MAKING CHANGE REAL

The State of AIDS in Black America 2009

EXECUTIVE SUMMARY

Black AIDS Institute
February 2009
As a 52-year-old Black gay man with HIV, I have many reasons to welcome the inauguration of Barack Obama. A big one is that an Obama administration has enormous potential to reinvigorate a struggle that has been allowed to flag over the last eight years: our national fight against HIV/AIDS.

With our country facing so many challenges—two wars, a financial meltdown and the growing threat of environmental devastation—it may be tempting to relegate the AIDS epidemic to the lower rung of national priorities. That would be a grave mistake. Every year, more than 56,000 people in this country contract HIV. The devastation is worst among Black Americans, who represent nearly half of all new HIV infections, including two-thirds of the new cases among women and 70 percent of the new cases among adolescents.

AIDS clearly has affected certain groups more than others. But as then-Sen. Obama said in 2006: “We are all sick because of AIDS—and we are all tested by this crisis. It is a test not only of our willingness to respond, but of our ability to look past the artificial divisions and debates that have often shaped that response.”

AIDS, in short, is a sickness at the very heart of the American family. Like any family, America must respond to the sickness in its midst by displaying both solidarity with those who are living with HIV and a determination to make sure no one else gets infected.

This report—Making Change Real, the 2009 installment of our annual State of AIDS in Black America series—details both the promise and the peril of the era we now enter.

We have elected a new president and a new Congress that have vowed to take aggressive action to end the epidemic, and to focus those efforts on Black America. Our community is more aware of the crisis we face than ever. And as the State of Our Movement section of this report details, Black leaders and organizers are also tuned in, making AIDS a part of their broader work like never before. That’s all the promise.

But 2008 brought shocking news of the danger we face, too. The U.S. Centers for Diseases Control and Prevention reported that the domestic epidemic is 40 percent larger than we have long believed. Even more troubling, the CDC learned, the epidemic is growing at a faster pace...
than we have understood. Black Americans are vastly overrepresented among the new infections in every population—men, women, youth, you name it.

The first half of Making Change Real spells out these details and explains the trends behind them. But it also discusses the many political and public policy challenges these findings created. The federal government’s response to the epidemic has been at best negligent over the past eight years, and our efforts to slow the virus’s spread and care for those already infected have suffered mightily as a result. The incoming administration has much work to do in reversing those trends.

We cannot, however, relegate the AIDS fight to the government alone, not even with President Obama at the helm. We must become involved in the political process, holding both Obama and his congressional colleagues accountable for the campaign pledges they made.

We must support efforts to develop a National AIDS Strategy and we must partner with the Obama administration to strengthen HIV prevention. When opposition surfaces to needle exchange or school-based HIV prevention programs, we must speak out and persuade decision-makers that true “family values” don’t allow more HIV infections to occur when proven methods exist to prevent them.

The disproportionate vulnerability of Black gay and bisexual men to HIV infection stems in no small part from the prevailing stigma associated with homosexuality. If we are serious about lowering the rate of new HIV infections, we must actively oppose stigma and promote acceptance in our churches, schools and local communities.

We must make knowing your HIV status a universal community norm. The CDC estimates that more than one in five people living with HIV don’t know they are infected. Such people are often diagnosed late in the course of disease, which significantly reduces life expectancy. Late HIV testing also contributes to the spread of HIV, because people who are unaware of their infection are at least three times more likely to expose others to the virus than are people who know they are HIV-positive. We need to urge everyone to get tested, and to explain, again and again, the benefits of doing so.

Throughout much of the HIV/AIDS epidemic, mainstream Black organizations stayed on the sidelines. Thankfully, that has changed. Organizations like the Black AIDS Institute, the Balm in Gilead and the National Black Leadership Commission on AIDS have assisted leading Black organizations and historically Black colleges and universities in developing organizational action plans on AIDS. In the State of Our Movement section of this report, we update you on the process of turning those plans into actions.

Unfortunately, despite the progress we’ve made, we’re still not where we need to be. That’s in no small part due to resources. In 2006, private U.S.-based foundations gave less than a tenth of their HIV-related contributions to activities in this country—less than a tenth! While we continue to help Africa and other hard-hit regions, we need to put out the fire here at home.

The new administration offers enormous promise for a new day in our nation’s long struggle against HIV/AIDS. However, President Obama and his team won’t be able to reinvigorate the national AIDS response on their own. Let’s roll up our sleeves and get to work.

Yes, we can!

Yours in the Struggle,

[Signature]

Phill Wilson
CEO, The Black AIDS Institute
The 2009 edition of the Black AIDS Institute’s annual State of AIDS in Black America report lays out both the promise and the peril of the unique moment at which we’ve arrived in this epidemic.

On one hand, the historic election of Barack Obama and a congressional majority that has been more supportive of the AIDS fight offers great opportunity. Similarly, Black America is engaged in the struggle to end AIDS like never before. Together, these two realities could create real, lasting change in the course of this epidemic.

At the same time, 2008 witnessed great setbacks, particularly in the effort to prevent the virus’s spread. We are seeing the outcome of too many years of neglect, at both the governmental and communal level.

The Challenges We Face

New infections

In 2008, the U.S. Centers for Disease Control and Prevention released its long-awaited study re-examining the size and depth of the U.S. epidemic. Using new technology that allows researchers to learn more detail about individual HIV infections, the CDC discovered, among other things:

- The U.S. epidemic is at least 40 percent larger than previously believed and growing by between 55,000 and 58,000 infections a year;
- The U.S. has never logged fewer than 50,000 new infections a year, contrary to prior belief that we leveled out at 40,000 new infections a year in the mid-1990s;
- Black Americans represented 45 percent of people newly infected in 2006, despite being just 13 percent of the population;
- Men who have sex with men accounted for 53 percent of all new infections in 2006, and young Black men were particularly hard hit;
- In 2006, Black gay and bisexual men between the ages of 13 and 29 accounted for more new HIV infections among gay and bisexual men than any other race or age group. And more than half, or 52 percent, of all Black gay and bi men infected that year were under 30 years old.

Deaths

The racial disparity in AIDS deaths continued in data released last year:

- In 2006, the latest year for which data is available, 7,426 Black Americans died from AIDS. That number represents a meaningful improvement over the previous year—a decline of 1,253 deaths.
But Blacks continue to represent a far outsized proportion of deaths each year. In 2006, Blacks accounted for just over half of all AIDS deaths.

The 2009 State of AIDS in Black America report includes a chart pack—“The Black Epidemic: By the Numbers” on page 58—which details key data about the Black epidemic.

**Resources**

The federal commitment to all areas of AIDS work—prevention, treatment and research—has all but disappeared.

- The CDC’s annual HIV-prevention budget has never topped $800 million—a fraction of what the U.S. spends on the Iraq war in a week;
- The prevention budget has been cut by 20 percent in the past five years, in real dollar terms;
- The CDC spent just under $369 million on Black-specific prevention and research in fiscal year 2008, or 49 percent of the overall budget.
- Between 2004 and 2008, the discretionary domestic AIDS budget remained virtually flat, while global spending increased by more than 20 percent annually.

**The Promise of a New Era**

While the challenges are great, Black America is perhaps better poised to meet them today than ever before.

The new Obama administration has vowed to take action on several fronts, including drafting America’s first comprehensive strategy to direct our efforts. (See “Call to Action for a National AIDS Strategy” on page 30, and “What Obama Has Promised” on page 21.) But just as crucial, our community is engaged like never before. From individuals on up to our traditional Black organizations, we’ve accepted the idea that this is our problem and we must find the solution.

In 2006, 16 traditional Black institutions launched the National Black AIDS Mobilization by signing on to the National Call to Action and Declaration of Commitment to End the AIDS Epidemic in Black America (see BlackAIDS.org for text and list of signatories). The 16 institutions are not typical AIDS organizations. These groups, many of which have histories that span generations, were founded to meet a wide range of communal needs and concerns; they have now formally added AIDS to their work.

This report offers an update on the progress each group has made in fulfilling its pledge to act. Many of them have made great strides; others are just beginning their work. In all cases, far more resources and support are required from both public and private funders who seek to impact the AIDS epidemic.

Some highlights from the State of Our Movement section of this report include:

- In 2008, two crucial groups joined the list of those that have completed strategic plans detailing how they will address HIV/AIDS: the National Association for the Advancement of Colored People and the National Urban League;
- 100 Black Men of America partnered with Aetna to create a website that members use as a healthcare management tool focusing on HIV/AIDS as well as prostate cancer/colorectal cancer, depression, cardiovascular disease and sickle cell anemia;
- The National Council of Negro Women hosted a panel discussion at its national convention, a town hall meeting and an online survey that all resulted in a series of recommendations for the next president, including a call for a national strategy to end AIDS;
- In the fall of 2007 the National Newspaper Publishers Association began a 25-week series of HIV/AIDS opinion pieces that were published in 200 Black newspapers each week;
- The Potter’s House continued its HIV work with Texas ex-offenders and expanded its AIDS work in southern Africa.

These are just a handful of the many initiatives traditional Black organizations undertook in 2008. A full accounting for each group can be found in the State of Our Movement section of this report, and each of their strategic plans are online at BlackAIDS.org.
How You Can Get Involved

So now you know—the State of AIDS in Black America is dire and getting worse. Moreover, over the past eight years Washington has done little to nothing about that fact. So what are you going to do about it? We’ve got some ideas.

Take Responsibility
First and foremost, make sure you’re taking personal responsibility for ending AIDS.

- **Get Tested.** If you’re sexually active, get tested on a regular basis—and take everyone you love with you, especially anyone you’re having sex with;
- **Challenge Stigma.** It’s killing us. Don’t let shame surrounding HIV—or sex, or drugs, or gay and bisexual relationships—cripple you or your community. Challenge it every time you encounter it, because silence still equals death.
- **Be Active Locally.** Find out where you can volunteer to help organizations that are combating HIV in your community. Contact one of the national organizations discussed in this report to find out if they have a local chapter.

One great way to get involved locally is to join our Test 1 Million campaign. (See “Test 1 Million” on page 37.) Launched on National HIV Testing Day 2008, the campaign aims to get one million Black Americans to learn their HIV status over the next two years—by National HIV Testing Day 2010, on June 27 of that year.

Organizations and individuals can sign up for the Test 1 Million campaign at www.BlackAIDS.org. Individuals interested in joining the campaign are asked to get tested for HIV/AIDS in order to become an official Test 1 Million member.

Tell Washington to Get a Strategy
Once you’ve taken responsibility for yourself and your loved ones, you’ve got to demand federal policy makers take responsibility, too. The Obama administration and Congress present a unique opportunity for our community’s fight against AIDS. But we must engage and support them to ensure their promises and potential lead to real changes.

The first thing you can do is join the Call to Action for a National AIDS Strategy. (See page 30 for details.) Below is a letter you can send to the White House urging President Obama to fulfill his pledge to draft a national strategy; it also contains principles for that strategy that the Call to Action signatories and the Black AIDS Institute have developed.

Log on to BlackAIDS.org and we’ll help you send the letter as an email. Once you’ve sent it to the Obama administration, forward a copy to the Congressional Black Caucus, to let them know you’ve joined the movement!
Dear President Obama,

I write to congratulate you on your new administration. As someone who cares about the devastating impact HIV/AIDS has had on the Black community, I know that your administration offers enormous promise for a new day in our nation’s long struggle against this epidemic. I’m especially encouraged by your promise to develop and implement a national AIDS strategy during your first year in office.

More than 27 years into the epidemic, America has never had a comprehensive strategy to direct its response to AIDS. That’s a simple, essential step that we require of any country seeking our foreign assistance, and it’s long overdue. Thank you for your commitment to making it happen.

More than 350 organizations and thousands of individuals have already signed a Call to Action for a National AIDS Strategy. I join those voices in urging your administration to begin work on drafting the strategy within its first 100 days. We urge that, in developing the strategy, you adhere to the principles articulated below, many of which you have already championed.


Thank you for your continued commitment and leadership in the movement to build a healthy Black America. I look forward to joining you as, together, we end this epidemic!

Yours in the struggle,

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My email:
My City and State:
Principles for Developing a National AIDS Strategy

The signatories of the Call to Action for a National AIDS Strategy have urged President Obama to create an open, orderly and accountable process for drafting his national strategy. The following recommendations incorporate both the Black AIDS Institute's own recommendations and those of the overall coalition.

Establish an inclusive, comprehensive panel to guide the process. The coalition recommends that the president, acting through the Domestic Policy Council, appoint a panel of experts on HIV/AIDS from every department of the United States government with responsibilities for responding to the epidemic. The panel must also include representatives of key non-governmental and civil society organizations, people living with and at risk for HIV, and other stakeholders.

This panel must reflect the diverse communities affected by HIV/AIDS. It should hold at least one meeting at which it receives public input into the development of the strategy, and at least two meetings at which its deliberations are open to the public. The panel should take into account stakeholder input—gathered in multiple ways—and the best available evidence on effective strategies to achieve HIV prevention, care, and research goals.

Begin work immediately. In keeping with President Obama's campaign pledge, the strategy should be fully developed no later than January 20, 2010, and be operational until December 31, 2014. Further, President Obama should appoint a national AIDS strategy panel within his first 100 days in office, as well as a White House-level presidential advisor to oversee the strategy's development and implementation.

Appoint an AIDS czar with meaningful power. President Obama should reinvigorate a White House–level office to direct federal AIDS policy—a longstanding function that waned under the Bush administration. The office should provide staffing to the national strategy panel and be headed by a presidential advisor with authority to oversee and coordinate all government agencies and federally funded non-governmental organizations involved in implementing the strategy.

Budget enough money to make meaningful planning possible. President Obama must request and Congress must appropriate sufficient funding for Fiscal Year 2009 to allow the White House–level AIDS office to plan and implement a national AIDS strategy. The president must commit to continued funding in his subsequent budget requests to assure the development, implementation, and
evaluation of the strategy. This funding must be in addition to the desperately needed investments for ongoing prevention, care, treatment and research efforts.

Have measurable, realistic and specific goals. The national AIDS strategy should not repeat or recreate the exhaustive set of goals that have characterized previous planning efforts to respond to the epidemic, though many of the goals these plans have described are important. Instead, the national AIDS strategy must:

- Describe a limited and focused set of strategic initiatives that will increase to the highest possible levels the number of Americans who know their HIV status and the number of HIV-positive Americans who are engaged in comprehensive, high-quality care and treatment for HIV and related conditions; reduce to the lowest possible levels the disparities in health outcomes that are experienced by gay and other men who have sex with men, communities of color, and women; and reduce to the lowest possible levels the number of new cases of HIV infection that occur annually;

- Prioritize initiatives targeting populations or jurisdictions with the highest prevalence and incidence of HIV/AIDS in the nation (consistent with current epidemiological data), with emphasis on outcomes related to African Americans and other communities of color, women of color, and gay men of all races and ethnicities;

- Describe the legislation, policies and programs that are necessary to carry out those initiatives;

- Set specific outcomes by which each of the initiatives will be evaluated, along with timelines for implementing them;

- Assign responsibility for implementation of each of the action steps to appropriate government agencies and create mechanisms to facilitate collaboration between these agencies and non-governmental organizations;

- Determine the annual cost and financing mechanisms necessary for implementing each initiative, along with recommended sources of funds. Sources may include the redirection of existing federal resources to the action steps contained in the strategy, as well as additional resources that should be sought by the president from the Congress; and

- Develop a mechanism by which existing sources of federal funding for HIV/AIDS will be made consistent with participation in the initiatives described in the strategy.
The Black Epidemic: By the Numbers
HIV Infection in America

Race of Newly Infected

An estimate 56,300 people were newly infected in 2006, the most recent year for which data is available. The racial breakdown among them was:

- Black: 45 percent
- White: 35 percent
- Latino: 17 percent
- Other Ethnicities: 3 percent


Race of All HIV-Positive

An estimated 1.1 million people are HIV positive in the United States. The racial breakdown among them is:

- Black: 46.1 percent
- White: 34.6 percent
- Latino: 17.5 percent
- Other Ethnicities: 1.8 percent

Rate of Infection

Black Americans were infected at a rate seven times that of whites in 2006—and Black women were infected at a rate almost 15 times that of whites. The number of people infected per 100,000, by race, was:

- Among Blacks: 83.7
- Among Latinos: 29.3
- Among Native Americans: 14.6
- Among Whites: 11.5
- Among Asian/Pacific Islander: 10.3


Infection Over Time

Black Americans' share of new infections has grown steadily over time. By the late 1980s, Blacks began accounting for the largest share of new infections.

Estimated new human immunodeficiency virus (HIV) infections, by race/ethnicity, extended back-calculation model, 50 U.S. states and the District of Columbia, 1977-2006:

HIV Infections, Up Close

Among Women

An estimated 14,410 Black, white and Latina women were newly infected in 2006. The racial breakdown among them was:

- Black 61 percent
- White 23 percent
- Latina 16 percent


Among Men

An estimated 39,820 Black, white and Latina women were newly infected in 2006. The racial breakdown among them was:

- Black 46 percent
- White 36 percent
- Latino 18 percent

### Among Gay and Bisexual Men

Gay and bisexual men accounted for more than half of all new infections in 2006. The racial breakdown among them was:

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Black</td>
<td>46 percent</td>
</tr>
<tr>
<td>White</td>
<td>35 percent</td>
</tr>
<tr>
<td>Latino</td>
<td>19 percent</td>
</tr>
</tbody>
</table>


### Where Newly HIV-Positive Live

The South is the modern epidemic’s geographic frontline, in part because of its sizable Black population. The regional breakdown for new infections in 2006 was:

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>South</td>
<td>46.7 percent</td>
</tr>
<tr>
<td>Northeast</td>
<td>25.4 percent</td>
</tr>
<tr>
<td>West</td>
<td>16.1 percent</td>
</tr>
<tr>
<td>Midwest</td>
<td>11.6 percent</td>
</tr>
</tbody>
</table>

MAP of the Black AIDS Epidemic
Black communities in the Northeast and Southeast—particularly in Florida, Maryland and New York—had the highest rates of HIV infection between 2002 and 2006. Overall, the prevalence of HIV among Blacks is nearly eight times that among whites.*


*CDC, HIV Prevalence Estimates—United States, 2006, MMWR, 57(39);1073-1076.
HIV Testing and Transmission in America

Race of Americans Tested

One in ten Americans said in 2006 that they got tested for HIV in the previous year, but Blacks tested at higher rates than any other racial or ethnic group. The share of people who reported getting tested was:

- Among Blacks: 21.7 percent
- Among Latinos: 12.6 percent
- Among Whites: 8 percent

Source: CDC, Persons Tested for HIV—United States, 2006, MMWR, 57(31);845-849. Data not available for any other racial or ethnic group.

Race of Undiagnosed HIV-Positive

An estimated one in five HIV positive Americans don’t know they are infected.* But the most recent race-based data shows more than half of positive Blacks are undiagnosed.


*CDC, HIV Prevalence Estimates—United States, 2006, MMWR, 57(39);1073-1076.
Undiagnosed Gay and Bisexual Men

A five-city study published in 2005 found 46 percent of Black gay and bisexual men to be HIV positive; well over half of them did not know it. The percentage of undiagnosed infections was:

- Among Blacks: 67 percent
- Among Latinos: 48 percent
- Among Multiracial: 50 percent
- Among White: 18 percent


How Black Men Get Infected

Male-to-male sexual contact was the primary risk factor for 72 percent of all men infected in 2006. Among Black men who tested positive, risk factors included:

- Male-to-male sex: 63 percent
- Heterosexual sex: 20 percent
- Injection drug use: 12 percent
- IDU and male-to-male sex: 4 percent

A person with an STD is two to five times more likely to contract HIV when exposed to it, and HIV positive people who have an STD are more infectious.* In 2006, Blacks had the highest rates of all STDs.

Infection rate among Black women vs. white women for:
- Chlamydia 7x higher
- Gonorrhea 14x higher
- Syphilis 16x higher

Infection rate among Black men vs. white men for:
- Chlamydia 11x higher
- Gonorrhea 25x higher
- Syphilis 5x higher


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**How Black Women Get Infected**

Black women got infected at a rate 18 times that of whites in 2006. Risk factors included:
- Sex with men 80 percent
- Injection drug use 20 percent

Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989.
## HIV Treatment and Death in America

### Who's Dying

In 2006, 7,426 Black Americans died from AIDS—more than twice that of any other group, but 1,253 fewer than the previous year. The racial breakdown for all Americans killed by AIDS as of 2006 is:

<table>
<thead>
<tr>
<th>Race</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>38.5%</td>
</tr>
<tr>
<td>White</td>
<td>42.3%</td>
</tr>
<tr>
<td>Latino</td>
<td>14.2%</td>
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</tbody>
</table>


### Who's Living

Black Americans are less likely to live 10 years with HIV infection. The share of people diagnosed between 1997 and 2004 who were still alive after nine years is:

<table>
<thead>
<tr>
<th>Race</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Among Blacks</td>
<td>66%</td>
</tr>
<tr>
<td>Among Native Americans</td>
<td>67%</td>
</tr>
<tr>
<td>Among Latinos</td>
<td>74%</td>
</tr>
<tr>
<td>Among Whites</td>
<td>75%</td>
</tr>
<tr>
<td>Among Asian/Pacific Islanders</td>
<td>81%</td>
</tr>
</tbody>
</table>

Advanced Disease

Since combination therapy became available in the mid-1990s, Blacks have represented the largest share of people with HIV infections that have advanced to AIDS.

Proportion of AIDS cases among adults and adolescents by race/ethnicity and year of diagnosis, United States and dependent areas, 1985-2006:


Note: Data have been adjusted for reporting delays.
The Black AIDS Institute, founded in 1999, is the only national HIV/AIDS think tank in the United States focused exclusively on Black people. The Institute’s mission is to stop the AIDS pandemic in Black communities by engaging and mobilizing Black leaders, institutions and individuals in efforts to confront HIV. The Institute conducts HIV policy research, interprets public and private sector HIV policies, conducts trainings, builds capacity, disseminates information, and provides advocacy and mobilization from a uniquely and unapologetically Black point of view.

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evelyn & walter HAAS, JR. fund

John M. Lloyd Foundation

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