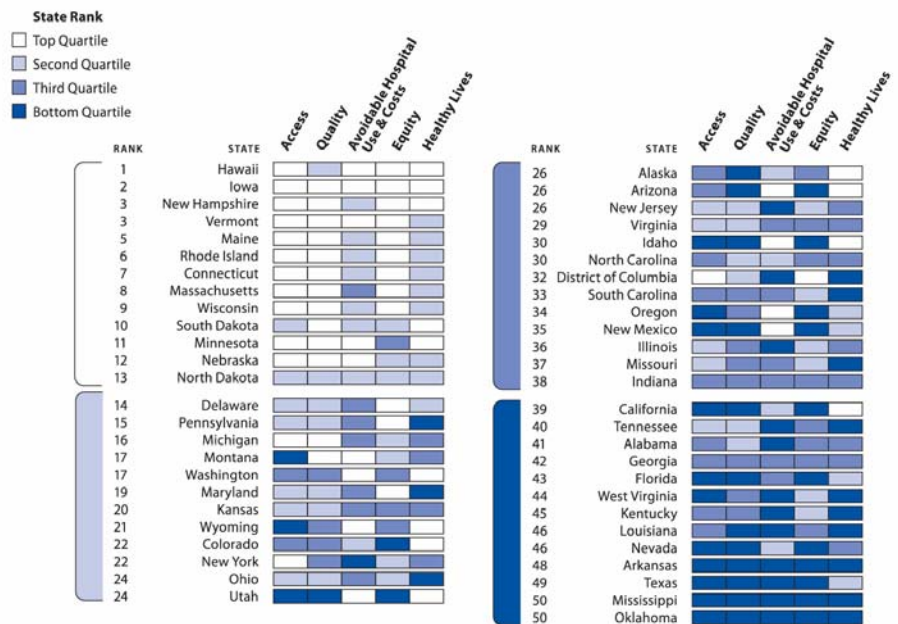
Further, according to the CDC and the updated Census:

- The South ranked first among the four regions of the U.S. in the percentage of medically disenfranchised persons in 2005 (25.3%), and the Northeast ranked fourth (10.3%).
- Of the 20 states that had the highest percent of medically disenfranchised persons in 2005, nine (45%) were Southern states.

Vulnerable Populations

Vulnerable populations in the South have greater health needs; are at substantially greater risk of poor physical, mental, and social health; and have much higher rates of illness and death than the general population.^{27,28} They also typically face greater barriers to

State Scorecard Summary of Health System Performance Across Dimensions



SOURCE: Commonwealth Fund State Scorecard on Health System Performance, 2007

Illustration 1.1

accessing timely, needed care and have worse health outcomes than others.² The proportion of the population that is medically vulnerable is increasing as a result of demographic shifts and socioeconomic trends. Those who are uninsured (see *Illustration 1.2*) are also disproportionately represented in the South.

Poverty and Unemployment

The South has fared worse than the nation as a whole in regard to poverty and income measures. According to 2006 U.S. Census data, among the top 11 states with the greatest number of people living in poverty, eight (80%) were in the South with an average of 17% of the population living at or below poverty level, compared to 12% nationally. Likewise, the per capita income in 2006 was lower in households in the South, which had the lowest median income of \$43,884, compared to \$48,201 for the rest of the country. The Deep South contains a majority of the most impoverished counties in the country.¹⁴ Of the ten counties with the highest poverty rates in the country, eight (80%) are in the South.¹⁰

The Uninsured and Under-Insured

The South has the highest rates of uninsured residents in the nation, and the rate of uninsured is increasing according to 2005 data (see *Commonwealth Fund Commission, Illustration 1.2*, on page 5). More than 18 million Southerners are uninsured, including many HIV-infected persons who must rely on Medicaid, Medicare, disability insurance, the Ryan White Act, and the AIDS Drug Assistance Program (ADAP) to receive necessary treatment. The uninsured rate in the South increased to 18.6% between 2004 and 2005. While 18.5% of whites were uninsured in the South, the percentages among blacks (28.5%) were significantly higher.¹⁰ The national average of the uninsured is 15.7% (data from the U. S. Census in 2004).

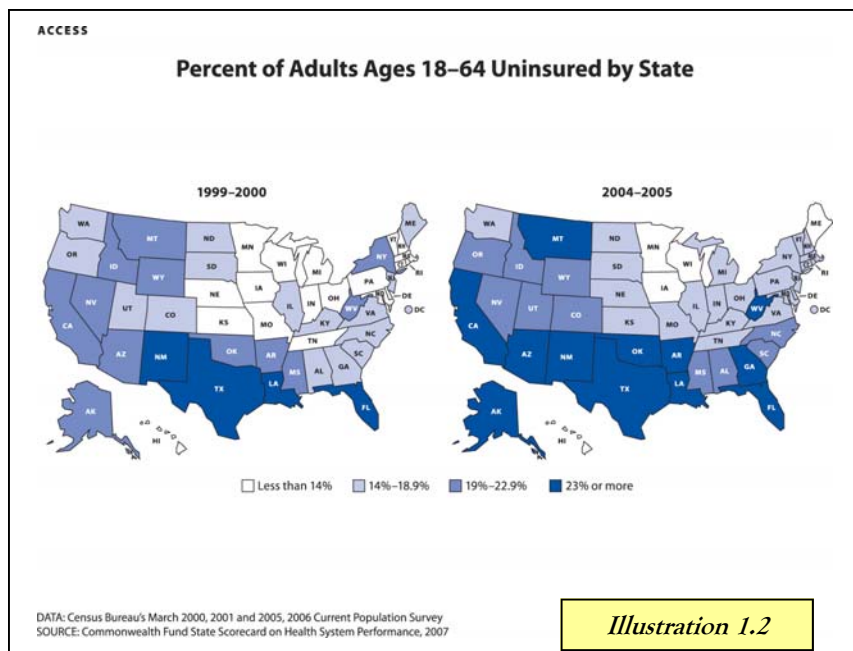
Stigma

Social conservatism is more pronounced in the South compared to the rest of the nation.¹³ Shame and fear of stigmatizing reactions on the part of

THE NEED AND THE NUMBERS, continued

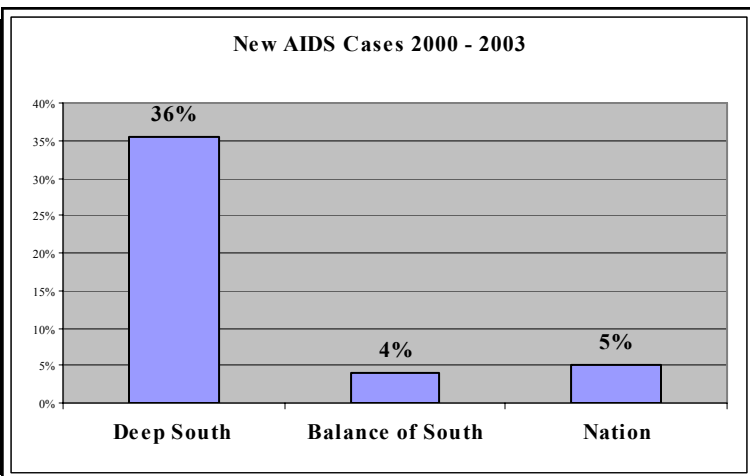
others may lead to reluctance to seek testing and treatment for HIV or other STDs. Men who have sex with men (MSM) may be less likely to be open about their sexual behaviors in such communities and may concurrently be sexually involved with women, who in turn may be unaware of the risk posed to them by their partners' MSM behaviors.¹⁴ Anecdotal evidence across the South indicates that the prominence of the church, with its sexual prohibitions, intensifies fear of stigma.

More than half the persons (117,890 of the 226,447) living with HIV (not AIDS) in the United States in 2006 were in the South (52%).



New AIDS Cases

In a newly released report from Funders Concerned About AIDS, *Spotlight: Alabama*, research from Drs. Whetten and Reif is utilized to highlight the extremely disproportionate growth of new AIDS cases in the Deep South, which is defined as Alabama, Georgia, Louisiana, Mississippi, North Carolina, and South Carolina. The report even characterized the HIV epidemic in the Deep South as "...similar to the epidemic in less wealthy nations than to other areas of the U.S."⁶⁴



Reported AIDS Cases and Rates for Adults and Adolescents by Region and Population of Area of Residence 2005-50 States and DC

Region	MSA of > 500,000		MSA of 50,000-500,000		Nonmetropolitan area	
	Number	Rate / 100,000	Number	Rate / 100,000	Number	Rate / 100,000
Northeast	9,433	26.2	492	9.6	331	7.2
Midwest	3,985	13.3	553	4.8	387	2.9
South	14,003	27.6	2,625	13.6	1,712	9.4
West	5,606	14.0	577	5.9	249	4.2

Minority HIV/AIDS Research Initiative and the Centers for Disease Control and Prevention.
 Note: Data based on residence at time of AIDS diagnosis. Presented at the 2007 HIV Prevention Conference, December 4, 2007.

The CDC Minority HIV/AIDS Research Initiative presented data from an in-house study at the 2007 HIV Prevention Conference entitled *Access to HIV Testing and Treatment in the Rural South*. The design of the study uncovered the fact that the South leads in AIDS cases and rates for adults and adolescents for metropolitan statistical areas of all sizes.

Anthony, Sutton, et. al.⁶⁷ identified recurring themes as barriers:

- Geographic distances;
- Social perceptions about privacy and confidentiality; and
- Economic disadvantages.⁶⁷

THE NEED AND THE NUMBERS, continued

More people are living and dying with AIDS in the South than in any other region of the country.

The church pictured to the right is located in Birmingham, Alabama, and posted this sign for a year during 2005-2006. While the congregation did divide over the words on the sign, the pastor continued to espouse his beliefs about God's view of MSM as defined by the word homosexual. The fact that the sign stood for one year and did not bring a larger outcry from other areas of the community also speaks to the acceptability of a conservative environment that is not welcoming to the range of diversity found in the community overall.



In the United States through 2006

52% of the reported, estimated, living HIV cases were from the South and 41% of the reported, estimated, living AIDS cases were from the South.⁵⁶

The Numbers

The most recent CDC HIV/AIDS Surveillance Report only includes data on persons living with HIV (not AIDS) for the 33 states that have had confidential, name-based HIV reporting for a sufficient length of time. Since living AIDS cases is the only verifiable statistic for comparison, we utilized these 2006 data from the CDC. The green bars on the chart to the right mark the states and city (Washington, DC) included in the Southern AIDS Coalition region. As can be seen from the review of both the data to the right and the rates on the CDC-supplied map on the bottom of *Page 10*, the rates that are higher in AIDS and HIV (those states reporting) also indicate a disproportionate share in the South, especially the HIV case counts. The map on the top of *Page 10* indicates the combined sexually transmitted disease rates for gonorrhea, syphilis, and chlamydia across the country. The South has extremely high rates of these three STDs, which points to the increased need for prevention as well as care and treatment services to reach the rural, suburban, and urban areas of the South. The needs of the South are the focus of the Southern AIDS Coalition (SAC). However, the overarching aim of the work of SAC will continue to focus on expanded funding and services for every resident of the United States and Territories living with HIV. While we continue to experience greater growth in diseases, we also face inconsistent true public health approaches to address prevention, care, treatment, and housing. Variable erratic funding from all sources (RWHATMA, CDC, STD, state) make forming a sustained response nearly impossible. In the following pages, we address the people of the epidemic, the original 2002 *Manifesto* "Calls to Action," and the future of the Southern AIDS Coalition. Our fervent hope is that this document will continue to bring focus to very underserved, disenfranchised populations throughout all of the United States.

THE NEED AND THE NUMBERS, continued

Estimated numbers of persons living with HIV infection (not AIDS) or with AIDS at the end of 2006, by area of residence and age category—United States						
	Living with HIV Infection (not AIDS)-			Living with AIDS		
	Adults or Adolescents	Children > 13 years of age	Total	Adults or Adolescents	Children > 13 years of age	Total
Alabama	5,469	17	5,486	3,744	11	3,755
Alaska	272	1	273	330	1	331
Arizona	5,744	49	5,793	4,922	7	4,929
Arkansas	2,291	7	2,298	2,139	6	2,145
California	—	—	—	61,451	105	61,555
Colorado	5,855	13	5,869	4,083	2	4,085
Connecticut	—	—	—	7,406	15	7,421
Delaware	—	—	—	1,753	7	1,760
District of Columbia	—	—	—	10,059	30	10,089
Florida ^a	35,461	263	35,723	46,469	194	46,663
Georgia	—	—	—	17,336	47	17,383
Hawaii	—	—	—	1,234	3	1,237
Idaho	356	0	356	313	0	313
Illinois	—	—	—	16,139	46	16,185
Indiana	3,849	21	3,870	3,996	14	4,010
Iowa	588	2	590	869	3	872
Kansas	1,230	7	1,237	1,272	2	1,274
Kentucky	—	—	—	2,589	13	2,602
Louisiana	7,361	101	7,462	8,052	21	8,074
Maine	—	—	—	512	2	514
Maryland	—	—	—	14,540	41	14,581
Massachusetts	—	—	—	8,806	20	8,826
Michigan	6,118	55	6,173	6,615	12	6,627
Minnesota	3,227	21	3,248	2,314	9	2,323
Mississippi	4,200	32	4,232	3,155	13	3,168
Missouri	4,999	33	5,033	5,479	7	5,486
Montana	—	—	—	205	0	205
Nebraska	688	12	700	771	2	773
Nevada	3,402	13	3,415	2,969	3	2,972
New Hampshire	—	—	—	556	3	559
New Jersey	16,059	153	16,212	17,168	57	17,226
New Mexico	910	0	909	1,252	3	1,255
New York	42,220	801	43,021	70,697	148	70,845
North Carolina	11,700	60	11,760	8,451	12	8,463
North Dakota	87	2	89	73	1	74
Ohio	8,266	57	8,323	7,054	30	7,084
Oklahoma	2,191	17	2,208	2,191	3	2,194
Oregon	—	—	—	2,840	4	2,844
Pennsylvania	—	—	—	18,633	71	18,703
Rhode Island	—	—	—	1,296	7	1,303
South Carolina	6,349	45	6,394	7,035	23	7,058
South Dakota	195	4	199	139	1	140
Tennessee	6,579	51	6,631	6,403	11	6,414
Texas	24,741	262	25,003	34,010	56	34,063
Utah	893	10	903	1,164	0	1,164
Vermont	—	—	—	238	2	240
Virginia	9,937	41	9,978	8,423	24	8,447
Washington	—	—	—	5,471	5	5,476
West Virginia	660	5	665	749	5	754
Wisconsin	2,322	15	2,337	2,153	12	2,165
Wyoming	86	2	88	102	1	103
Subtotal	224,303	2,174	226,477	435,621	1,115	436,736
SAC States	116,939	901	117,840	177,098	517	177,613
SAC Percentages	52%	41%	52%	41%	46%	41%

Note. These numbers do not represent reported case counts. Rather, these numbers are point estimates, which result from adjustments of reported case counts. The reported case counts have been adjusted for reporting delays, but not for incomplete reporting. Total number of persons living with AIDS includes persons whose area of residence is unknown. Because column totals were calculated independently of the values for the subpopulations, the values in each column may not sum to the column total.

^a See Technical Notes for the list of areas that have had laws or regulations requiring confidential name-based HIV infection reporting since at least 2001.

^b Florida has confidential name-based HIV infection reporting for only the diagnoses made during July 1997 or later.

^c Persons reported from areas with confidential name-based AIDS reporting, who are residents of other areas.

^d Total number of persons living with HIV infection (not AIDS) includes persons reported from areas with confidential name-based HIV infection reporting who were residents of other states or whose area of residence is unknown.

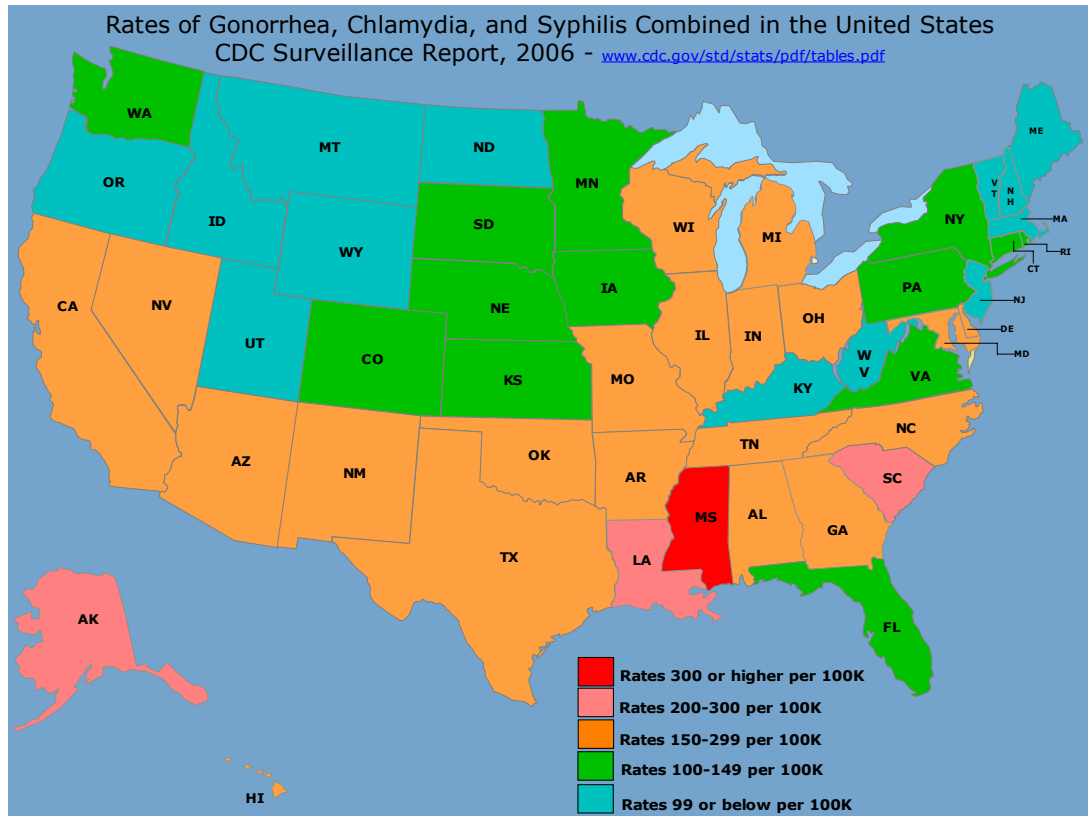
^e SAC developed this chart using the CDC May 2008 data.

THE NUMBERS, continued

Sexually Transmitted Diseases

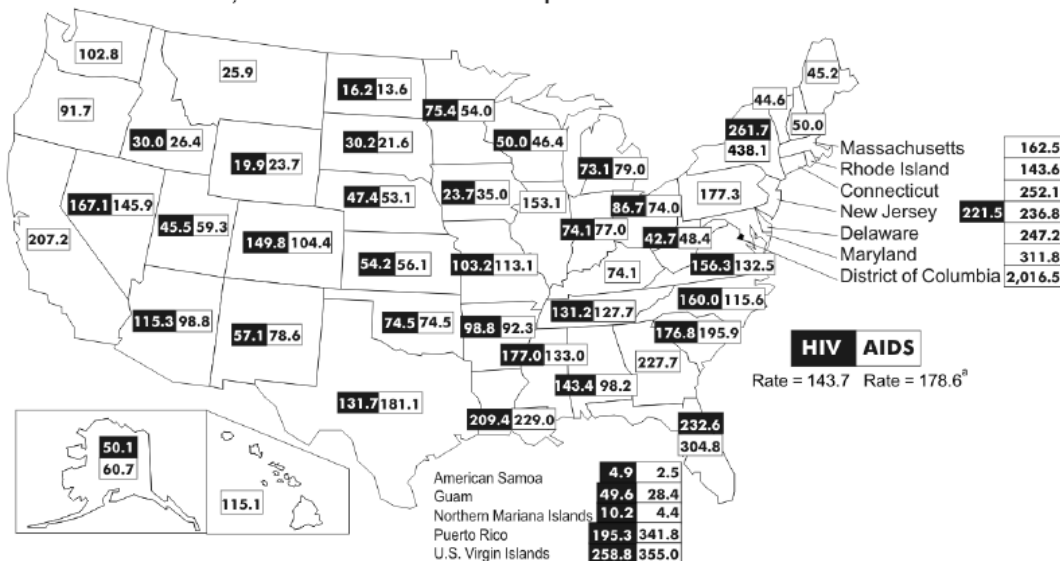
Another indicator for the continued need of prevention messages in the South around STDs continues to be the high level of infection rates reported.

- Chlamydia—nine of the top 15 states are in the South.
- Gonorrhea—13 of the top 20 states are in the South.
- Syphilis—seven of the top ten states are in the South.



Map 1 below: Estimated rates (per 100,00 population) for adults and adolescents living with HIV infection (not AIDS) or with AIDS in 2006 for the United States

Map 1. Estimated rates (per 100,000 population) for adults and adolescents living with HIV infection (not AIDS) or with AIDS, 2006—United States and dependent areas



Note. Rates adjusted for reporting delays. Rates of HIV infection include only persons living with HIV infection that has not progressed to AIDS. Since 2003, the following 38 areas have had laws or regulations requiring confidential name-based HIV infection reporting: Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming, American Samoa, Guam, the Northern Mariana Islands, Puerto Rico, and the U.S. Virgin Islands.

^a Includes persons whose area of residence is unknown.

Introduction

Greater numbers of people without access to basic medical care live in the South than anywhere else in the nation.⁶⁵ Although living with HIV/AIDS is difficult for anyone, the disease is far worse for those who must access resource poor and compromised health care systems, which are characteristic of many southern states. Physical and socioeconomic barriers are compounded by persistent stigma surrounding HIV disease, regardless of sexual orientation, gender, or ethnic background.

Studies have shown that blacks receive a lower quality of care even in our best medical facilities,^{7,8,13,12} and that Latinos face language barriers and the fear they will be suspected of being illegal immigrants, whether they have documentation or not.²² The rural poor of all racial and ethnic backgrounds face barriers of distance and lack of privacy in communities so small that the HIPAA's (Health Insurance Portability and Accountability Act of 1996—Public Law 104-191) privacy protections become irrelevant. The misperception that HIV/AIDS is a disease of gay white males is belied by dramatic increases in heterosexual women, especially in women of color. An added challenge for women is the propensity to place the wellbeing of their families and children before their own health needs.

MSM continue to have the highest proportion of transmission rates in the United States.⁴ Ironically, as providers and funding sources target newly impacted populations (women, minorities, rural), efforts to prevent transmission in MSM receive less attention. Therefore, those most at risk of HIV infection receive less funding and focus, resulting in poor public health.

The moral compass of the nation and the South's specific cultural underpinnings include fundamentalist beliefs, such as blaming those who are diagnosed with HIV disease due to *sinful* behaviors, such as MSM and/or those who use or abuse drugs. These ideologies have created an environment that is indifferent at best and hostile

at worst to the plight of men, women, and children alike, regardless of how they contracted the disease. While true in communities nationwide, the prevalence and perception of being ridiculed is well documented in the South.^{12,13,14} Yet many faith-based entities across the South have become educated, have started or enhanced existing AIDS ministries, and have shown support for persons living with HIV/AIDS.

Even with new federal and state funding for several southern states over the last two years, people living with HIV/AIDS who move to the South for the first time or who move back home to the South are often surprised to learn that they are not afforded the same level of services as elsewhere in the country. Few studies of inward migration to the South exist, but this anecdotal experience is reported in every state through the annual required planning processes. This dichotomy was especially pronounced as HIV-positive persons were displaced during hurricane Katrina.

Those displaced by hurricanes Katrina and Rita discovered that whatever difficulties they may have faced living with HIV/AIDS in their normal world were multiplied many fold in the face of a natural disaster. Our nation's infrastructure has proven to be woefully inadequate to manage the needs of so many displaced people with chronic and acute illnesses. Many people found them-

selves without life-giving medicines, without a way to prove their need, and without a system that could provide access to health care and medicines in time to prevent their health from deteriorating. While Louisiana suffered through the devastating break in the levees, the actual hurricanes struck parts of Alabama and Mississippi equally hard, creating massive displacement of people and permanent infrastructure damage. While the people of Texas, Alabama, Louisiana, and Mississippi still toil to move forward, the local and state communities and governments also caught in the struggle continue to heroically respond.

Although the issues are unique, they all lead to the same result—more disease, higher health care costs, less access to care, and earlier deaths. Scientific and medical progress in diagnosing and treating HIV/AIDS is meaningless for a person who cannot access the treatment.

Men Who Have Sex with Men (MSM)

Men who have sex with men (MSM) continue to represent the highest number of annual new HIV infections as



The cross on the altar at St. John's Church in Raleigh, NC, has been draped for HIV awareness events in the red ribbon symbol since the first World AIDS Day in 1988.



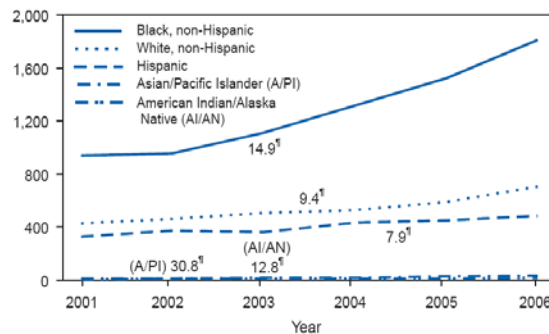
THE PEOPLE, continued

well as the largest group of people living with HIV/AIDS in the South and in other parts of the United States.⁴ However, MSM in the South face particular barriers that affect their access to HIV prevention, care, and support. The South in general has fewer metropolitan centers that have historically supported openly gay communities. These larger population centers provide the settings for community-based interventions targeting gay-identified MSM. In smaller cities, towns, and rural communities, even gay-identified men continue to live in and with communities and families of birth, a pattern which encourages secrecy, invisibility, and social isolation.

In Tennessee, for example, there were 56 and 60 anti-gay hate crimes reported to the Tennessee Bureau of Investigation in 2007 and 2006 respectively, almost *three times* the number (21) reported in 2005 and prior years, causing small wonder that most men in the rural south fear being labeled as homosexual.^{12,13} This fear is particularly pronounced for blacks, especially in rural communities, where homosexuality is often perceived as rare and abnormal, based on cultural constructs of a dominant heterosexual masculinity.¹⁸ Bisexually-active men may deny risky behavior or expect women partners to take responsibility for health checks, including for HIV/AIDS.

Ironically the secrecy caused by this stigma leads to increasing HIV rates for women, especially black women. Interventions to inform MSM are many; however, government resources and abstinence-only education is politically more acceptable than comprehensive sexual education, open forum conversations, and media campaigns to caution men that unprotected sex with other men is putting them at risk for HIV and other STD transmissions. State AIDS Directors, community advocates, members of Congress, and people liv-

FIGURE 2. Estimated* number of HIV/AIDS† diagnoses and estimated annual percentage change (EAPC) among men who have sex with men aged 13–24 years, by race/ethnicity and year of diagnosis — 33 states,‡ 2001–2006



* Adjusted for reporting delays and missing risk factors for HIV.

† Diagnosis of HIV infection, regardless of whether or when AIDS was also diagnosed.

‡ Alabama, Alaska, Arizona, Arkansas, Colorado, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

† EAPC.

ing with HIV are all put at a disadvantage, due to perceptions of community, political, faith, corporate, and social leaders who believe that knowledge of how to have safe sex with anyone encourages the act itself. There is no data that can be found to substantiate this claim. However, data support the fact that more MSM keep their behaviors secret and private to avoid the stigma.¹³ Thus, the conflict of implementing successful education strategies for MSM conflicts with the political, public, and moral belief systems, perpetuating the result that MSM are still the highest group of people infected annually.⁴

“Black Americans have been disproportionately affected by HIV/AIDS since the epidemic’s beginning, and that disparity has deepened over time. Blacks account for more HIV and AIDS cases, people estimated to be living with AIDS, and HIV-related deaths than any other racial/ethnic group in the U.S.”⁶¹

Those who are living with HIV disease, whether or not they are aware of their status, continue to be influenced by the stigma that exists in their cultures.^{12,13}

According to the June 27, 2008, edition of the CDC’s *Morbidity and Mortality Weekly Report*, the number of HIV/AIDS diagnoses among MSM overall during 2001–2006 increased 8.6%. Of these new cases, a 12.4% increase was seen in black MSM; in black MSM ages 13 to 24, an increase of 93.1% was observed. Black MSM ages 13 to 24 experience twice the growth rate as white MSM. Of the 33 states utilized in this report, the MSM population in the South comprised 55% of the total or 53,710 of the 97,577 MSM.⁶⁶

The shame connected with HIV, even if one identifies as heterosexual or bisexual can still cost primary relationships, employment, housing, and social disconnects from needed support systems.

People of Color

Blacks and Latinos continue to be disproportionately affected by the HIV/AIDS epidemic in the South and are infected with HIV at a greater rate than other racial/ethnic groups. Black and Latino MSM continue to have the highest incidence of any risk groups in black and Latino communities.

Blacks and Latinos are more likely to be uninsured⁴¹ and, therefore, less likely to receive timely preventive care. Blacks and Latinos are also at a higher risk of receiving inadequate care. According to the Institutes of Medicine (IOM), several reports indicate that blacks and other racial/ethnic minorities may receive lower quality health care and treatment, regardless of their insurance status. Blacks and Latinos in particular have fared poorly on each of the outcomes that evidence suggests is improved by the care of physicians whose training or clinical experience would make them eligible for certification as “HIV special-

THE PEOPLE, continued

ists.”²² Specifically, members of these minority groups have greater odds of dying,^{10,11} lower odds of receiving antiretroviral therapy,^{12,13} and more frequent hospital admissions¹⁴ when compared with whites.

HIV/AIDS Among Blacks

Over the past 25 years, AIDS has had a devastating impact on black communities in the South. Today blacks become infected with and die from HIV/AIDS far more than any other racial or ethnic group.

- 12% of the U.S. population is black, yet 47% of the new HIV/AIDS diagnoses in 2006 were among blacks.^{56,60}
- HIV/AIDS was the leading cause of death for black women ages 25–34 years in 2002.⁶⁰
- Black MSM have the highest incidence of HIV/AIDS.
- More blacks reside in the South than in any other region of the country.
- Over half (52%) of blacks living with AIDS and 58% of new AIDS cases reported in 2006 among blacks occurred in the South; yet blacks represent approximately 19% of the South’s population.
- Of the ten states with the highest number of blacks living with AIDS, five or 50% are in the South.
- Of the ten states with the highest rates of new HIV diagnoses for blacks in the US, five or 50% are in the South.

The lack of viable employment, quality education, access to medical care, decent housing, and overall community infrastructure perpetuates economic inequalities among blacks in the South. In many southern states where the percentage of blacks in the population is the highest in the country, half of blacks live below 200% of the poverty line, and they have significantly less access to health care than people of other races and ethnicities.^{24,29,39}

Ecological studies demonstrate that high incarceration rates are correlated with elevated rates of sexually transmitted infections. Although blacks account for 12% of the population in the United States, approximately 40% of incarcerated persons are black, and 12% of black men 18-29 years old were incarcerated in 2005.

Young black women in the South are the fastest growing population with heterosexually-acquired HIV.

Distrust of the public health system among blacks and Latinos is an important barrier that cross-cuts all categories of risk behavior. The perception that medical providers neither respect nor understand the concerns of black clients is reinforced by the insensitive treatment of blacks.⁴⁶

HIV/AIDS Among Latinos

Although Latinos represent approximately 15% of the U.S. population, they account for 19% of the AIDS cases diagnosed in 2006 and 17% of HIV/AIDS cases diagnosed in 2006, which includes 33 states with confidential, name-based HIV reporting.^{56,63}

The AIDS case rate per 100,000 among Latino adults/adolescents was the second highest of any racial/ethnic group in the U.S. in 2006, 3.3 times that of whites.⁶³

Latino MSM continue to have the highest incidence of any risk group in Latino communities.

- Of the ten states with the highest rates of new HIV diagnoses for Latinos between 2002 and 2006, seven (70%) were in the South.⁶²
- Of the new cases among Latinos in Louisiana diagnosed in 2006, 33% were diagnosed with AIDS at the time of first detection, compared to 25% among whites and 21% among blacks.²

Across the United States the Latino population is growing rapidly; between 1990 and 2004 there was a 58% increase in the number of persons of Latino origin living in the United States. One of the most striking aspects of recent migration to the South has been the extraordinarily high rate of Latino migration to areas outside of metropolitan districts. Over the past fifteen years the greatest increases have taken place in rural areas of the South. In the 1990s Latino non-metropolitan growth was more than 70%, which exceeded their metropolitan growth rate of 60% during

the decade and accounted for more than 25% percent of the total growth of rural areas in the United States during the 1990s.

Latinos face special challenges in accessing HIV services in the South.²² Latinos experience longer waits and are denied services due to language barriers, lack of insurance, and lack of cultural understanding on the part of providers and their staff. Social isolation makes it difficult for Latinos to access traditional prevention education; as a result disproportionate numbers of Latinos are becoming infected with HIV and are in need of access to primary care. For many undocumented immigrants, fear of community rejection and deportation often prevent HIV-infected persons from accessing care. This concern has become increasingly prevalent over the last year during the national debate on immigration and access of immigrants to public services. In addition Latinos are often diagnosed at later stages of disease progression, requiring more specialized services than if they were diagnosed at earlier stages.

Women

The HIV death rate (per 100,000) among black women ages 25 to 44 was 23.1 compared to 1.3 for white women. HIV/AIDS was the leading cause of death for black women ages 25-44 years in 2004.⁶¹ Sixty-six percent (66%) of women in the U.S. diagnosed with AIDS are black.^{60,61} In some parts of the South women (mostly black) comprise over thirty percent of the HIV-positive population (Alabama Department of Public Health, 2007). In some rural, southern counties, this figure is closer to 50% (Dill & Mobley, 2002). The figure is higher than in the United States as a whole and is attributed in large part to sexual relations with infected men. Continued parental transmission indicates the need for expanded outreach to pregnant women. Parental testing laws should be reviewed from state to state to ensure that access to education is available. Complexities of being a mother and living with HIV also abound, given the intersection of schools, daycare, doctors, providers, and other systems of care that come into contact with an HIV-positive mom.

Section III—ACCOMPLISHMENTS

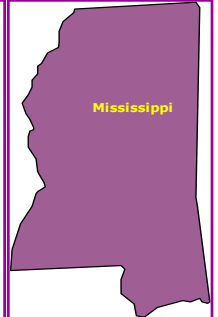
The 2002 initial release of the *Southern States Manifesto* met with unprecedented attention from elected officials, media, and community leaders, resulting in significant improvements for people living with HIV/AIDS in the South and in other under-funded areas. The last six years have met with many accomplishments, some of which are highlighted.

Changes in Reauthorized Ryan White Legislation

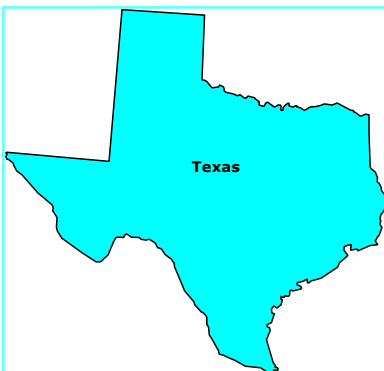
The reauthorization of the Ryan White CARE Act resulted in significant changes, many of which were supported by the Southern AIDS Coalition. While the changes are beneficial to many areas that had been under-funded in previous years, the success is short-lived. The Ryan White program is slated to sunset on September 30, 2009. Some highlighted changes are below:

- Change in distribution methodology so that funding follows the epidemic;
- \$70 million increase for Title II Base;
- Creation of Title II supplemental funding stream for states in need, although funding may not be available due to hold harmless provisions;
- Increased set-aside of ADAP supplemental from 3% to 5%;
- Required minimum drug list;
- Hold harmless to minimize losses to most jurisdictions;
- Counting of HIV cases (allows code-based HIV data to be counted);
- Shift to living AIDS cases;
- Plan for unobligated balances to go back into program;
- Establishment of core services;
- Protection of most current Title I Eligible Metropolitan Areas;
- Capping of administrative expenses;
- Inclusion of hepatitis co-infection;
- “Severity of Need Index” to be developed;
- Increase in coordination and accountability; and
- Codification of the Minority AIDS Initiative.

Mississippi will open a new HIV-specific medical clinic in a high-need area of the state, allowing rural residents to have access in more than one area of the state for the first time. The state legislature set aside funding in 2007 to support the clinic.



North Carolina increased ADAP financial eligibility from 125% to 250% of Federal Poverty Level, launched a major statewide patient management system with targeted health outcomes, and initiated an aggressive statewide HIV screening initiative entitled *Get Real, Get Tested*. This initiative increased HIV testing by 18% in one year. This targeted program included non-traditional testing sites with HIV-positive test rates of 1,013 per 100,000, which is substantially higher than rates found in the general population.



The Texas ADAP program responded immediately to the evacuees of Katrina and ensured immediate medication delivery during the nation's largest recent natural disaster.

A new State Pharmacy Assistance Program was funded to ensure that those on Medicare Part D could be financially assisted for all the co-pay requirements.



For the first time Alabama's ADAP added all HIV and opportunistic infection medications, as well as critical diagnostic screenings, with no waiting list for participants. The state legislature and AIDS Alabama launched the first state-funded HIV supportive services program.



ACCOMPLISHMENTS, continued



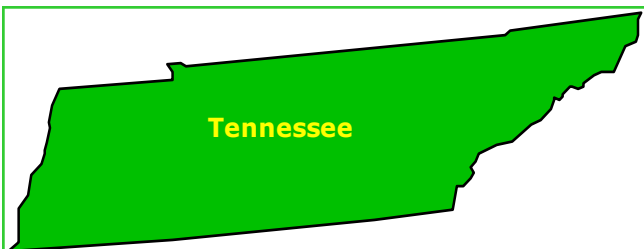
NO/AIDS Task Force has seen an increase in the utilization of all of its programs and services over the past three years. The Primary Medical Care program expanded from a part-time clinic (two and half days a week) to a full-time medical practice with a dedicated physician, nurse practitioner, two RNs, and a phlebotomist, who are currently providing medical care to 700 individuals. The clinic will open an on-site pharmacy in September 2008. The agency has also acquired a mobile medical unit which allowed the agency to increase HIV testing by 30%.



Virginia developed the first State Pharmaceutical Assistance Program (SPAP) specifically for those living with HIV who are Medicare Part D recipients.



The South Carolina HIV/AIDS Council's Project F.A.I.T.H. (Fostering AIDS Initiatives That Heal) creates community mobilization to eliminate stigma and strengthen the ability of churches to create local solutions and now funds 30 multi-denominational, faith-based entities across the state of South Carolina.



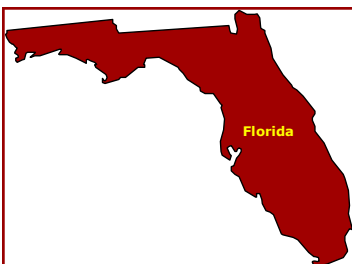
Tennessee received two new Ryan White Transitional Grant Areas for Nashville and Memphis that added more than \$6 million for those two metropolitan communities and established a coordinated planning effort between these two new entities and the state program. These efforts include input from the HIV-positive population, although not required by the federal legislation.



The Alliance has added pastoral, substance abuse, nutritional, and mental health counseling services to maintain clients in comprehensive medical care. In June 2008 AASC began offering HIV, syphilis, gonorrhea, chlamydia, and hepatitis testing four days a week in Raleigh and surrounding areas. The addition of a Latino coordinator now allows services to be accessed in English or Spanish.



Nashville CARES introduced rapid HIV screening in hospital emergency departments, using first- and second-year medical students who are trained and certified to provide HIV counseling and testing. The agency also developing a community-wide intervention services system to link HIV-infected individuals not in care into HIV medical care and support to sustain care over time.



Florida tested more than 300,000 persons in 2007, marking a 43% increase over eight years in the number of persons tested in one year, becoming the first state to cross this threshold. Screening remains a major priority of the state.

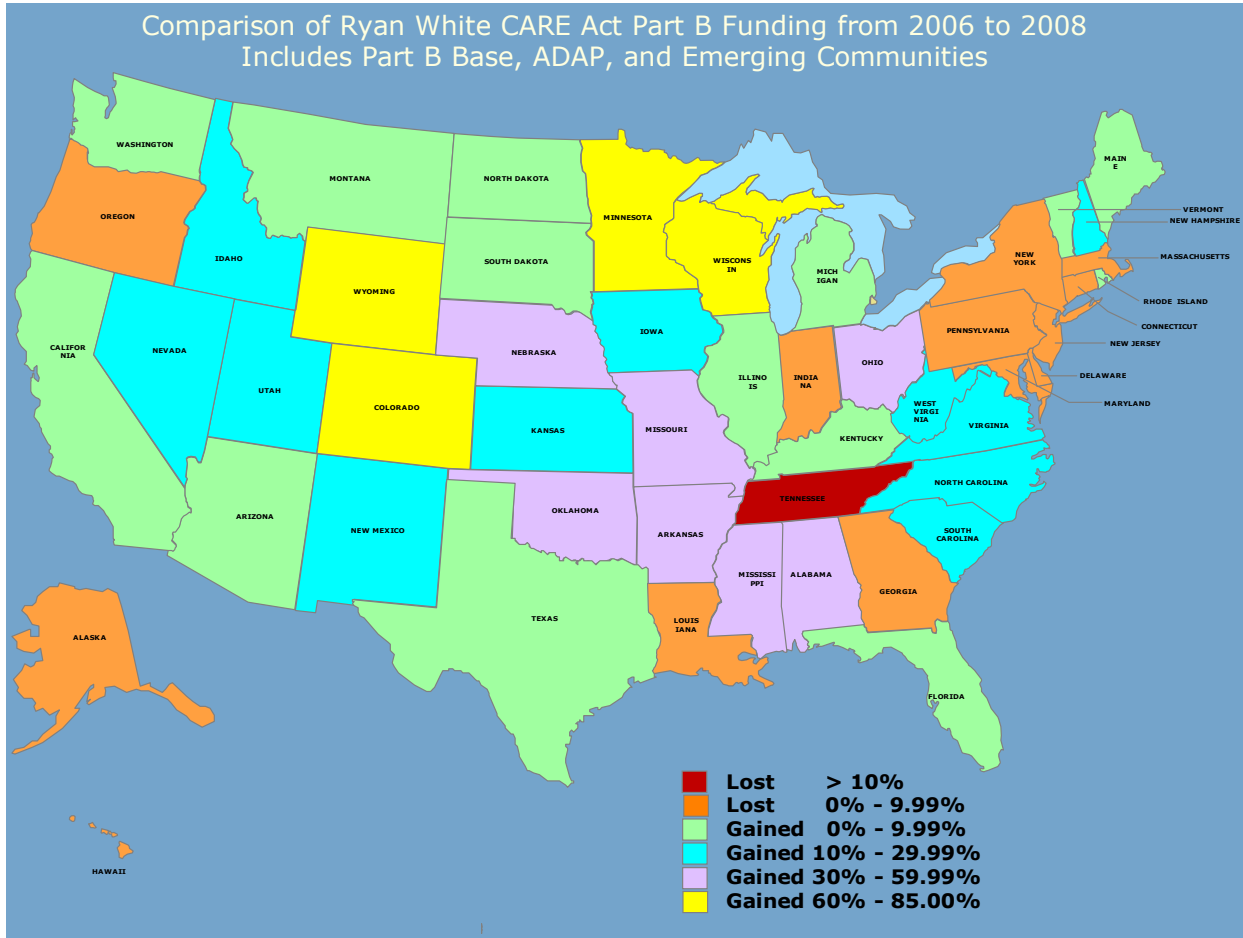


South Carolina eliminated its ADAP waiting list of more than 500 persons in need of HIV medications, thanks to collaborative efforts to increase state and federal funds.



Louisiana government, community, and private sectors demonstrated heroic humanitarian response and passionate perseverance in the delivery of services to the HIV-positive population despite the complete devastation of infrastructure, as well as a slow and ineffective federal response to Hurricane Katrina. Despite these challenges, Louisiana expanded its formulary from 23 to 62 available medications, transitioned people to a new Transitional Grant Area, and successfully competed for an additional \$2.2 million of CDC funding to expand HIV testing.

Section IV—THE CHALLENGES



After the 2002 release of the *Southern States Manifesto*, the reauthorization of Ryan White occurred, and CDC screening and treatment guidelines were updated. The Southern AIDS Coalition continued its work to find solutions for the challenges we face together. This section details some of the challenges that still remain.

Fund Distribution

Federal funds for HIV/STDs are allocated by different funding formulas and at times conflicting regulations. The methods used in federal funding distribution for HIV/STDs are not mirroring the epidemics. One of SAC's major principles is that all federal funding should follow the HIV and STD epidemics. While the map above indicates the results of the Ryan White Act of 2006 on Part B funding, the changes in funding from

2006-2007 obviously do not meet the overarching needs across the nation, including the South. Federal funding has failed to provide increases in prevention, care, treatment, and housing.

Flat base funding coupled with CDC rescissions for multiple years has resulted in all programs across the country being forced to make choices between needed services. SAC fought hard to bring about a combination of parity and increased funding levels. While the funding levels for many southern states has increased and some may argue that it is a bit more equitable in terms of distribution, the fact remains that the overall funding for every state is inadequate. The impact of these shortages results in higher cases of HIV and STDs and less access to care and treatment. Further, as the adjacent chart illustrates, the South remains in the position with the highest number of living AIDS cases in the country.

**Person Living with AIDS in 2005
By Region**

	Rank	Number
North	2	126,867
Midwest	4	45,666
South	1	169,972
West	3	83,405

CDC HIV/AIDS Surveillance Report—Nov. 2006, Vol. 17

THE CHALLENGES, continued

Health Care Infrastructure

Historically the South has been challenged to create quality health care systems. These challenges stem from a geographically dispersed population unable to afford specialized health care that manages communicable and chronic diseases. To further exacerbate the situation, low-paying jobs without health insurance and high rates of poverty are common. Those in poverty struggle to find consistent Medicaid-reimbursed medical care providers. States struggle to fund these entitlement health care programs requiring state match with dwindling state revenues and resources.

Public health has played a more prominent role in the South compared to other regions of the country to compensate for these inadequacies. Complex diseases are difficult to manage in public health settings for several reasons:

- Persons living with HIV are less likely to seek ongoing health care at a county health department;
- Most county health departments are not prepared to handle a disease as complex as HIV;
- The providers are less informed about the state of the art treatment regimens; and
- Adherence programs to encourage consistent treatment are limited or nonexistent.

People who need to be but are not on treatment (drugs) as assessed by medical professionals are more likely to be infectious to others. Treatment adherence reduces the number of new infections. These health care disparities are exacerbated by the underlying and still quite prevalent stigma associated with HIV disease. The stigma stems from the transmission of HIV through sex and/or sharing of needles, which further perpetuates the stigma.

Overall Health Ranking

Rank	State	Rank	State
50	Mississippi	40	Georgia
49	Louisiana	39	Nevada
48	Arkansas	38	New Mexico
47	Oklahoma	37	Texas
46	Tennessee	36	North Carolina
45	Alabama	35	Missouri
44	West Virginia	34	Delaware
43	Kentucky	33	Arizona
42	South Carolina	32	Indiana
41	Florida	31	Michigan

** DC data not available

United Health Foundation-America's Health Rankings, 2007

Federal Funding for HIV/AIDS Dollars Spent per Person Living with AIDS By Region, 2005

	Total Federal Funding for HIV/AIDS		CDC HIV/AIDS Funding		Ryan White HIV/AIDS Funding	
	Rank	\$ Spent	Rank	\$ Spent	Rank	\$ Spent
North	1	\$6,963	3	\$1,179	1	\$4,785
Midwest	3	\$6,581	1	\$1,365	4	\$4,317
South	4	\$6,565	4	\$1,082	2	\$4,548
West	2	\$6,718	2	\$1,293	3	\$4,424

Kaiser Family Foundation: www.statehealthfacts.org

People of the South are dispersed geographically and racially in different ways than the balance of the country. The 2005 data to the left highlights disparities in total CDC and Ryan White funding.¹¹ This data represents the South's share of funding prior to the passage of the RWHATMA in 2006 and new CDC funds released in 2007. Both of these signify significant shifts in funding meet a 2002 SAC "Call to Action" that the funds should follow the epidemic.

The South's current per-person ranking for Ryan White funds continues to improve the access to care and treatment; however, HIV/AIDS case rates continue to soar in the South. Additional and substantial funding for comprehensive education and testing must increase before a decrease in new cases will be possible.

Section V—OPPORTUNITIES

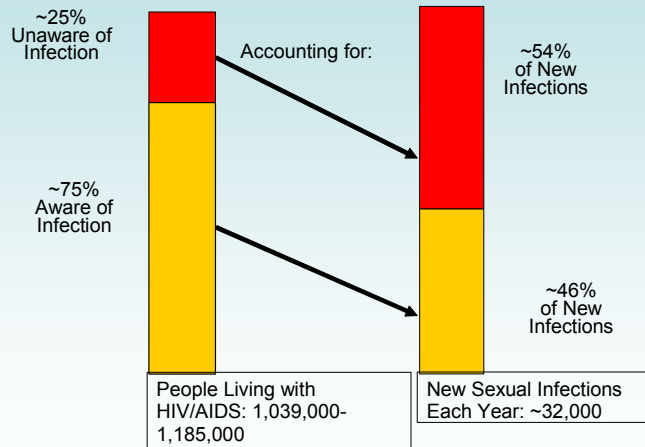
SAC sees the upcoming three- to five-year period as filled with opportunities to achieve the overarching goals set out on “Page 3.” Those opportunities include:

- Linking of HIV infected individuals into care within 30 days of a positive result and maintaining them in care and/or on treatment, if prescribed;
- Acute and routine screening to ensure the identification of people who are unaware of their status at the earliest opportunity;
- Safe, decent, and affordable housing;
- Mental health and substance use treatment and support;
- Collaboration among our government, community, faith-based, and business partners to focus efforts on these achievable goals; and
- Reduction of new infections through age-appropriate education and effective prevention interventions.

Opportunities

Recent data prove that persons unaware of their HIV serostatus are responsible for the majority of new annual HIV infections; this important revelation is particularly pertinent in the South. The South has the highest

Awareness of Serostatus Among People with HIV: Estimates of Transmission



Marks, G., Crepez, N., Janssen, R.S., Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA, AIDS 2006, 20:1447-50.

number of living HIV cases with at least 25% unaware of their status, which is a major factor as to why the South continues to experience the highest incidence of HIV.

Implementation of the September 2006 *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings* is essential in the South, the fastest growing region for new HIV infections.

The barriers for implementation in-

clude the lack of resources and political will. Leadership from public, private, and community sectors will be necessary to overcome the barriers to implementation of these needed guidelines.

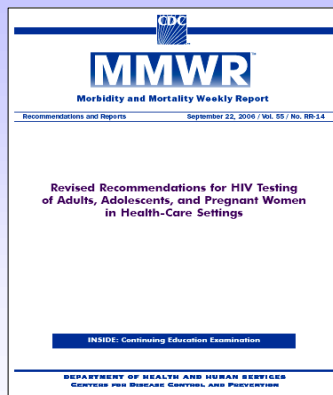
Most providers believe that the implementation of these guidelines would result in a reduction of new infections. However, knowing one's status is just the beginning of the process. Discovery that one is HIV-positive requires counseling and support. Persons at high risk who are not positive also need age-appropriate education to avoid infection in the future.

The CDC's recommendations for all pregnant women will protect unborn infants of HIV-positive mothers. The focus on health care settings, especially emergency departments, substance abuse programs, residential care facilities, and other health care environments, will also greatly increase the opportunity for persons to learn of their status.

Counseling and linkage to care programs for those who test positive and those who disclose risks are also critical components for overall reduction of new HIV cases.

Resources must be targeted for testing and linkage to care to see the full impact of the CDC's recommendations.

CDC Recommendations Routine Testing for HIV-1



- ▶ Routine voluntary testing for patients ages 13-64 in health care settings – not based on patient risk
- ▶ Opt-out testing
- ▶ No separate consent for HIV
- ▶ Pre-test counseling not required
- ▶ Repeat HIV testing left to discretion of provider, based on patient risk

MMWR, Volume 55, No. 1, RR-14, Recommendations and Reports, September 22, 2006

14

OPPORTUNITIES, continued

Mental Health and Substance Abuse

Intrinsically linked to conditions of overall mental health, studies show that substance abuse co-morbidity exists among those living with HIV in ranges from 35% to 78%.^{47,48,49} Clinicians and treatment adherence specialists struggle with whether or not to: 1) start therapy in patients with mental health concerns that affect their daily living activities; 2) continue treatment when laboratory test results indicate non-adherence; 3) switch patients to regimens that may be easier from a compliance point of view; and 4) be more deeply involved in convincing patients they must stabilize their mental health and substance abuse issues. Research specifically focused on the South indicates that 72.5% of rural patients have at least two types of traumatic events during their lifetimes, and more than half of the patients (52.5%) experienced abuse (sexual/physical) in their lifetimes.⁵¹

Post-Traumatic Stress Disorder (PTSD) and trauma in general have been seen as the underlying cause of legal and illegal substance abuse/misuse for decades. Several presidential reports of blue ribbon committees have highlighted the need to gain a better handle on mental health treatment for the traumas of life in order to reduce and prevent the burgeoning amount of legal and illegal substance abuse/misuse in the United States.^{50,51}

PTSD is directly linked to hospitalizations, emergency room visits, increased medical visits, and acting out emotionally through the practice of unprotected sex without identification of HIV status.⁵¹

The lack of available mental health practitioners for the low-income populations across the country leads to physical health care disparities.¹⁷ When it comes to chronic diseases that require treatment and care regimens such as HIV, hepatitis, and other sexually transmitted diseases, mental health interventions with skilled practitioners can provide models that alleviate the barriers to treatment and adherence.

Many low-income health care settings do not

have any kind of mental health assessment or mental health therapeutic support in rural or less urban settings across the South. In fact, the AIDS Drug Assistance Program (ADAP) data from the 2007 National Alliance of State and Territorial AIDS Directors (NASTAD) ADAP Report indicate that most ADAP programs have approximately a 76% fill rate of prescriptions for those approved and prescribed ADAP-covered medicines. There is no good data on the reasons why this pick-up rate is less than 100%; however, anecdotal evidence points to mental health/substance abuse, stigma, and transportation as primary reasons for this statistic.

Many communities have substance abuse treatment programs that do successfully achieve identification, linkage, and completion of treatment for substance abuse. However, relapse and other psychosocial conditions related to housing and living environments show relapse rates by some studies of as many as 60% of those completing at least a 28-day treatment program for alcohol, crystal methamphetamine, cocaine, or prescription medication addiction. The underlying traumas and/or reasons for the substance use, including the principles of addiction, are often not included in these standard treatment protocols.

Added to this burden are the limited number of trained therapists in HIV, PTSD, and substance abuse who are employed in settings where the greatest need exists. Yet federal funding continues to move away from mental health care and toward a medical-based model. Often mental health issues must be addressed before medical interventions can be effective. The mentally ill and/or substance abusing populations are also less adherent by the nature of their diseases and chronically access the system in a more costly manner.

Unprotected sex for survival, including the need for shelter and food, by those living with HIV is documented in a wide-ranging survey completed by AIDS Housing of Washington. This survey also indicates that of those who are HIV-positive and homeless, which comprised 3%-10% of the homeless population (ten times the rate of the general population), 80% had some form of mental illness and more than 50% of those on the street had been incarcerated. Further, more than 50% of those living on the street had traded sex for shelter, food, or drugs.

When most patients receive consistent, effective therapies, the viral load decreases and CD4 cells rise, and the chances for transmission of the virus greatly decrease.⁵² It is further known that the limited resources available to clinicians for payment of therapies sometimes guides the therapist to withhold prescribing for a patient whose adherence is greatly in question. This cycle, while defensible, leads to increased infection rates, given the issues of addiction, mental health, and unstable living conditions.

There is growing evidence of the number of correlations between poverty, trauma, victimization of women, and the regional disproportionate presence of these conditions in the South. The region has the most new cases of HIV disease and more new cases that are identified as having progressed to an AIDS diagnosis than in any other region of the country.

We need to prioritize mental health and substance abuse assessment, treatment, and access for persons with HIV in the South.

OPPORTUNITIES, continued

National AIDS Housing Coalition (NAHC)

Ginny Shubert of Shubert Botein Policy Associates and Dr. David Holtgrave, Chair of Johns Hopkins Bloomberg School of Public Health

In June 2005, October 2006, and March 2008, public health experts gathered to share research findings on HIV and housing. SAC is represented on the NAHC Board of Directors, as access to appropriate housing remains a barrier to testing, care, and treatment strategies. The Housing Research Summit Series now provides a regular venue for the presentation of research of significance to HIV/AIDS housing policy, coupled with dialogue about the public policy implications of findings. For information on the Summit Series and to read the Summit policy papers, visit www.nationalaidshousing.org.



Housing

The National AIDS Housing Coalition (NAHC) is the leading national entity documenting the relationships between housing stability, HIV care and treatment, and prevention of HIV disease through stabilizing lives. New reporting from the federal Housing Opportunities for Persons with AIDS (HOPWA) program shows high levels of housing stability at relatively low per-unit costs. For example:

- 89% of households receiving an average annual rental assistance of \$3,750 remain stably housed after one year
- 79% of residents of supportive housing remain stably housed at one year at an average cost of \$9,000.

Ongoing evaluations of supportive housing programs for persons with

HIV/AIDS and other special needs show that the stability created by appropriate housing sharply reduces utilization of costly emergency and inpatient health care services. A 2002 study found that such service cost savings offset 95% of the annual cost of supportive housing for mentally ill, homeless persons. These cost-offset analyses support the provision of supportive housing for persons living with HIV/AIDS, even before taking into account the substantial costs associated with heightened HIV risk among homeless persons or the costs resulting from delayed or inconsistent care among unstably housed persons living with HIV/AIDS.

An ongoing housing and health study conducted by the U.S. Department of Housing and Urban Development and the CDC examines the relationship of HIV/AIDS housing to HIV prevention and care, including comparing the costs of HIV/AIDS housing services to the

savings associated with prevented HIV infections. Preliminary findings from this study indicate that HIV/AIDS housing is both:

- Cost-effective (service costs divided by medical cost saved plus a value for each quality-adjusted life year saved when an infection is prevented) and
- Cost-saving (service costs divided by life-time medical cost savings when a transmission is prevented).⁵³

National research shows that 40% to 60% of all persons living with HIV/AIDS report a lifetime experience of homelessness or housing instability. Simultaneously, people with housing needs who receive any level of housing assistance are almost four times as likely to enter into medical care as those who do not receive assistance.⁵⁴

Housing as Prevention

Important new research demonstrates a direct and independent relationship between improved housing status and reduction in HIV risk behaviors among HIV positive persons with multiple behavior issues, highlighting the significance of housing as an exciting new structural intervention to reduce the spread of HIV. Homeless persons face enormous pressures of daily survival needs that supersede efforts to reduce HIV risk, as well as multiple barriers to risk reduction resources. Homeless or unstably housed persons were two to six times more likely to use hard drugs, share needles, or exchange sex than stably housed persons with the same personal and service use characteristics.⁵⁵

Research also shows a strong association between change in housing status and HIV risk behavior change. Over time, persons whose housing status improved reduced risk behaviors by half, while persons whose housing status worsened over time were four times as likely to exchange sex. Access to housing also increases access to antiretroviral medications, which lower viral load and may reduce the risk of transmission.

OPPORTUNITIES, continued

Housing Funding

The need for categorical HIV housing resources has been questioned as an example of “AIDS exceptionalism,” a term used to describe policies that differ from a traditional infectious disease control or chronic care approach (Schilts, 1987; Wachter, 1991). As stated in the Institutes of Medicine (IOM) report on health care delivery, HIV disease remains unique in that it combines an infectious agent, potentially fatal consequences, rapid spread in vulnerable populations, and the potential for development of drug-resistant strains, while being highly treatable with anti-retroviral therapy that substantially reduces mortality and morbidity (IOM, 2004).

The federal Housing Opportunities for Persons with AIDS (HOPWA) program serves only 67,000 households per year nationwide, 91% with incomes of less than \$1,000 per month, which is 60% less than needed to afford housing at Fair Market Rents. Yet the need is estimated at 500,000 households that will need financial housing support at some time during their illness. National research continues to document housing as the single greatest consumer need across the country, including in the South.

“It would seem like a no-brainer to me that you need a roof over your head to maintain your health.”

Cassandra Ackerman

HIV/AIDS Consumer Advocate and National AIDS Housing Coalition Board Member



This Rural Studio house for families, developed by AIDS Alabama, Auburn University, and AIDS Outreach of East Alabama, uses railroad cars for bedrooms.

National AIDS Housing Coalition Policy Tool Kit for Housing

www.nationalaidshousing.org

The National AIDS Housing Coalition has established a baseline of policy imperatives to connect housing to HIV disease and all of the co-factors that accompany HIV, such as poverty, stigma, homelessness, employment challenges, mental health issues, and substance misuse/abuse. The following policy imperatives have been adopted by the Southern AIDS Coalition. A toolkit is available for use by advocates across the country at the website above.

The Policy Imperatives

Research findings provide the basis for *a re-visioned, data-driven HIV/AIDS housing policy agenda* that can be framed in terms of *four public policy imperatives*, articulated by participants in the first National Housing and HIV/AIDS Research Summit:

1. **Make subsidized, affordable housing available** to all low-income people living with HIV/AIDS (including supportive housing for those who need it);
2. **Make housing assistance a top prevention priority**, since housing is a powerful HIV prevention strategy;
3. **Incorporate housing as a critical element of HIV health care**; and
4. **Collect and analyze data** to assess the impact and effectiveness of housing as an independent, structural HIV prevention and health care intervention.

With evidence to back their positions, policy makers can secure the resources we need to provide housing assistance and related services to people living with HIV/AIDS (PLWHA):

- As a *basic human right*;
- As a *necessary component of systems of care* to enable PLWHA to manage their disease; and
- As an *exciting new mechanism to end the HIV/AIDS crisis* by preventing new infections.

Section VI—THE FUTURE FOR SAC

Summary

The South has the highest number of new cases of HIV and the largest number of diagnosed AIDS cases. There are vast geographic areas that encompass large cities, less urban areas, and rural areas that result in screening, care, treatment, and housing challenges. Historically, the South has also received the least amount of federal funding. Southern states often have less ability to absorb even small cuts to already under-funded programs. While it is too soon yet to determine the full impact of new funding shifts, there is little doubt that without it many southern states would have been unable to meet minimum requirements for testing, prevention, care, treatment, and housing programs.

The *Southern States Manifesto: Update 2008, HIV/AIDS and STDs in the South* marks six years since the initial *Southern States Manifesto* was released. Many accomplishments have been achieved in the last six years, such as federal funding shifts and state-level systemic improvements. Additionally, many states have increased their HIV/AIDS financial contributions, often surpassing the state-to-federal percentages for HIV funding of many larger states. However, the challenges for preventing new infections and caring for those living with HIV remain as we continue to face an ever-growing southern epidemic. SAC's Board of Directors thanks the Centers for Disease Control and Prevention, State Legislators, State Departments of Health, AIDS Service Organizations, Health Resources and Services Administration, and Members of Congress for taking deliberate actions to help people with HIV/AIDS and STDs in the South.

The Future of the Southern AIDS Coalition

The incorporation of the Southern AIDS Coalition as a nonprofit 501 (c) 3 organization signals the desire and forward momentum established by the Board of Directors. The vision for our future includes a strong partnership to meet the goals set forth in the introduction of this document. In order to accomplish those weighty goals, we will hire a full-time Executive Director. The outcomes of these major infrastructure changes for SAC will allow us to provide technical assistance to one another on the topics below, as well as many others:

- Targeted testing initiatives, including legislation that supports the routinization of CDC recommended opt-out testing;
- Successful models to distribute CDC, Ryan White, and HOPWA funds that reach all counties of a state and that allow community organizations and health departments to maximize these limited resources;
- Increasing the capacity and skills of community organizations to promote financial stability and to expand the potential for programs that move and keep people in care, treatment, and stable housing; and
- The provision of science-based, age-appropriate, and successful HIV and STD education programs.

The Southern AIDS Coalition must ensure that the South, the region of the country with the most living HIV/AIDS cases and some of the highest rates of STDs in the nation, plays a dominant role in any national dialogue, including the development of a National AIDS plan or strategy. Traditional HIV/AIDS and STD coalitions have not been formed along regional lines in the past, which makes SAC an even richer resource that is needed at the national level. We hope the *Southern States Manifesto: Update 2008* provides solid documentation and insight into the needs of the South and into our abilities to provide services and strategies that work if adequately funded.

The Southern AIDS Coalition's perspective on collaboration is simple: it takes all of us to tear down the silos that limit the integration of prevention, access to care, treatment, housing, and other services. We must change the false belief that state boundaries or even national boundaries are where our responsibilities begin and end. Join the Southern AIDS Coalition today and be a part of the solution to diseases that threaten us and our future generations.

If the society today allows wrongs to go unchallenged, the impression is created that those wrongs have the approval of the majority.

Barbara Jordan, U.S. Congresswoman
from 1973 to 1979

SAC Accomplishments and Activities—the South in Crisis, 2005-2008

- Two Congressional briefings to bring attention to the disparities in care, treatment, and funding in the region.
- National satellite broadcast to present data to illustrate the state of emergency in southern, minority, rural, and female populations.
- Major national media attention from *USA Today*, *National Public Radio*, *Washington Post*, *San Francisco Chronicle*, *Kaiser Family Foundation Daily Report*, *POZ Magazine*, *HIV Plus*, *Congressional Quarterly*, *Newsweek*, dozens of other local periodicals, and other media outlets.
- Private industry's increased involvement through programs such as:
 - Pfizer's Southern HIV/AIDS Prevention Initiative
 - National AIDS Fund's Southern Reach Program (Ford Foundation, Elton John AIDS Foundation)
- The South and other under-funded areas of the country received substantial funding increases through the *Ryan White HIV/AIDS Treatment Modernization Act of 2006*.
- *Expanded and Integrated HIV Testing for Populations Disproportionately Affected by HIV, primarily African-Americans*, launched in May 2007 by the CDC, requested proposals to increase testing opportunities with 11 southern states receiving funding.

The Southern AIDS Coalition (SAC) is incorporated as a 501 (c) 3 not-for-profit organization based in Birmingham, Alabama. The Officers and Board of Directors oversee all operations. Membership is open to anyone interested in the scope and work of the Southern AIDS Coalition, and a membership form is on page 27. Annual membership dues start at just \$1. All contributions are tax deductible as allowable by law. SAC works on behalf of the Department of Health and Human Services South Region which includes 14 states and the District of Columbia. The states are: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia. Requests for inclusion of additional states and jurisdictions are currently under consideration.

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Section VII—THE SAC MANIFESTO ORIGINAL CALLS TO ACTION

State's Role

1. Respond to identified needs through passionate leadership to maximize federal and state dollars through effective strategies to prevent the spread of the virus and care for those already infected.
2. 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.
3. Develop a mechanism to increase the level of PLWA involvement in all HIV/AIDS program areas.
4. 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.
5. Seek federal action calling for emergency funding to address HIV/AIDS and STD epidemics in the South.
6. Conduct a consultation with HRSA/CDC to insist on coordinated technical assistance and site visits.
7. Ensure core STD prevention programs are in place in each of the southern states.
8. Engage more medical groups or other new partners in addressing HIV/AIDS/STD issues.
9. 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.
10. Work with HRSA to identify reimbursement mechanisms to support providers in screening and prevention activities.
11. Develop an adequate and effective public health workforce by identifying performance standards and appropriate compensation.
12. Adapt known effective interventions to local needs and then evaluate these adapted prevention intervention models to determine efficacy.
13. 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.
14. Use HIV/AIDS/STD and hepatitis and other related data to determine "full trend" analysis of our community needs.
15. Implement the recommendations in the NASTAD black monograph.
16. 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.
17. Actively develop and implement quality assurance and evaluation processes across all programs to ensure accountability /effectiveness of

Leadership

We call upon

1. The political leadership and policy makers to be courageous and responsible in addressing the unique health care disparities in the southern states.
2. The President and 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.
3. The President 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.
4. The President, Congress and the 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.
5. The President and Congress to ensure that STD prevention funding is increased to ensure core STD control strategies can be implemented in the South.
6. CDC and HRSA to provide leadership through policy development and strategic planning in partnership with southern states AIDS/STD directors in addressing the unique health care disparities in the southern states.
7. 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.
8. 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

We call upon

1. Black legislators, black religious affiliates, and black national organizations to partner with AIDS/STD directors and southern communities; to embrace the information provided in this document; to 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 black communities.
2. 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 black focused agencies to provide quality services, ensure access to services, and ensure viability of agencies providing services to the black community (NASTAD Monograph, *HIV/AIDS: black Perspectives and Recommendations for State and Local AIDS Directors and Health Departments*, 2001).
3. AIDS/STD directors to develop formal linkages with black 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.
4. 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 black and Latino cultures.
5. CDC, HRSA, and state and federal legislators to work with AIDS/STD directors to provide expanded medical and service capacity in communities of color that is culturally and linguistically appropriate to individuals.

Background

The *Southern States Manifesto* was released in March 2002. The original Calls to Action are repeated in this section of the *Southern States Manifesto: Update 2008* as a reference and historical reminder of the challenges that faced the HIV community in the South at that time. The *Update* will highlight successes based on the *Calls to Action*, as well as the barriers, challenges, and opportunities that remain.

Funding

We call upon

1. Congress to increase appropriations of Ryan White CARE Act Title II based in FY 2004 and to ensure appropriate funding is targeted to the South and other areas of the country that demonstrate severe need.
2. Congress to increase funding for Ryan White CARE Act AIDS Drug Assistance Program (ADAP) earmark in FY2004.
3. 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.
4. CDC, NASTAD, and NCSD to help ensure that any new funding to address the resurgence of HIV/STDs among MSM also go to southern states in order to help enhance and improve existing MSM initiatives, especially among minority MSM who do not self identify.
5. 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.
6. CDC to prioritize allocations of funding based on HIV/AIDS and STD trend data and cases in black communities.
7. HRSA and CDC to review funding allocations for care, prevention, and surveillance to ensure equitable distribution of federal resources.
8. HUD to ensure that the Housing Opportunities for Persons with AIDS (HOPWA) formula mirrors the Ryan White CARE Act distribution system of dollars, instead of basing the distribution solely on the cumulative AIDS case counts.
9. 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.

Partnerships

We call upon:

1. State AIDS/STD directors to develop and maintain relationships with organizations and entities that are links to their local health care system.
2. 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.
3. Pharmaceutical companies to simplify the application process for compassionate care programs serving the HIV/AIDS population.
4. 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

We call upon

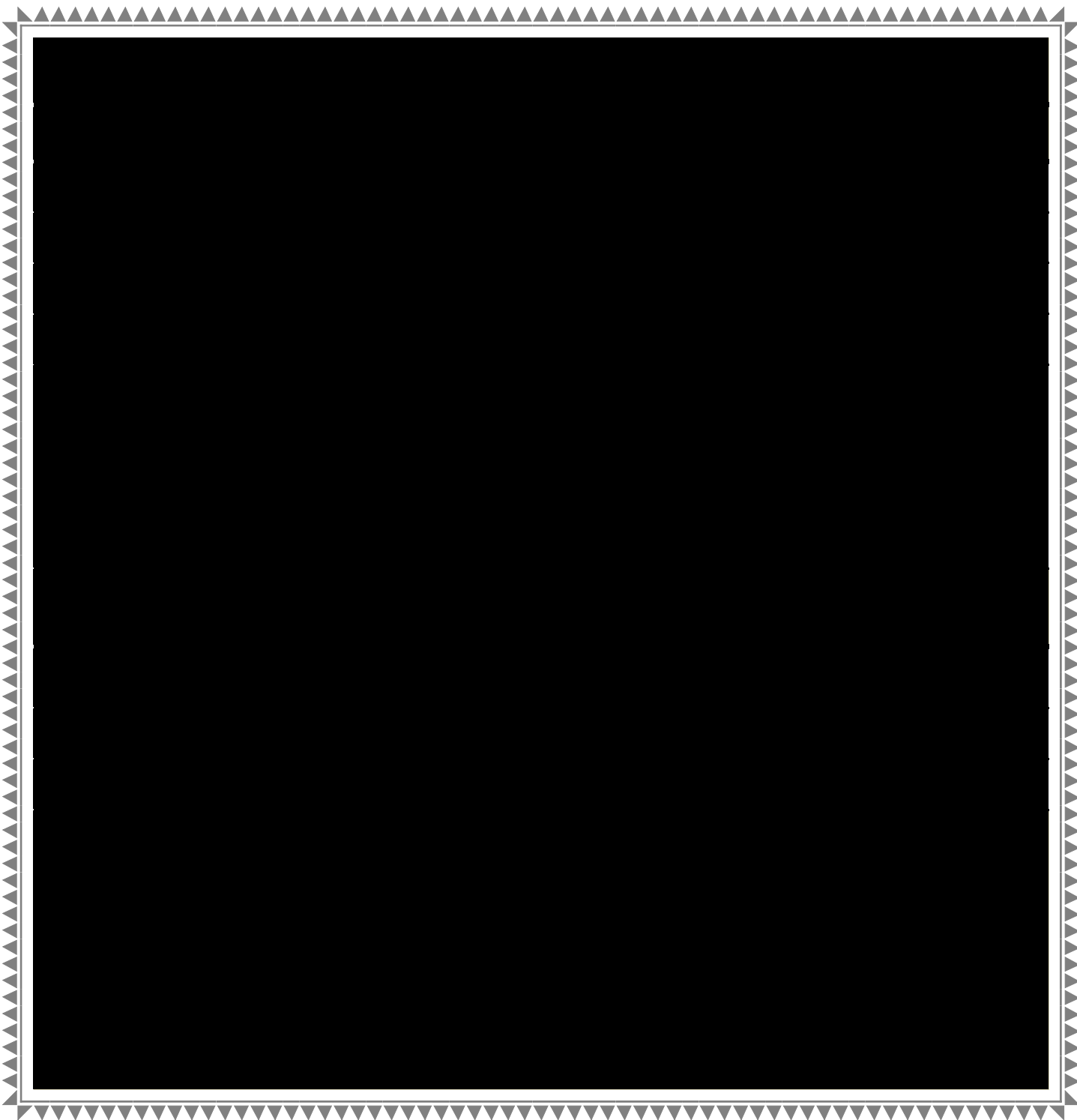
1. The federal government, within one year of the date of this document, to work in collaboration with state AIDS/STD directors to outline the minimum HIV/AIDS and STD core services that must be guaranteed to all individuals.
2. The federal government to develop program policies to ensure greater equity 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.
3. 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.
4. 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.
5. 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.
6. The federal and state government to improve the system of recruitment and incentive for health care professionals to provide services in underserved rural areas.
7. 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.
8. Federal partners to provide technical assistance to Georgia as that state moves toward implementation of HIV reporting.
9. 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.
10. HUD to require housing plans for all persons receiving medical treatment through any federally funded system.
11. 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.

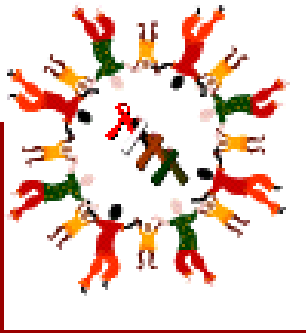
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Everyone who is HIV-positive or has any form of sexually transmitted disease has a right to access a range of health care and necessary support services to achieve and maintain optimal health regardless of gender, sexual orientation, geographic location, economic condition, race, or social status.

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