Passing the Test

The Challenges and Opportunities of HIV Testing in Black America

Black AIDS Institute
June 2009

Passing the Test: The Challenges and Opportunities of HIV Testing in Black America by Michael T. Isbell is a publication of the Black AIDS Institute, 1833 West Eighth Street, Los Angeles, California 90057-4257, 213-353-3610, 213-989-0181 fax, info@BlackAIDS.org, www.BlackAIDS.org.

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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 offers training and capacity building, interprets and makes public and private sector HIV policy recommendations, disseminates information, and provides advocacy and mobilization from a uniquely and unapologetically Black point of view.

The National Association of People with AIDS advocates for the lives and dignity of all people living with and affected by HIV/AIDS.

This report was made possible by the generous support of the Ford Foundation, Elton John AIDS Foundation, Broadway Cares, Evelyn & Walter Haas Jr. Fund and Northrop Grumman Foundation.

The Black AIDS Institute wishes to thank the Global Business Coalition on HIV/AIDS, Tuberculosis & Malaria for generously helping to underwrite this report. Since its founding, GBC has worked to stem the spread of infectious diseases globally, with a particular focus on hard-hit regions of Africa, Asia and Central Europe. In response to the surging U.S. epidemic, GBC is coordinating across sectors to fight HIV/AIDS in the U.S. by mobilizing its 220 member companies, and the U.S. corporate sector more generally, to work in collaboration with community-based organizations and local health departments to bring corporate-sector expertise, brand power, and resources to bear in a renewed, collaborative effort to fight HIV/AIDS in the U.S., with a particular focus on HIV testing.

Rev. 1.0

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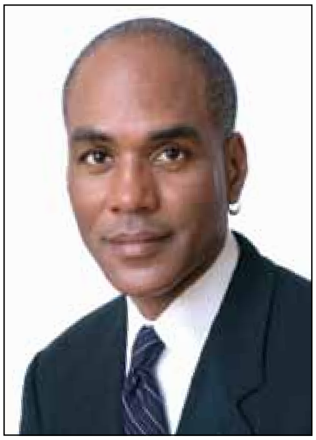
FROM THE CEO

Our Right and Our Responsibility



Welcome to *Passing the Test: The Challenges and Opportunities of HIV Testing in Black America.* We are pleased to partner with the Global Business Coalition on HIV/AIDS, Tuberculosis & Malaria (GBC) and the National Association of People with AIDS (NAPWA) on this edition of the state of AIDS in Black America series by the Black AIDS Institute.

Knowing your HIV status is a right and a responsibility. Knowing the HIV status of your partner can save your life, and finding out your HIV status has never been easier. HIV tests are affordable. There are agencies offering free HIV tests in nearly every city in America. HIV tests are painless. The most common form of HIV testing today uses an oral swab—no more blood or needles. The days of waiting a week to get your results are over. With the rapid tests, you can get your results back in less than an hour.

People who are diagnosed late in the course of HIV infection have a much poorer prognosis than individuals whose HIV diagnosis is timelier. In New York City, individuals whose HIV and AIDS diagnoses occur within 31 days of one another are twice as likely to die within four months of diagnosis as people with a non-concurrent AIDS diagnosis. Early knowledge of HIV infection plays a key role in reducing HIV-related morbidity and mortality.

So, let's think about it. HIV tests are free, easy, painless, quick, and you get information that just might save your life. What's not to love about that? You would think everyone in America would get tested for HIV.

Yet, 1 in 2 of Black people in the U.S. infected with HIV don't know their HIV status. Many people living with HIV are diagnosed only in response to symptoms, usually several years after initial exposure to the virus. In Washington, D.C., 69% of AIDS cases were diagnosed with HIV less than a year earlier. Among HIV-positive Black gay and bisexual men who participated in a CDC-sponsored multi-city study, 67% were previously unaware of their infection.

Clearly, when it comes to the challenges and opportuities of HIV testing in Black America, we have not yet passed the test. This report looks at the reasons Black Americans get tested for HIV or not; describes the evolution of HIV testing technology; and looks at the impact of stigma on our willingness to get tested.

The energy around testing is important, but it can also be dangerous—if the work stops there. This report explores the range of challenges that go hand-in-hand with testing—most importantly, the connection between testing, prevention and treatment—and the ways in which individuals, community leaders and policymakers can help take on those challenges. Most importantly, the report proposes solutions. In addition to government initiatives to close the testing gap, the report specifically examines the under-utilized potential of social marketing and other testing-promotion efforts to increase knowledge of HIV status in Black America like the new CDC initiative, Act Against AIDS and the Black AIDS Media Partnership, the National Medical Association's Physicians Testing Initiative, NAPWA's Mayor's Testing Initiative and the Test 1 Million campaign.

As always, we are ever mindful that "nobody can save us from us, but us." At the end of the day, it all boils down to what you do. If we come together, we can meet this challenge and pass the test. Enjoy the report. We look forward to hearing from you. Until then, please take care of yourself and your blessings.

Yours in the Struggle,

Phill Wilson

Phill Wilson
CEO, The Black AIDS Institute

> "If we come together, we can meet this challenge and pass the test."

FORWARD

We Can Survive, If We All Know Our Status

By Frank J. Oldham, Jr.
President and CEO, National Association of People with AIDS

AIDS is no longer a new problem. But it remains one of the greatest health problems in Black America.

Although treatment breakthroughs over the last decade and a half have dramatically lowered AIDS deaths for the U.S. as a whole, Black Americans are often not reaping the benefits of these medical advances. An HIV-positive Black person has roughly double the chance of dying as an HIV-positive white person of the same age. Even in the era of effective treatment, AIDS is still one of the leading causes of death in the Black community.

This new report by the Black AIDS Institute helps explain why. Twenty-five years after the discovery of a test to diagnose HIV infection, well over 100,000 Black Americans are still unaware that they are living with HIV.

This report describes the devastating consequences of inadequate testing. Because so many Black Americans don't know they are infected, the virus continues to spread—silently, but surely. And because many Black people are diagnosed with HIV late in the course of their infection, their risk of dying is much greater.

Changing this state of affairs isn't just the responsibility of the federal government or our health care system. While these institutions have a critical role to play in promoting testing—and this report details what they need to do—each one of us has a job to do, too.

When Magic Johnson announced in 1991 that he was living with HIV, Black America began a long-overdue conversation about AIDS. We talked to our friends, family members and fellow churchgoers about the disease. A lot of us got tested as a result of these conversations.

In 2009, though, we hear a lot less about AIDS—on television, in the newspapers and in our daily lives. With the decline in public discussion about AIDS, it's hardly surprising that

HIV testing rates among Black Americans have stalled or even begun to decline over the last decade.

As this report emphasizes, Black America needs to become re-engaged and re-energized about AIDS. Every Black person needs to know his or her HIV status. Those who are at highest risk should be tested annually. And we should be offered an HIV test every time we seek medical care.

Unless Black America joins together to make knowing one's HIV status a social norm in our communities, the AIDS problem is only going to get worse. When life-saving HIV drugs are available, that would be more than a tragedy. It would be an historic blot on all of us.

This report includes recommendations for action by Black America, by President Obama, by public health agencies and medical providers, and by the private sector. It's my hope that all of us will take these recommendations seriously and get to work putting them in place.

HIV is preventable and treatable. But first it has to be diagnosed.

> "HIV is preventable and treatable. But first it has to be diagnosed."

Oprah Winfrey takes the first HIV test January 6, 2007 at her new $40 million South African school for disadvantaged girls in Johannesburg, South Africa. Photo: AFP/Getty Images.

EXECUTIVE SUMMARY

Black America and HIV Testing

One of the most effective public health tools against AIDS is also one of the simplest: the HIV test. Yet our collective performance on HIV is disappointing, enabling the rapid spread of infection and resulting in unnecessary AIDS deaths. Our HIV testing failures have particularly dire consequences in Black America, where the country's most serious levels of HIV infection demand much higher rates of testing than have been achieved.

However, there are important signs of hope. At both the governmental and community level, a renewed push is underway to universalize HIV testing. With the aim of ensuring that this momentum is followed through, this report focuses on the challenge of making knowledge of one's HIV status a social norm in Black America.

AIDS in America: A Black Disease

Over the course of a lifetime, Black men are 6.5 times more likely to become infected than white men. These disparities are even more pronounced for Black women, who are 19 times more likely than white women to contract HIV. Outside of sub-Saharan Africa, only four countries have HIV prevalence as high as the most conservative estimate for Black America.

Although combination HIV therapy has helped drive down AIDS deaths for the United States as a whole over the last decade, much of Black America is not benefiting from the treatment revolution. AIDS remains one of the leading causes of death for Black men and women. In New York City, Black people living with HIV have an age-adjusted death rate that is twice as high as their white peers.

Black America and HIV Testing

Blacks are more likely than other racial/ethnic groups to have reported having been tested for HIV. In 2009, 52 percent of Black people surveyed reported having taken an HIV test, compared to 38 percent of Hispanics and 34 percent of whites.

But with HIV infection levels many

> “Blacks actually need to be tested at much higher rates to ensure prompt diagnosis.”

times higher than for the country as a whole, Blacks actually need to be tested at much higher rates to ensure prompt diagnosis. Nationwide, well over 100,000 Black Americans are currently unaware that they are living with HIV. In Washington, D.C., nearly half of all Blacks surveyed said they had never taken the test. In a multi-city survey of young gay and bisexual men, two-thirds of Black men who tested HIV-positive had previously been unaware they were infected.

The high prevalence of undiagnosed HIV infection is a key reason why the epidemic is so much worse in Black America than in other parts of the U.S. Up to 70 percent of all new infections in Black America are the result of risky behavior among people who do not know they are infected. And because Black people are more likely to be diagnosed late in the course of infection, they are also more likely to die.

Although the AIDS crisis in Black America demands significantly greater testing uptake, evidence suggests that testing rates have flattened or may even be on the decline among Black people. Surveys by the Henry J. Kaiser Family Foundation found that the percentage of Black people under age 65 who reported recent testing remained stable between October 1997 (39 percent) and March 2009 (40 percent). A separate analysis of results from CDC-sponsored behavioral surveys suggests that testing rates among Blacks actually declined between 1999 and 2007.

> “President Obama must make good on his commitment to develop a national AIDS strategy that includes a comprehensive plan to promote HIV testing.”

How Traditional HIV Testing Falls Short

Throughout most of the epidemic, public health authorities have concentrated on promoting testing for people at high risk of infection, such as gay men and drug users. But this risk-based approach to testing misses the large number of Black people who become infected despite engaging in low levels of risk behavior. One study in South Carolina, where Blacks make up nearly three-quarters of all people living with HIV, found that risk-based testing would miss 79 percent of all HIV infections.

The historic use of blood-based testing technologies also limits testing uptake in Black communities. According to surveys, Blacks are more likely than other racial or ethnic groups to prefer testing of urine or oral fluids.

The Public Policy Response

In 2006, CDC announced a radical shift in national HIV testing policy. The CDC recommended that health care settings inform all patients between the ages of 13 and 64 that an HIV test will be performed unless the patient expressly declines one (or “opts out” of testing, as it’s known in public health parlance). Under this new testing framework, which is today the federally-recommended standard, neither separate written consent nor prevention counseling should be required for testing in health care settings—hospitals, clinics, doctor’s offices, etc. The guidelines also recommend that individuals with high risk of HIV infection be tested at least once annually and that HIV should be incorporated into the routine panel of tests for pregnant women.

The 2006 guidelines reject the old risk-based paradigm for testing. The CDC guidelines have important implications for increasing the number of people tested in Black communities. In contrast to the U.S. as a whole, where HIV infection is heavily concentrated in particular, discrete populations, HIV is widely generalized throughout Black America. By making testing a routine part of regular medical care, the approach in the CDC guidelines would cast the testing net much more broadly in Black communities, reaching many who would be missed through risk-based testing strategies.

Although an important sign of progress, the 2006 guidelines are not a panacea. While the CDC recommends elimination of the mandate for counseling in connection with testing in medical settings, the Black AIDS

Institute continues to encourage providers to capitalize on the testing encounter to talk to their patients about HIV. Moreover, while the CDC guidelines are influential, they do not have the force of law, since states have historically handled most health care regulation. At least 11 states revised their laws between 2006 and 2008 to make them consistent with CDC's recommended approach.

Why We're Not Making More Progress

Despite favorable public policy changes and improvements in HIV testing technologies, the gap between current testing rates and what is needed to meet the AIDS challenge in Black America remains enormous. There are several reasons for this.

Stigma

Although the stigma associated with HIV has lessened over the course of the epidemic, many Black Americans still avoid becoming tested out of fear that they will suffer harm if they test positive. Surveys of HIV-positive Black men and women indicate that many experience discrimination or social stigma as a result of their infection. One study of an uninsured, inner-city Black population found that stigma was among the most common reasons cited by study participants for avoiding HIV testing.

Unfortunately, the visibility of HIV awareness and anti-stigma efforts has declined; between 2004 and 2009, the percentage of Black Americans who report having heard a lot about AIDS in the previous year fell from 62% to 33%.

Written Consent

While many states have changed their laws to bring them into line with CDC's 2006 testing guidelines, many still require written informed consent before an HIV test can be performed. A study by researchers from New York University found that written consent requirements are significantly associated with a reduced likelihood of HIV testing among Blacks.

Doctors Don't Offer Tests

Notwithstanding CDC's 2006 recommendations, many health care providers still fail to offer an HIV test to their Black patients. Seventy percent of Blacks surveyed in 2009 said no doctor or health care provider had ever recommended that they be tested for HIV. Among the 80 percent of participants in the above-noted 2008 survey of Black residents of Washington, D.C., who had seen a health care provider in the previous year, nearly half (49 percent) had not been offered an HIV test. Lack of reimbursement for HIV testing and associated counseling is an important reason that many providers do not encourage their patients to be tested.

This fact may be related to a larger challenge: Extensive research has shown that Blacks receive poorer quality of care for a range of health issues. It may also be related to the fact that Blacks and Latinos are more likely to seek primary care through emergency room visits, where doctors are less likely to recommend HIV testing.

Failure to Market Testing

While the CDC and state and local health departments have allocated considerable resources for HIV testing services, substantially less support has been provided for marketing initiatives that aim to establish knowledge of HIV serostatus as a social norm in Black communities. Even as AIDS remains one of the leading killers in Black America, visible testing promotion campaigns have virtually disappeared. Where marketing efforts exist, they are often too meager to make much of an impact.

> “Congress should also fully fund the Minority AIDS Initiative.”

This is an important shortcoming. Studies in the U.S. and in other countries have consistently found that well-designed, well-funded marketing campaigns can increase testing rates.

> “Energetic efforts should focus on full implementation of CDC's 2006 testing guidelines.”

The Community Mobilization for Testing

After Magic Johnson announced in 1991 that he had tested HIV-positive, testing rates among Black Americans began to increase throughout that decade. Increased testing was aided by the strong support of Black political leaders and traditional Black institutions, and by extensive community efforts.

But testing rates in Black America have stalled since the late 1990s. This reflects the fragmented, episodic and under-resourced nature of earlier initiatives to promote testing in Black communities. To recapture earlier momentum and to ensure sufficiently high testing rates to meet the AIDS challenge in Black America, efforts to promote testing will need to be stronger and more sustained.

With the technical support of the Black AIDS Institute, 14 of the most prominent national Black organizations and four historically Black colleges and universities have for the first time developed and begun to implement strategic national AIDS action plans. With the launch of its Act Against AIDS Leadership Initiative in 2009, CDC has begun to provide financial support to aid these organizations in translating their plans into action.

Black political leaders are also working to increase the visibility of testing efforts. Earlier this year, 79 members of Congress wrote the House Appropriations Committee, requesting $610 million for the Minority AIDS Initiative in FY2010, or an almost 50 percent increase in funding over FY2009. Rep. Maxine Waters has introduced bills to mandate the offer of a voluntary HIV test to all federal prisoners and to require insurers to cover HIV screening. Rep. Charles Rangel and a bipartisan group of Congress members have sponsored legislation to authorize the federal government to make grants for HIV testing initiatives in Black communities.

Recommendations: Strengthening the Fight Against AIDS in Black America Through Testing

The evidence is clear: The AIDS crisis in Black America will not be effectively addressed without substantially stronger action to encourage Black people to be tested for HIV.

Recommendations for Black America

All Black Americans should talk openly about AIDS, and every Black American should know his or her HIV status by getting tested annually—sexually active Black men who have sex with men should get tested at least twice a year. Local community testing coalitions should be formed, and leading Black organizations should set annual testing goals for their membership and constituents. National Black organizations should offer HIV testing at their national and regional conferences and conventions.

Recommendations for President Obama

The President should deliver a high-profile speech on AIDS in Black America, placing particular emphasis on the need for all Black Americans to know their HIV status. President Obama must make good on his commitment to develop a national AIDS strategy that includes a comprehensive plan to promote HIV testing. The President should order the Centers for Medicare and Medicaid Services to provide adequate coverage for HIV testing.

Recommendations for Joint Action by Congress and the Obama Administration

The federal government should implement a well-funded, multi-year, state-of-the-art media campaign to make knowledge of HIV status a social norm in Black America. Legislative initiatives to strengthen HIV testing efforts should be swiftly enacted. Congress should also fully fund the Minority AIDS Initiative.

Recommendations for the CDC and State and Local Health Departments

The CDC should provide significantly greater funding for targeted testing promotion initiatives in Black communities. Capacity-building support should be provided to local community testing coalitions in Black communities. Significantly stronger support is required for anti-stigma efforts and for initiatives to increase HIV science literacy in Black communities. Energetic efforts should focus on full implementation of CDC's 2006 testing guidelines. A comprehensive strategy is needed to increase the ability of clinicians to diagnose early HIV infection, when the risk of further HIV transmission is most acute.

Recommendations for the Private Sector

Companies and government agencies that employ large numbers of Black workers should energetically promote HIV testing. Media companies should collaborate in developing and implementing high-profile campaigns that promote HIV testing in Black America. All professional medical groups should endorse the CDC's 2006 testing guidelines, and all insurance companies should adequately reimburse medical providers for HIV testing services.

> “Media companies should collaborate in developing and implementing high-profile campaigns that promote HIV testing in Black America.”

Rev. Jerry Maynard encourages his congregation to get an HIV test, as he takes one himself, during the service at Southside Community Church in Nashville, Tenn. on June 29, 2008. Brad Beasley, left, with the Metro Health Department administered the test. Photo: Mandy Lunn, The Tennessean, AP.

Mayor Ronald V. Dellums (right) takes an HIV test administered by Sonya Richey on the steps of Oakland (Calif.) City Hall on June 27, 2007. Staff member Vince Mackey (from left) and Rev. Dr. Charley Hames Jr. of Beebe Memorial Cathedral look on.

Passing the HIV Test for Black America

HIV is a complicated virus, and combating it has demanded everyone involved—from scientists to community activists to policymakers—to develop inventive, often complex solutions. But one of the most powerful public health tools for controlling infectious disease is also among the most straightforward: HIV screening. That is what makes our collective performance on HIV testing so disappointing. And it is what makes recent efforts at both the governmental and the community level to finally universalize HIV testing so exciting.

In the last decade, Black community leaders and federal and state policymakers alike have focused like never before on increasing the number of people who know their HIV status. In doing so, they have challenged long-held assumptions and reexamined foundational ideas about how and why HIV testing should be done. These are welcome developments, which this report will explore in detail.

But these efforts, while promising, also show signs of being unsustainable. That's because they have largely been neither coordinated nor fully resourced. Policymakers and community leaders are now working to correct both of these shortcomings; their success in doing so will determine, perhaps more than any other factor, whether America's AIDS epidemic can be brought to an end, or whether it will continue spiraling out of control.

Our HIV testing failures have particularly dire consequences in Black America. With HIV prevalence several times higher among Blacks than in the U.S. as a whole, HIV testing is a central component of health care for all Black Americans. While Black Americans are indeed more likely to report to have ever been tested than people of other races and ethnicities, current testing rates are far short

No Doctor's Orders

Among Black Americans, individuals between 30-49 years are most likely to report that a health care provider had recommended an HIV test (36 percent), according to surveys conducted in 2009 by the Henry J. Kaiser Family Foundation. Only 28 percent of Blacks between 18-29 have been advised by a doctor to be tested, while fewer than one in four Blacks over age 50 (24 percent) received such advice.

Positive, but Not in Care

Although the HIV test is the gateway to proper medical care, studies indicate that too many Black people who test HIV positive do not enter medical care after being diagnosed, which increases their risk of experiencing a life-threatening opportunistic illness.

According to Lucia Torian and colleagues at the New York City Department of Health and Mental Hygiene, Black people are significantly more likely to delay entering medical care after testing positive. In 2003, newly diagnosed Black New Yorkers were nearly 24 percent less likely than their white peers to see a doctor within three months of their HIV diagnosis and more than twice as likely as whites to be without medical care one year after their positive HIV test result.

The New York study found that being diagnosed in a facility that provided medical care significantly increased the odds of seeing a doctor soon after diagnosis.

of what is needed to mount an effective fight against the disease in Black America.

Up to 70 percent of all new infections in Black America are the result of risky behavior among people who do not know they are infected. And because these individuals don't know of their infection, they first seek medical services for their condition only late in the course of disease, when they are at considerably higher risk of experiencing a life-threatening opportunistic illness. The late diagnosis of HIV infection is a critical reason why HIV-positive Black Americans are twice as likely to die as HIV-infected whites.

As this report explains, the CDC, state and local health departments, and professional medical groups have joined together in recent years to revolutionize the policy approach to HIV testing. Moving away from the historic "risk-based" focus of HIV testing initiatives, the public health consensus now recommends routine HIV testing in health care settings and annual testing for individuals at high risk. Yet this change in national policy has resulted in remarkably little follow-through. According to recent surveys, most Black Americans are still not offered an HIV test when they receive medical care.

Community-based efforts to promote HIV testing follow a similar pattern—a strong start that hasn't been sustained. Beginning with the announcement by basketball great Earvin "Magic" Johnson in 1991 that he was HIV-positive, Black leaders increasingly urged their constituents to know their HIV status. Public awareness campaigns encouraged Black Americans to get tested, and Black politicians, clergy and celebrities publicly served as role models by publicly taking an HIV test. The number of Black Americans receiving an HIV test soared as a result. In recent years, though, testing rates in Black America have flattened or even begun to decline.

This report argues that community efforts to encourage HIV testing must be dramatically intensified. Black Americans from all walks of life need to become re-engaged in promoting HIV testing—by talking to their friends, families and neighbors; by volunteering at a community-based AIDS organization or becoming involved in a local HIV testing coalition; and by urging their political and community leaders to raise awareness of the importance of knowing one's HIV status.

The take-home message of this report is simple: Unless knowing one's HIV status becomes the norm in Black America, AIDS will continue to devastate Black communities nationwide.

AIDS in America: A Black Disease

AIDS in America today is a Black disease. Regardless of the lens used to study the epidemic—gender, age, class, sexual orientation, or geography—Black people are more heavily affected by HIV than any other group.

Black people account for 46 percent of all Americans living with HIV[1] and for 45 percent of all new HIV infections[2] each year, though we represent just 12 percent of the U.S. population.[3] In 2006, Black people were 7.3 times more likely than whites to become newly infected with HIV.[4] Over the course of a lifetime, Black men are 6.5 times more likely to become infected than white men, while Black women are more than 19 times more likely than white women to contract HIV.[5]

Although HIV's burden upon the Black community has grown steadily over the course of the epidemic, the epidemic's disproportionate impact in Black America is not new. As early as the mid 1980s, when AIDS was still considered a disease relevant only to white gay men, Blacks were already logging more new HIV infections every year than whites.[6]

Today, Black America is experiencing what's called a generalized epidemic—meaning it touches even individuals who engage in relatively low levels of risky behavior, like having unprotected sex or sharing needles. If Black America were a country in its own right, it would rank 16th globally in the size of its HIV-positive population. Outside of sub-Saharan Africa, only four countries have HIV prevalence as high as the most conservative estimate of HIV prevalence in Black America.[7] (For more detail on the comparison between the Black American epidemic and the worst epidemics globally, read the Black AIDS Institute's 2008 report, *Left Behind—Black America: A Neglected Priority in the Global AIDS Epidemic.)*

The emergence of highly active antiretroviral therapy—known as HAART, or more popularly as "combination therapy"—has helped drive down AIDS deaths for all of the U.S. over the last decade. Yet, much of Black America is not benefiting from the treatment revolution. Even in the era of effective HIV therapies, AIDS is still one of the leading causes of death among Black men and women.[8] In New York City—home to one in seven AIDS cases nationwide—Black people living with HIV have an age-adjusted death rate that is twice as high as their white peers.[9] Nationally, in 2006, Blacks accounted for nearly 4 in 10 AIDS deaths.[10]

National Testing Day

The National Association of People with AIDS was among the first major AIDS groups to begin urging widespread HIV testing. Recognizing that access to testing alone was unlikely to generate widespread HIV testing levels needed, NAPWA in 1995 launched the National HIV Testing Day campaign to raise awareness of the need for testing and local HIV testing resources. Each year, on June 27, over 10,000 AIDS organizations, state and local health departments, media outlets, faith-based organizations, and interested citizens from across the nation come together to mount high-profile, HIV awareness and testing events in their communities.

As the principal sponsor of National HIV Testing Day, NAPWA provides extensive support to build local capacity to undertake HIV awareness and testing events. Each year, NAPWA distributes thousands of print and electronic versions of HIV testing posters, tools and resources to more than 250,000 partners and works with local partners to plan and implement testing initiatives. During 2008, National HIV Testing Day generated more than 90 million print media impressions.

In concert with OraSure Technologies, NAPWA mobilizes mayors from around the country to help promote local HIV awareness and testing initiatives. In 2009, 100 cities will participate in the Mayor's Campaign Against HIV. Leaders who will lend their active support to local testing efforts on National HIV Testing Day in 2009 include prominent Black leaders: Congresswoman Maxine Waters (D-Calif.), Congresswoman Barbara Lee (D-Calif.), Congresswoman Eleanor Holmes Norton, Mayor Michael Nutter (Philadelphia) and former Mayor Johnny Ford (Tuskegee, Ala.).

> “Unless knowing one's HIV status becomes the norm in Black America, AIDS will continue to devastate Black communities nationwide.”

Congresswoman Barbara Lee takes an HIV test on World AIDS Day, December 1, 2006 at the AIDS Project of the East Bay in Oakland, Calif. Photo: Jane Philomen Cleland.

Television personality Regina King takes an HIV test on June 25, 2007 at a Test 1 Million event held in connection with the Screen Actors Guild and the American Federation of Television and Radio Artists.

Black America and HIV Testing

An estimated 21 percent of people living with HIV in the U.S.–or 232,700 people—are unaware of their infection.[11] We don't know the exact racial breakdown of those nearly quarter of a million undiagnosed infections. But because Blacks account for such a large share of the epidemic, it is likely that they account for a large number of the undiagnosed, as well. If we assume Blacks account for the same share of undiagnosed infections as they do diagnosed ones, then more than 100,000 Black Americans are walking around with HIV and don't know it.

But that's a conservative estimate. Definitive data on the population of undiagnosed people may be unavailable, but existing clues suggest that the number of HIV-positive but undiagnosed Black Americans is significantly higher than 100,000. This section describes what is known—and still not known—about who gets tested in Black America, when they get tested and what they think about it all.

Better, but Not Enough to Save Us

Here's the good news: A remarkable number of Black people are taking steps to learn their HIV status. On average, Black Americans are significantly more likely than other racial/ethnic groups to report having ever been tested for HIV. According to national health interviews conducted by CDC in 2007, 52% of Black people above age 18 reported having been tested, compared with 38% of Hispanics and 34% of whites.[12] In another CDC study, the share of Blacks who reported getting tested in the previous year was double the national rate.[13] (See "Black HIV Testing and Transmission in America" beginning on page 57.)

But here's the bad news: Despite these higher-than-average testing rates, the share of Black Americans who haven't been tested is still significantly higher than other groups. How can that be the case? Largely because HIV prevalence—or, the amount of HIV present among a given population—is far higher among Blacks than among other racial/ethnic groups. In other words, Black America's marginally higher testing rates are

> “Fifty-two percent of Black people above age 18 reported having been tested.”

still insufficient to ensure an appropriate and commensurate public health response to the AIDS crisis in Black America.

That fact becomes clear when you look closely at the numbers. For example, in Washington, D.C.—where Black residents account for more than half of diagnosed cases of HIV or AIDS—health officials estimate that between a half and a third of residents are unaware of their HIV status.[14] A 2008 survey of low-income Black Washington, D.C., residents living in neighborhoods with high HIV prevalence found that 5.2% of participants were HIV-positive, but nearly half (47.4 percent) did not know their HIV status.[15] The study also found that nearly 40% of study participants had not been tested in the prior 12 months.[16] This is alarming data, given that the same study found this group engaged in considerable amounts of sexual and drug-related activity that could expose them to HIV.

In a 2004-2005 survey of gay and bisexual men in five U.S. cities, a shocking 46 percent tested positive and two-thirds of them were previously unaware of their infection. In this CDC-sponsored study, the rate of undiagnosed HIV infection was nearly four times higher among Black men than among their white peers.[17]

Black America is experiencing a much worse epidemic, and therefore the testing response also has to be much more robust—and sustained.

Why Traditional Testing Falls Short

America as a whole seems to have what is known as a “concentrated” epidemic.[18] That means HIV infections are densely clumped in certain sub-populations, rather than spread widely across the entire national population. In the case of the U.S., the specific populations are gay and bisexual men, and injection drug users.

Black America, by contrast, suffers from a “generalized” epidemic,[19] with extremely high rates of infection across a broad cross-section of the community. As we reported in *Left Behind,* conservative estimates indicate that HIV prevalence among Blacks exceeds 2 percent, which is well above the threshold UNAIDS uses to define a generalized epidemic.

In March, for instance, Washington, D.C.’s public health officials announced that HIV prevalence among Black residents is a whopping 3 percent—and that’s counting only the people who have been tested, not the undiagnosed. Seven percent of Black men were positive, and 3 percent of Black women. “Our rates are higher than West Africa,” Shannon L. Hader, director of the D.C.’s HIV/AIDS Administration told the *Washington Post.* “They’re on par with Uganda and some parts of Kenya.” Significantly, Hader added, “We have every mode of transmission going up, all on the rise, and we have to deal with them.”[20]

Furthermore, although HIV infection for the U.S. as a whole is largely concentrated in urban settings nationwide, many Black rural communities are experiencing extremely high HIV infection rates, as well.[21] Everything we know about the Black epidemic points to one that is generalized and spread across the broad population.

Federal, state and local health departments have, however, used the lens of a concentrated epidemic in their response to HIV in America, focusing public health efforts on gay men, drug users, and others known to be at high risk for infection. *This approach is far too limited for Black America, where HIV infection is broadly dispersed, extending well beyond so-called “high-risk” groups.*

Risk-based targeting of HIV testing efforts inevitably misses many Blacks who are either living with the virus or at risk of becoming infected. A CDC-sponsored study in South Carolina—a state where Blacks account for nearly three out of four people living with HIV—estimated that risk-based testing would miss 79 percent of HIV infections.[22] Similarly, a separate CDC study of rapid HIV testing in emergency departments in Los Angeles, New York and Oakland—in which Blacks represented 51% of newly diagnosed individuals—found that testing only "high-risk" individuals would have missed almost half (48%) of HIV-infected individuals.[23]

A major reason for the inadequacy of risk-based targeting is that it fails to capture the sex partners of so-called "high-risk" individuals. For example, Black Americans account for a disproportionate share of injection drug users, and Blacks also likely account for the large majority of such individuals' sexual partners. Risk-based testing would target only the drug user; a more generalized testing strategy would capture both the user and his or her sex partner.

In the generalized epidemic in Black America, everyone is potentially at risk. Clearly, for Black America, narrowly targeted HIV testing is the wrong strategy.

What Blacks Say About Testing Options

Surveys consistently demonstrate that many Black Americans prefer testing approaches that do not involve the taking of blood. In a multi-ethnic, multi-site study of testing preferences among people at high risk for HIV infection, Blacks were significantly more likely than other racial or ethnic groups to prefer urine or other non-blood testing.[24] Among the more than one-third of Black Washington, D.C., residents who were not tested in the prior 12 months, more than one-third (34 percent) said that an important reason for avoiding testing was their personal aversion to needles.[25]

Another potentially important reason Blacks avoid HIV testing is the traditional wait to receive test results. According to surveys, Blacks appear to prefer rapid testing techniques that obviate the need to wait for results.[26]

Are We Losing Ground?

The combination of inadequate testing and extremely high HIV prevalence means that many Black Americans who are HIV-infected are unaware of their HIV status. Worse, even as AIDS continues to devastate Black communities across the U.S., disturbing signs suggest that testing rates among Blacks have stagnated or even declined in recent years.

According to surveys of Black Americans conducted by the Henry J. Kaiser Family Foundation, the percentage of Black people under age 65 who report having been tested for HIV in the prior 12 months remained stable between October 1997 (39%) and March 2009 (40%).[27] But a New York University analysis of results from the CDC's Behavioral Risk Factor Surveillance System suggests that testing rates among Blacks may actually be falling. According to this analysis, the percentage of Blacks who reported having been recently tested fell from 30% in 1999 to 25% in 2007.[28]

It's important to remember that testing's failures echo well past preventing the virus's spread. Yes, when people are undiagnosed they cannot take steps to protect their sex partners from infection. But they also cannot get treatment for themselves. HIV-positive Black Americans fare much worse than their peers in other racial and ethnic groups, progressing from HIV to AIDS and dying at higher rates. Research suggests these trends are driven at least in part by the fact that so many Black Americans have not been tested and, thus, are only diagnosed once they become sick—when treatment is much less likely to succeed. In South Carolina—where 73% of new AIDS cases are among Blacks[29]—41% of AIDS cases reported between 2001-2005 were in people who had been diagnosed with HIV within the previous year.[30]

> “For Black America, narrowly targeted HIV testing is the wrong strategy.”

The Evolution of HIV Screening: Faster, Easier Testing

Twenty-five years after the development of the first test to detect antibodies to HIV, an impressive battery of technologies exists for diagnosing HIV infection. These advances have reduced or eliminated many of the technical weaknesses of first-generation HIV tests—making it far easier for patients to take HIV tests, and giving providers far more tools for catching new infections quickly. Here's an overview of the evolution of testing.

In the beginning… Standard antibody tests

The primary method for diagnosing HIV does not test for the virus itself but instead screens for "antibodies" for the virus. The ELISA test (short for "enzyme-linked immunosorbent assay"), is used to screen for HIV antibodies in the blood or other body fluids. A positive result on an ELISA screening test is subsequently confirmed by a second test, called the Western Blot. Standard antibody tests are most commonly administered on blood, although federal authorities have also approved HIV antibody tests in oral fluids and urine.

The two-step, standard antibody tests are highly accurate, with only a remote risk of a false positive result. Standard antibody tests have long been common in a variety of venues, including physicians' offices and stand-alone HIV testing and STD clinics.

An individual will test positive on a standard HIV antibody test only if antibodies to infection have appeared. The Food and Drug Administration advises that detectable antibodies tend to develop within two to eight weeks after exposure, with 22 days representing the average time it takes for antibodies to appear.

This interval between HIV infection and appearance of detectable antibodies is known as the "window period." Because individuals are especially infectious immediately after becoming infected, the window period has been a major weakness of traditional antibody tests and an important vulnerability of HIV screening efforts overall. In the first decade or so after the development of the antibody tests, individuals who tested negative were advised to seek follow-up testing at least six months later to confirm that they were, in fact, uninfected. Over time, however, antibody testing technologies and laboratory expertise have significantly improved, leading authorities to conclude that virtually all cases of infection are detectable by standard antibody tests within three months of exposure.

Because the ELISA screen must be confirmed, standard antibody testing has traditionally involved a wait of up to two weeks before individuals receive their test results. Standard antibody testing has historically been accompanied by pre- and post-test counseling that aims to ensure that individuals understand the purpose of an antibody test and are educated regarding the importance of HIV risk reduction.

A revolutionary development… Rapid testing

Historically, a significant portion of people who have had blood drawn for HIV tests have failed to return to receive their test results. This weakness in standard antibody tests has largely been addressed through the development of rapid HIV tests that deliver results during the same office visit in which testing occurs.

Since approval of the OraQuick Rapid HIV Test in 2002, the Food and Drug Administration has approved six tests for the rapid detection of HIV. All of these tests may be used with whole blood, but only one is available for use with blood and/or saliva. All are available for use in point-of-care and non-clinical settings. These tests have proven to be reliable, at levels comparable to standard antibody tests. They've also proven to increase both testing and the likelihood that individuals will actually receive their results.

Like standard antibody tests, rapid tests detect antibodies to HIV but not the virus itself. As a result, rapid tests share the drawback that they are unable to detect the virus during the window period between exposure and the emergence of antibodies. However, rapid tests have demonstrated their ability to ensure receipt of test results among individuals who might otherwise have failed to return for their results.

Like traditional antibody tests, rapid test results must be confirmed. To accelerate swift confirmation and immediate referral for follow-up care, some providers use a combination of rapid tests rather than the more time-consuming Western Blot. CDC has yet to endorse this strategy.

Rapid tests that use oral fluid have been shown to be particularly effective in boosting testing. According to clients of a major testing center in New York City, 90 percent of individuals prefer testing with oral fluids as opposed to blood. The New York center's move to oral fluid testing resulted in a 30 percent increase in testing since 2005. Although most rapid tests that have received FDA approval are blood tests, approval has also been given for rapid tests for oral fluids and urine. In addition, FDA has also approved tests that use fingerstick or dried blood spots.

The new cutting edge… Non-antibody tests

Non-antibody testing technologies now enable clinicians to diagnose HIV infection within days of exposure, before detectable antibodies are present. Unlike antibody tests, these non-antibody technologies actually test for the virus itself. Making the window period for HIV as short as possible is a critical public health priority, as people in the very early stages of HIV infection play an outsized role in the spread of infection within social networks.

RNA-based tests are the optimal method for diagnosing early HIV infection. These tests identify the actual genetic material of HIV rather than antibodies to the virus. RNA testing can identify infection well before a newly infected individual would test positive under standard antibody testing. RNA testing has long been used to screen the U.S. blood supply, but has only been commonly used for diagnosing HIV in individual patients in recent years.

Another method for diagnosing early HIV infection is testing for the presence of a protein that is part of HIV, called the p24 antigen. The p24 antigen is typically detectable a few days after viral genetic material can be identified but before the appearance of HIV antibodies.

Although these non-antibody tests have significantly increased clinical capacity to identify early infection and thereby prevent unknowing HIV transmission, they are infrequently used for diagnostic purposes due to several factors.

One factor is cost: These tests are more complex and costly to perform than standard antibody tests. One way to reduce that cost is what's called "pooled" RNA screening. Pooled testing involves the application of a single RNA test to multiple specimens that are divided into separate pools. If HIV is detected in the master pool, the lab technician identifies which of the individual pools has the infected specimen. RNA tests are then performed on each specimen in the identified pool until the HIV-infected, antibody-negative specimen is identified.

Another impediment to widespread use of non-antibody tests is the failure of many clinicians to order a test in the first place, even when one is clearly called for. In one study of 46 individuals with acute HIV infection, most came to the attention of a medical provider, creating an opportunity for immediate diagnosis of HIV during the most infectious stage of the disease. But only 25 percent of those who saw a doctor during their seroconversion were correctly diagnosed.

Rev. Jesse Jackson takes an HIV test at Cook County Jail in Chicago on February 23, 2007. Dozens of prisoners lined up for the tests behind Jackson who was at the jail to demonstrate how easy the tests are. He is supervised by Jeannette Bailey. Photo: Charles Rex Arbogast, AP.

The Public Policy Response

Public health policy regarding HIV testing has a long and contentious history. HIV was the first major infectious disease to emerge in the post-World War II era of human rights. So laws regulating HIV testing have reflected policy makers' efforts to balance traditional public health concerns with our national values of privacy and confidentiality. [31]

Beginning in the 1980s, every state, as well as the District of Columbia, adopted HIV-specific legislation to guide public health's response to the epidemic. Such laws typically regulated who could administer an HIV test, mandated pre- and post-test counseling, and required the individual's specific, written and informed consent before an HIV test could be performed.[32] Federal guidelines buttressed these state regulations by encouraging public health authorities to cast a narrow net with its tests. The 1987 guidelines recommended that HIV testing focus on individuals who engaged in "high-risk behaviors" or sought treatment for a sexually transmitted disease.[33]

In addition to emphasizing a risk-group focus for testing services, public policy in the epidemic's first decade also placed little emphasis on repeat testing for individuals at risk. On the contrary, many public health authorities used such pejorative terms as the "worried well" to refer to individuals who had previously tested HIV-negative but desired another test. Implicit in the early public health approach was the assumption that a negative HIV test, combined with pre- and post-test counseling, would be sufficient to ensure that HIV-negative individuals would refrain from taking future risks that could cause them to acquire HIV.

Moreover, AIDS advocates in the epidemic's first decade displayed a consistent and unrelenting resistance to most testing initiatives. That's because two difficult realities made testing seem like it presented high risks with few benefits. No treatment options had demonstrated effectiveness in prolonging life, and at the same time, no national law ensured access to health care or protected against HIV-related discrimination.[34] So why get tested and open yourself to potential bias? The Reagan administration's ostrich-like approach to the epidemic didn't help. Rather than funding HIV prevention, treatment and research, the administration imposed punitive, mandatory HIV testing regimens in a number of federal programs.

Two major developments in the 1990s

pushed new thinking about the HIV test. First, in 1992, Congress passed, and President George H.W. Bush signed into law, the Americans with Disabilities Act. It was the first national law that broadly banned discrimination on the basis of an individual's HIV status. Second, the FDA approval of a new class of antiretroviral compounds, called protease inhibitors, ushered in the era of Highly Active Antiretroviral Therapy. As evidence from clinical trials and the real world demonstrated the striking effectiveness of HAART in preventing HIV-related illness and death, the thinking on HIV testing radically shifted.

HIV at Its Most Infectious Stage

The likelihood of HIV transmission is strongly associated with the infected individual's viral load. When an individual first becomes infected, viral load spikes until reaching a peak about three weeks after infection. This is called the "acute" stage of infection.

Individuals with acute HIV infection can play a significant role in the rapid spread of HIV within social networks. Not only are individuals with recent infection highly infectious, but since they are unaware of their infection, they are likely to continue the risky behaviors that resulted in their own infection—thereby placing their sex and/or needle-sharing partners at considerable risk of acquiring HIV, too.

For half or more of individuals who become infected, flu-like symptoms accompany seroconversion. However, diagnosis of HIV seroconversion is complicated by the fact that the symptoms associated with acute HIV infection are difficult to distinguish from many common ailments.

The role of acute infection in the rapid spread of HIV underscores the importance of prompt diagnosis. Health education programs are urgently needed to alert clinicians to the signs and symptoms of acute infection. As antibody tests are often unable to identify HIV infection soon after exposure, clinicians should prescribe PCR testing for patients who show signs of possible early HIV infection.

Many clinicians also believe that early initiation of antiretroviral therapy during acute HIV infection may confer long-term clinical benefit by minimizing the explosion of viral activity that accompanies early infection. However, this hypothesis has not been validated by clinical studies.

Studies have demonstrated the feasibility of targeted testing for acute infection that focus on high-incidence clinical and geographic settings.

A New Approach to HIV Testing

CDC first began to move away from risk-based targeting of HIV testing in 1993, when it issued guidelines recommending routine, voluntary testing and counseling for patients in hospitals where HIV prevalence in the surrounding community was 1 percent or greater.[35] A number of studies have demonstrated that most patients in emergency rooms and other settings are willing to be tested for HIV during the course of medical care.[36]

But the major shift didn't come until more than a decade later. In 2006, CDC announced a sharp departure from prior national HIV testing policy. CDC recommended that health care settings inform all patients between the ages of 13 and 64 that an HIV test will be performed unless the patient expressly declines one (or "opts out" of testing, as it's known in public health parlance). Under this new testing framework, which is today the federally recommended standard, neither separate written consent nor prevention counseling should be required for testing in health care settings—hospitals, clinics, doctor's offices, etc. The guidelines also recommend that individuals with high risk of HIV infection be tested at least once annually and that HIV should be incorporated into the routine panel of tests for pregnant women.[37]

The 2006 guidelines represent a dramatic departure from prior practice for several reasons. The CDC's new approach recognizes that, as discussed above, the historic focus of testing initiatives on high-risk populations misses substantial numbers of people who are, in fact, at high risk of infection, particularly in the Black community.[38] The 2006 recommendations also reconsider the relative import of public health interests and privacy concerns, concluding that the public health interest in lowering AIDS deaths and preventing new HIV infections may override the more protective instincts reflected in earlier approaches to testing. CDC's recommendations appear to signal that many public health watchers believe the stigma associated with a positive HIV test result, while still real, has significantly diminished since the epidemic's early years.

The approach reflected in the 2006 guidelines has important implications for increasing the number of people in Black communities who know their HIV status. As discussed above, the Black epidemic is a "generalized" one, and a testing policy that is equally broad-based is far more likely to identify Black HIV infections in real time—rather than years after the fact, when it is often too late. According to one study, broad-based screening of Black men significantly reduced the percentage of missed diagnoses when compared to risk-based screening.[39]

CDC has also rightly noted that broad-based HIV testing can help reduce stigma associated with HIV, by disentangling it from specific groups of people or behaviors that create the most risk for HIV transmission. President Obama's newly appointed CDC director, Dr. Thomas Frieden, says that's one reason he has been among the nation's most outspoken proponents of broad-based testing. As he explained on World AIDS Day 2005, while serving as New York City's health commissioner, "Our outdated approach to HIV screening means that we not only fail to identify infected patients promptly and thus allow the epidemic to continue to spread, but we may also perpetuate HIV-related stigma by targeting screening only to those perceived to be at risk."

Although the CDC guidelines recommend elimination of the mandate for counseling for HIV testing in health care settings, the Black AIDS Institute continues to encourage providers to capitalize on the testing encounter to talk to their patients about HIV. Black America's literacy about and understanding of HIV remains remarkably, disturbingly low. The testing moment offers an ideal place to begin the education process through meaningful counseling, both before and after the test itself. Testing can be more than a chance to learn your status; it is also an opportunity to learn about the virus and, thereby, combat stigma as well.

There are other limitations to the new testing framework. While CDC recommendations are influential, they do not have the force of law, since states have historically handled most regulation of public health. And many state regulatory regimes, adopted earlier in the epidemic, are inconsistent with various elements of the 2006 CDC recommendations.[40] In particular, many state laws continue to mandate prevention counseling and written informed consent for an HIV test to be performed.[41] At least 11 states have revised their laws between 2006 to 2008 to make them consistent with CDC's new approach, but substantial inconsistencies remain in many states.[42]

Moreover, even state regulatory regimes do not always determine what occurs in clinical settings. At the end of the day, health care providers determine which medical tests to recommend to their patients. Factors that may influence provider decisions include the availability of third-party reimbursement for particular procedures, the prospect of incurring legal liability, or the provider's awareness of the most up-to-date standards in a particular clinical field.

> "The testing moment offers an ideal place to begin the education process through meaningful counseling."

Bishop T.D. Jakes takes an HIV test on World AIDS Day, December 2, 2007. Members of his ministerial staff also took the test. Photo: Anna Macias.

Why We're Not Making More Progress

Despite important improvements in HIV testing technologies and the adoption of a significantly more proactive public health approach to testing, the gap between current testing rates and what is needed to meet the AIDS challenge in Black America remains enormous. As this section explains, numerous factors continue to discourage Black people from learning their HIV status. Closing the testing gap will require major additional efforts to address these critical impediments.

Stigma

While much has changed since the epidemic's early years—when leading political commentators urged that HIV-positive people be tattooed or quarantined—HIV continues to be associated with social stigma in many communities. A survey of young HIV-infected gay and bisexual men (45 percent of whom were Black) found considerable experience of social stigma associated with HIV infection, with particularly prominent fears associated with disclosure of HIV status.[43] Evidence indicates that Black women living with HIV also experience high levels of stigma as a result of their infection.[44]

Studies demonstrate that HIV-positive

Campaign to Test a Million Black People

TEST 1 Million

The Black AIDS Institute has joined with the Magic Johnson Foundation, Screen Actors Guild, American Federation of Television and Radio Artists, and leading Black organizations to launch the Test 1 Million campaign. The campaign aims to ensure that one million Black Americans get tested for HIV by June 27, 2010. The campaign provides opportunities for individuals, community-based organizations, traditional Black institutions, Black college students and Black celebrities to work together to encourage Black Americans to learn their HIV status. Additional information is available on the Institute's website, www.BlackAIDS.org.

Black people are particularly likely to perceive HIV-related stigma if they lack strong social support networks.[45] An important source of HIV stigma among Black Americans is the enduring perception that HIV is a “white gay man’s disease.”[46]

Stigmatizing attitudes about HIV often deter Black people from seeking HIV testing services. A study of an uninsured, inner-city African-American population found that stigma was among the most common reasons cited by study participants for avoiding HIV testing.[47]

In the epidemic’s early years, CDC and state and local health departments invested considerable resources in efforts to reduce HIV-related stigma and discrimination. Over the years, however, as the epidemic has evolved into one that primarily affects Black people, the visibility of HIV as an issue has diminished. The percentage of Black Americans who report having heard a lot about AIDS in the previous year fell nearly by half between 2004 and 2009—from 62% to 33%.[48]

Written Consent

Although CDC’s 2006 guidelines recommend elimination of longstanding requirements for written and informed consent for HIV testing, many states have yet to align their laws with the new guidelines.

Evidence suggests that written consent requirements reduce HIV testing rates in Black America. The above-noted NYU study of testing practices, drawing from data from the CDC’s Behavioral Risk Surveillance System, examined a number of state policy options to determine their effect on testing rates among Black Americans. This study found that written consent was the sole policy change in the CDC’s 2006 guidelines that significantly correlated with a reduced likelihood of HIV testing among Blacks. Eliminating a requirement for written consent increased the likelihood of testing by 7 percent, according to the study.[49]

Aiming in the Dark: Still No National AIDS Strategy

As a type of intervention that touches the breadth of the AIDS response—from HIV prevention to treatment—testing promotion efforts ought to be situated within a comprehensive national AIDS strategy. But that’s impossible, because America doesn’t have one.

Unlike most countries, the U.S. has never had a national strategy to fight AIDS. This failure has dire consequences for efforts to promote HIV testing, because the field of testing and its implications stretches across government agencies and departments. For example, while CDC is responsible for funding most HIV testing services, the medical programs to which people who test HIV positive must be referred are administered by the U.S. Health Resources and Services Administration. And CDC’s testing mandate, for instance, does not reach the drug treatment sites supported by the Substance Abuse and Mental Health Services Administration, even though such settings offer prime venues for testing services. The same is true for housing programs financed by the Department of Housing and Urban Development.

In the absence of a national strategy specifying how these agencies should work together, testing promotion efforts are inevitably fragmented.

President Obama promised during the presidential campaign to develop and implement a national AIDS strategy, and Congress has appropriated funds to support this effort. Along with hundreds of other AIDS organizations nationwide, Black AIDS Institute strongly endorses the development of a national AIDS strategy and urges that it pay particular attention to the implementation of a plan to promote and deliver HIV testing services, and with particular attention to the urgent need to increase testing in Black America.

> “Stigmatizing attitudes about HIV often deter Black people from seeking HIV testing services.”

Access to Quality Care

CDC has the authority to issue recommendations to health providers, but it is up to the providers themselves and to their state regulators to ensure that these recommendations are put into practice. Unfortunately, evidence suggests that many providers have yet to incorporate CDC's recommendation for routine testing into their clinical practice.

Although Black people are more than twice as likely as whites to report talking to their doctor about HIV,[50] many health care providers fail to counsel their Black patients to be tested. Seventy percent of Blacks surveyed in 2009 said no doctor or health care provider had ever recommended that they be tested for HIV.[51] Among the 80 percent of participants in the above-noted 2008 survey of Black residents of Washington, D.C., who had seen a health care provider in the previous year, nearly half (49 percent) had not been offered an HIV test.[52] Among Black and Hispanic men reached at Gay Pride events in nine U.S. cities in 2004-2006, 74 percent had visited a health care provider in the prior year but only 41 percent had been offered an HIV test.[53]

Extensive research has established that Black Americans from all walks of life are less likely to get quality care, on a range of health issues, than their white peers. HIV is no different. Black Americans and Latinos are also more likely to be uninsured or underinsured, less likely to regularly see doctors and, according to physicians with large Black practices, less likely to be actively engaged in their care. All of this makes the already difficult conversation around HIV testing more complicated still. Blacks and Latinos are also more likely to depend upon the emergency room for routine health needs than their white peers. And despite high rates of HIV and STDs in emergency departments, emergency room physicians are less likely than other doctors to recommend HIV screening.[54]

In 2000, only 28 percent of U.S. physicians recommended HIV screening for their patients.[55] While dozens of medical associations have endorsed the CDC's 2006 guidelines, many had yet to do so as of August 2008.[56] Surveys also indicate that lack of third-party reimbursement for HIV testing services discourages many clinical settings from offering an HIV test.[57]

Silence Still Equals Death

Perhaps above all, HIV testing efforts suffer from the common assumption that merely offering such services will be sufficient to ensure widespread service utilization. While the CDC and state and local health departments have allocated considerable resources for HIV testing services, substantially less support has been provided for marketing initiatives that aim to establish

Bias in the Waiting Room

Although various misconceptions and policy barriers inhibit testing utilization among Black people, human failings on the part of health care providers also often discourage people from seeking HIV testing. In a series of 10 focus groups with Black people in a high-prevalence city in North Carolina, Chandra Ford and colleagues found that group participants commonly cited their perceptions of rude treatment from clinic staff as a reason for avoiding testing services.

Evidence suggests such fears are all too often grounded in reality. Angela Thrasher and colleagues report that 40 percent of minority participants in the HIV Cost and Services Utilization Study report having experienced discriminatory health care services since they were diagnosed with HIV, and nearly one in four (24 percent) said they did not completely trust their health care provider.

> “Seventy percent of Blacks surveyed in 2009 said no doctor or health care provider had ever recommended that they be tested for HIV.”

Why Offer 'Opt-Out' Testing?

Experience has shown that moving from an opt-in approach—where patients must affirmatively agree to be tested—to the now-recommended opt-out approach—where patients are routinely tested unless they specifically decline—significantly increases testing uptake and aids in the identification of cases of previously undiagnosed HIV infection.

Studies have demonstrated this to be the case in diverse health settings, including public health clinics, emergency departments and prenatal settings. According to Yu-Hsiang Hsieh and colleagues, 6 percent of individuals tested in emergency rooms are HIV-positive—a seropositivity rate that is several times higher than the rate reported for the typical public HIV testing site (Hsieh, 2008). Economic analyses have determined that routine, voluntary testing is well within standard cost-effectiveness ranges for public health interventions.

Who Pays for HIV Testing?

The primary public funder for free HIV testing services is the Centers for Disease Control and Prevention. The CDC supports public testing sites through cooperative agreements with state and local health departments, and direct support is provided to dozens of community-based organizations for HIV prevention programs that frequently include HIV testing.

Most people are tested in hospitals or physicians' offices, not in publicly funded testing sites. However, surveys indicate that many physicians do not strongly encourage their patients to be tested because third-party payers frequently do not reimburse for costs associated with HIV testing and counseling. California Rep. Maxine Waters has introduced legislation—the Routine HIV/AIDS Screening Coverage Act—that would require health insurance plans to cover routine HIV tests under the same terms and conditions as other routine health screenings.

> “Despite evidence showing that advertising increases AIDS awareness, there's almost no marketing to inform District residents of the problem's magnitude.”

knowledge of HIV serostatus as a social norm in Black communities.

Even as AIDS remains one of the leading killers in Black America, visible testing promotion campaigns have virtually disappeared. In a June 2009 article, the Washington Post noted “the rarity with which . . . billboards or bus stop advertisements tell residents that AIDS is a major health threat in the city.” According to the Post, “Despite evidence showing that advertising increases AIDS awareness, there's almost no marketing to inform District residents of the problem's magnitude.”[58]

Where advertising efforts exist, they are often too meager to make much of an impact. In response to evidence of extraordinarily high HIV prevalence and low rates of HIV testing, the Washington, D.C., government has committed $500,000 annually toward a five-year advertising campaign. Yet in one of the most expensive media markets in the world, it's reasonable to question whether such a campaign will make a difference.[59]

Through partnerships with MTV and other networks, Henry J. Kaiser Family Foundation has pioneered innovative strategies to leverage limited resources to reach millions. Likewise, the Black AIDS Institute has forged working partnerships with Black Entertainment Television and with Black newspapers and radio stations to disseminate HIV-related messages. Without financial and technical support, however, most Black communities do not have the resources or skills to plan and implement such labor-intensive strategies to spread the word about HIV testing.

The diminished visibility of testing promotion campaigns permits fears, misconceptions and attitudes to flourish that often deter individuals from seeking an

HIV test. For example, numerous studies indicate that fear of receiving a positive test result is a principal reason many people avoid HIV testing,[60] highlighting the lack of understanding among many Black Americans that life-saving therapies exist for the treatment of HIV infection.

Many Black people appear to be unaware that free testing services are easily accessible. In Washington, D.C., one out of four untested Black survey participants said they did not seek testing because they lacked money or insurance.[61] Given that Blacks with undiagnosed HIV infection are quite likely to be low income, uninsured and dependent on Medicaid and other public health programs,[62] it is critical that public campaigns emphasize that HIV testing and treatment services are available without charge.

Studies consistently find that a sizable portion of Black Americans also avoid HIV testing due to fears regarding confidentiality or privacy.[63] Acceptance of HIV testing increases when confidentiality protections are in place and clearly understood by the patient.[64]

President Obama and HIV Testing

As a presidential candidate, President Obama twice took an HIV test to draw attention to the continuing AIDS crisis—first in Kenya, then later in the U.S. with the Rev. Rick Warren.

The President's first executive budget calls for a $53 million increase in HIV-related funding at CDC. This welcome, if modest increase of 8 percent in CDC funding follows years of decline in real funding during the Bush administration.

An increase in CDC funding in FY2010 would permit the agency to support innovative strategies to promote HIV testing in Black America. As it deliberates on FY2010 appropriations, Congress should build on the president's budget to increase CDC's financial leeway to promote knowledge of HIV status.

To learn more about what President Obama pledged to do on HIV as a candidate, check out the Institute's report, *We Demand Accountability: The 2008 Presidential Elections and the Black AIDS Epidemic.*

> “Many Black people appear to be unaware that free testing services are easily accessible.”

Significant numbers of Black Americans have misconceptions about HIV that could affect their motivation to be tested. For instance:

- 37 percent of Black people incorrectly believe that basketball star Earvin “Magic” Johnson has been “cured” of AIDS (or are unsure of the correct answer);
- 36 percent believe a vaccine is currently available to prevent HIV infection; and
- 30 percent believe drugs are available to cure HIV infection.

These rates are all notably higher than responses reported for Latino and white survey participants.[65] A survey of emergency department patients found that 28 percent believed that rapid tests were less accurate than standard antibody tests.[66]

The prevalence of these sorts of misconceptions is related to the low HIV science literacy in many Black communities. The primary community-based vehicles for promoting HIV science literacy—such as San Francisco's Project Inform or the treatment education programs housed in major AIDS service organizations—were originally created by and for largely white gay communities. Relatively few HIV literacy initiatives specifically aim to increase understanding of HIV-related scientific concepts in Black communities. An exception is the Black AIDS Institute's AIDS Science and Treatment College, a component of the Institute's African American HIV University. This year-long capacity-building initiative includes intensive classroom instruction and supervised internships for individuals working in Black organizations.

The declining visibility of HIV as an issue in Black communities decreases the likelihood of many individuals reflecting on their individual risk. According to a recent review of the public health and behavioral

Home Testing for HIV

FDA has approved one product to enable individuals to learn their HIV status in their own home. The Home Access Express HIV-1 Test System—manufactured by the Illinois-based Home Access System—can be purchased at a pharmacy, by mail order, or online. The system requires consumers to collect a blood specimen and mail it to a laboratory for testing. Consumers are given a personal identification number that allows them to obtain their results over the phone anonymously. Home Access Express provides consumers with pre- and post-test counseling—either through written materials or by phone.

The single home testing system for HIV is unlike home pregnancy test kits, which permit users to interpret the results on their own. As Home Access is an antibody test, it is unable to detect infection during the window prior to the appearance of antibodies.

Several home test products that have not received FDA approval are widely promoted on the Internet and in publications. Makers of some of these products have made false claims in advertising, such as that their products have been approved by FDA.

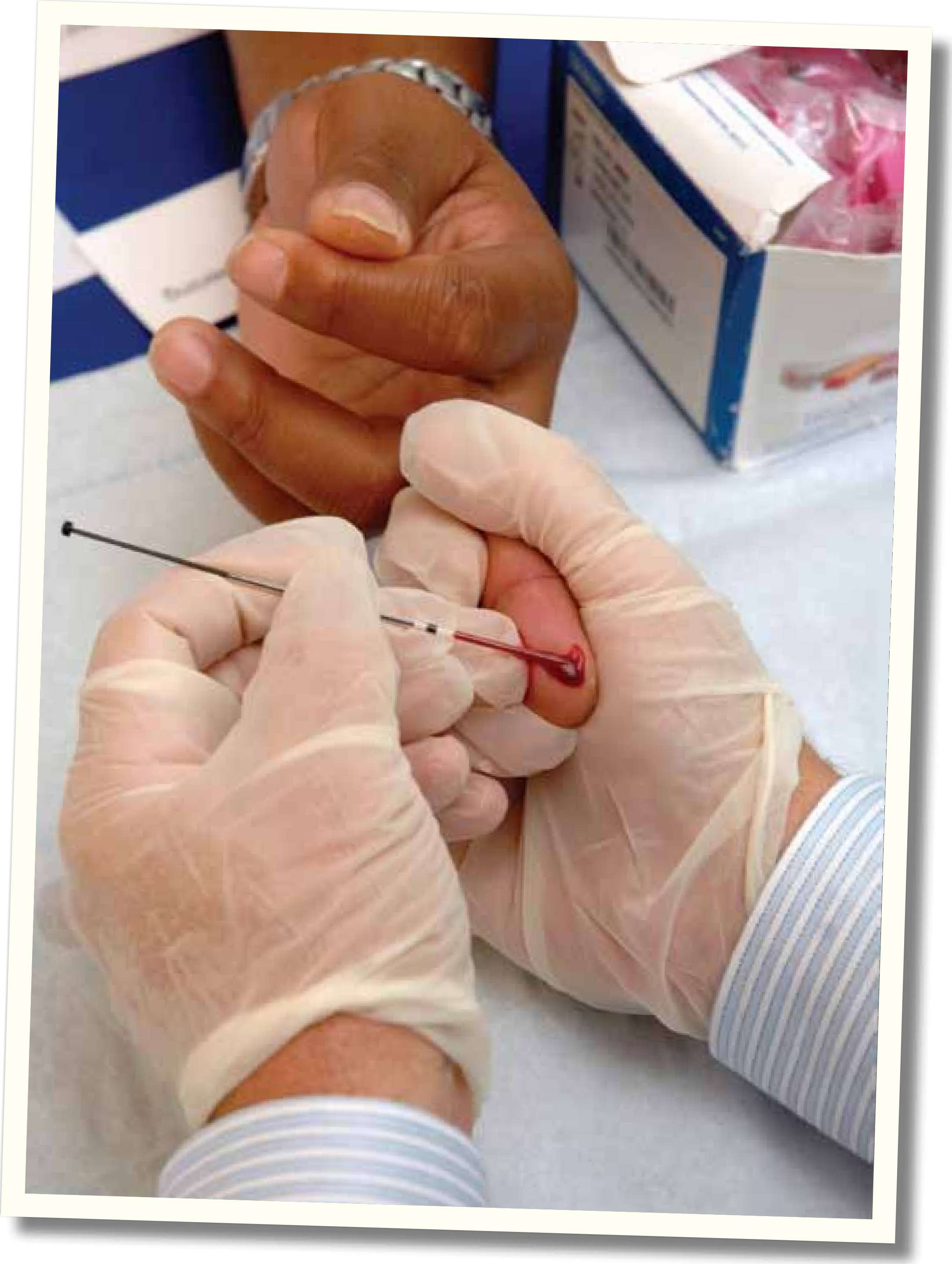
Reliable utilization figures are not available regarding the single FDA-approved home test kit. Although it was approved with great fanfare years ago by FDA, the home test option does not appear to have significantly expanded the number of Americans who know their HIV status. However, for individuals who are concerned about confidentiality or are uncomfortable encountering another person when asking for an HIV test, the home test kit provides another option to learn one's HIV status.

literature from high-income countries, individuals are more likely to be tested when they perceive their personal risk for HIV and understand the benefits of testing.[67] This is consistent with evidence derived from experience during the first decade of HIV testing.[68] In New York City, testing rates increased by 20 percent in 2008 following the city health department's launch of a Bronx-wide campaign to promote HIV testing in the New York borough with the highest AIDS death rate.[69]

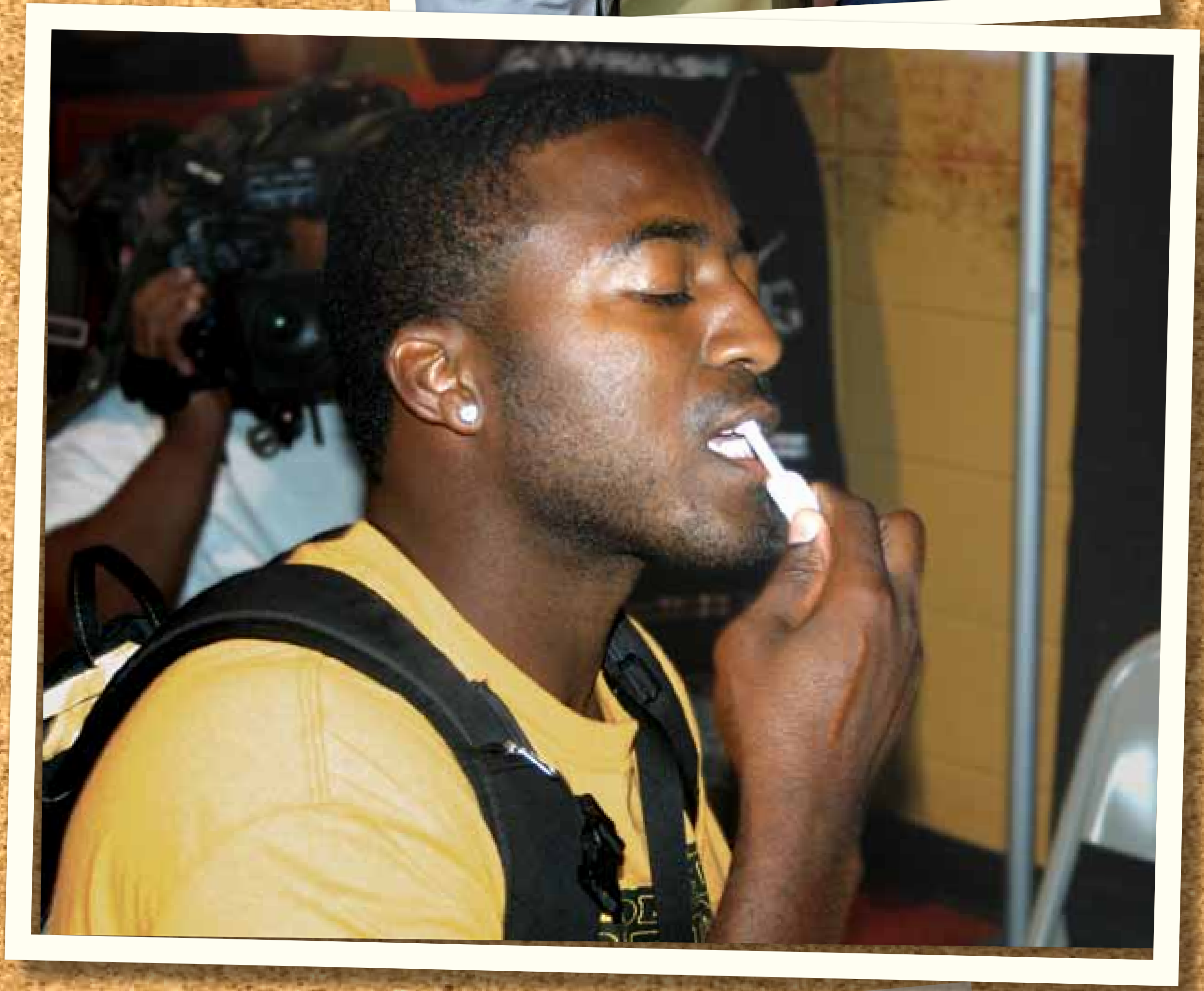
Studies in the U.S. and throughout the world have consistently demonstrated that well-planned, targeted campaigns can significantly increase testing among people at risk.[70] In particular, the use of media has been documented as an effective strategy to increase testing.[71] Among D.C. residents who reported seeing an HIV testing initiative in 2008, 64 percent also reported that the initiative made them want to get tested.[72]

National Black AIDS Mobilization Partners

American Urban Radio Networks
Congressional Black Caucus Foundation
National Action Network
National Association of Black County Officials
National Association of Black Journalists
National Association for the Advancement of Colored People
National Black Justice Coalition
National Black Nurses Association
National Coalition of 100 Black Women
National Coalition of Pastors' Spouses
National Council of Negro Women
National Medical Association
National Newspaper Association: The Black Press of America
National Pan-Hellenic Council
National Urban League
100 Black Men
Phi Beta Sigma
Rainbow Push Coalition
Southern Christian Leadership Conference
The Potter's House



Miss Universe 2008 Dayana Mendoza, from Venezuela, holds up her left arm, after having her blood drawn for an HIV test at the Xochiquetzal Foundation in Managua, January 23, 2009. Photo: Esteban Felix, AP.



Pittsburgh Steeler and two-time Super Bowl winner DeShea Townsend takes an HIV test at the Pay It Forward Health Fair in Batesville, Miss. on May 16, 2009. Photo: Myra Bean.

The Community Mobilization for Testing

Black America has long taken HIV testing seriously. Op-ed commentaries in the Black media have focused on the importance of testing, and HIV awareness and testing promotion activities are held each year in association with National Black HIV/AIDS Awareness Day.

These and other efforts have achieved results. Notwithstanding early perceptions that AIDS was a "white gay disease," HIV testing rates among Black Americans steadily rose during the 1990s. Today, reports by Blacks indicate they are significantly more likely than whites or Hispanics to have been tested.

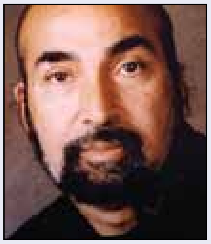
Still, the community mobilization has often been scattered and episodic, focused on one-shot efforts to promote testing. To achieve the levels of HIV testing required to save Black America from AIDS, the call for HIV testing must become a constant drumbeat in Black communities. Just as with public policy, Black America must know that it has a "generalized" epidemic, reaching broadly across Black communities. Therefore, nothing short of a broad-based, commonly shared community norm that every Black American should know his or her HIV status will suffice to turn the tide against AIDS.

A History of Testing Awareness in Black America

Popular understanding of the AIDS threat in Black communities came into sharp focus in November 1991, when Earvin "Magic" Johnson announced to the world that he had tested HIV-positive. The effect of Johnson's announcement on Black people's willingness to be tested was immediate. Even though Johnson's announcement occurred during the holiday season, when testing utilization is typically low, one study found a 52 percent increase in the number of Black women who were tested in the six weeks following the announcement. A smaller, yet substantial, increase in testing was also reported among Black men.

In the following years, Black leaders took up the AIDS cause, with particular efforts focusing on the promotion of HIV testing. Black leaders—ranging from the Rev. Jesse L. Jackson and NAACP Chairman Julian Bond to Bishop T.D. Jakes and President Barack Obama—took public HIV tests, in an effort to encourage their constituents to do the same. In 1999,

Oasis Spearheads Physician-Based HIV Screening


Dr. Wilbert Jordan

Recognizing the HIV/AIDS crisis in Black America, in 2006, the board of directors of the National Medical Association adopted a resolution calling for the creation of an outreach program that would help to identify 95% of HIV-positive African Americans not in care through three basic activities:

- Physician-based model: Asking all Black physicians and all physicians who treat Black patients to provide HIV screening to all their patients twice a year.
- Zip code-based model: Work with local health departments and AIDS service organizations in key cities to identify zip codes with the highest rates of HIV, STD and teenage pregnancy and offer community-wide HIV screening in those zip codes.
- Focused intervention model: Recruit patients currently in HIV care and treatment to bring in their friends and associates to be screened for HIV.

Dr. Wilbert Jordan, from the Oasis Clinic in South Los Angeles, is working with local and state NMA presidents, and the Association of Black Women Physicians, on a pilot for the physician-based model.

In the first year of the pilot, 903 physicians were recruited. One hundred and four cases of HIV were diagnosed. 20 per cent had CD4 counts less than 350. Twenty four hundred were recruited in the second year. And, 4,400 were recruited in the third year.

five CDC-funded organizations joined together to launch the first National Black HIV/AIDS Awareness Day. Leading Black organizations—such as The Balm in Gilead and the National Black Leadership Commission on HIV/AIDS—have helped mobilize Black clergy to promote HIV testing. The Black AIDS Institute has mobilized hip-hop artists and other Black celebrities to promote HIV testing by taking HIV tests themselves.

In part as a result of these initiatives, the percentage of Black Americans who have been tested for HIV is significantly higher than the share of whites or Latinos who have done so. Yet, as discussed above, the share of Blacks who report having been tested has not risen since 1997, and the percentage of Blacks who have heard a lot about AIDS in the past year has sharply declined.

With 48 percent of African Americans indicating they have never been tested for HIV, the limitations of episodic, if courageous, efforts to promote HIV testing are clear. There is an urgent need for a dramatically scaled-up campaign that uses state-of-the-art advertising and social marketing techniques to promote HIV testing as a social norm in Black America.

To be effective, such a campaign will require major new resources. Yet the first step—even before resources are mobilized—is for the Black community to take action on its own. Black Americans need to talk to each other about AIDS—openly, loudly and repeatedly. That costs nothing, and is the necessary beginning of a revolution.

Black Organizations Lead the Charge

For years, the growing health crisis in Black America remained largely hidden from public consciousness, eliciting only the most minimal public health response. In the absence of clear public health warnings, the Black community itself was also slow to recognize the severity of the epidemic.

In recent years, that has begun to change. In 2009, Black Americans are 11 times as likely as whites to regard HIV/AIDS as the single most urgent health problem, according to a Henry J. Kaiser Family Foundation survey. And, according to the same national survey, Blacks are four times as likely as whites to tell pollsters that AIDS has become a more serious problem in recent years.[75] Black Americans are also notably more likely than whites or Latinos to have ever donated to an HIV-related charity.[76]

In 2006, the Black AIDS Institute, in concert with The Balm in Gilead, the National Black Leadership Commission on AIDS and the Magic Johnson Foundation, launched the National Black AIDS Mobilization. Under the umbrella of the campaign—and with the technical support of the Black AIDS Institute—14 of the most prominent national Black organizations and four historically Black colleges and universities have for the first time developed and begun to implement strategic national AIDS action plans. Promoting HIV testing is a core component of most of the strategic plans developed by these leading Black organizations. (See *Making Change Real: The State of AIDS in Black America, 2009* for a detailed update on the Mobilization.)

With the launch of its Act Against AIDS Leadership Initiative in 2009, the CDC has begun to provide financial support to aid these organizations in translating their plans into action. The initiative offers 14 Black organizations funding for a full-time staff person to direct AIDS programming. As a part of CDC's Act Against AIDS campaign, the Act Against AIDS Leadership Initiative is explicitly designed to build the capacity of traditional Black organizations. It is a visionary step by the CDC with the potential to help Black organizations with the resources they need to bring AIDS "out of the closet" and to forge a new social norm in favor of HIV testing. To ensure its long-term success, this initiative should be accompanied by additional supportive steps, including major funding for Black-focused HIV testing promotion campaigns and the active engagement of diverse opinion leaders and community sectors in the AIDS response.

Political Action by Black Leaders

A milestone in the Black response to AIDS occurred during the second term of President Bill Clinton, when members of the Congressional Black Caucus spearheaded passage of the Minority AIDS Initiative. This initiative aimed to strengthen HIV testing, prevention and treatment programs in heavily affected communities of color through targeted funding.

Unfortunately, under President George W. Bush's subsequent administration, funding for the Minority AIDS Initiative

Mom's Status Opens Daughter's Eyes

I'm only 18, but it's funny how your life can suddenly change. My mom was diagnosed with HIV a few years back. Before her diagnosis, I didn't know anything about HIV or AIDS. I never knew a lot of people had it. If my mom didn't have it, then I wouldn't know or even care. Even though things have been rough, my mom's diagnosis brought the family together. My sister and I can talk to her about anything now.


Alyssa

The media only shows sick people. They don't show everyday people. But you can't tell who has HIV. They are normal people.

I get tested all the time, and now I know a lot. I talk to my friends about it. It is especially important for Black women to get tested because they are the fastest growing population of those affected. I know because I help with my mom's organization, Open Hearts, to help spread the word about HIV/AIDS.

> "To achieve the levels of HIV testing required to save Black America from AIDS, the call for HIV testing must become a constant drumbeat."

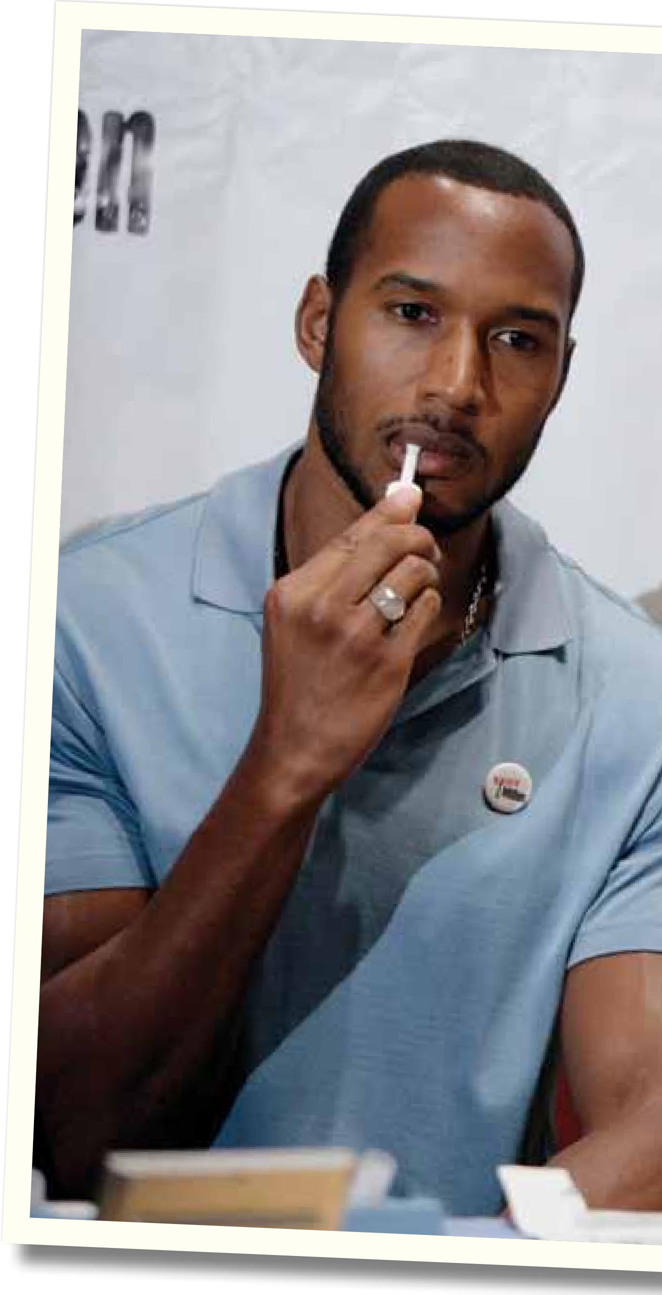
declined in real terms. Black Congressional leaders are now working to reverse this recent history of neglect. Under the leadership of California Rep. Maxine Waters, 79 members of Congress wrote the House Appropriations Committee requesting $610 million for the Minority AIDS Initiative in FY2010, or an almost 50 percent increase in funding over FY2009.

Black political leaders are taking additional steps to promote knowledge of HIV status in Black communities. In 2007, Rep. Waters introduced the Stop AIDS in Prison Act, which requires the Federal Bureau of Prisons to test all prison inmates for HIV unless inmates specifically decline a test. The bill also requires comprehensive HIV prevention and treatment for all inmates. The legislation passed the House of Representatives in 2007 but was not endorsed by the Senate prior to the adjournment of the 110th Congress. In 2009, Rep. Waters reintroduced the legislation, along with a bipartisan group of co-sponsors.

In April 2009, New York Rep. Charles Rangel introduced the National Black Clergy for the Elimination of HIV/AIDS Act. Endorsed by a bipartisan group of co-sponsors, the bill would authorize different parts of the Department of Health and Human Services to make grants to public health agencies and faith-based organizations to conduct HIV testing and other HIV-related activities. Among the bill's provisions is authorization for intensified capacity-building support for Black communities to respond to AIDS and for a national media outreach campaign to encourage sexually active individuals to be tested for HIV.

These visionary initiatives deserve far broader support and visibility than they have thus far received. President Obama and congressional leaders should embrace them and work for their swift approval.

In summary, the evidence from community groups, traditional Black institutions, and Black political leaders indicates that much of Black America is ready to respond to the AIDS crisis. However, Black America has to date lacked the resources, infrastructure and broad-based commitment to convert such episodic actions into a high-level, coordinated national campaign that can be sustained over time and can make knowledge of HIV status a social norm in Black communities. If the AIDS epidemic in Black America is to be reversed, this must change.



Actors Henry Simmons and Vanessa Williams, along with Producer and Casting Director Robi Reed, take an HIV test on June 25, 2007 at a Test 1 Million event held in connection with the Screen Actors Guild and the American Federation of Television and Radio Artists.

Then Illinois Senator Barack Obama and his wife Michelle take HIV test in a special van in Kisumu, Kenya, August 26, 2006. Photo: Sayyid Azim/AP.

Recommendations

Ending AIDS in Black America Through Testing

The evidence is clear: The AIDS crisis in Black America will not be effectively addressed without substantially stronger action to encourage Black people to be tested for HIV. To this end, the Black AIDS Institute makes the following recommendations to increase testing in Black America.

Recommendations for Black America

- Get tested. Every Black American should take the test. Knowing your HIV status is a right and responsibility. Knowing your partner's HIV status can save your life. Today, there is no excuse for not knowing the status of your status.
- Talk about AIDS. Black Americans from all walks of life must wake up to the continuing threat posed to their communities by the epidemic. Black people should engage each other in discussions about the importance of getting tested and the need for a stronger community response to the crisis.
- Build community-testing coalitions. In collaboration with traditional Black institutions and their local health departments, community members should join together to plan community-driven initiatives to encourage Black people to be tested for HIV. Making innovative use of local media, opinion leaders and faith-based organizations, these community coalitions should work to establish knowledge of HIV status as a social norm in Black communities.
- Leaders must lead. Many national Black institutions have developed strategic action plans to address the HIV/AIDS epidemic. (Organizations which do not have AIDS strategic action plans should develop and implement a plan immediately.) These plans should include annual testing goals for their membership and constituents, and commitments to offer HIV testing at their national and regional conferences and conventions. These organizations should implement their plans and fullfill their testing commitments. Organizations funded through the Act Against AIDS Leadership Initiative should use resources from the CDC to implement their plans. Black leaders and institutions should establish knowledge of HIV status as a cultural norm in Black America.

Recommendations for President Obama

■ Use the bully pulpit. President Obama should deliver a high-profile speech on the AIDS crisis in Black America, placing particular emphasis on the need for all Black Americans to know their HIV status. The President should use this speech as an opportunity to convene Black opinion leaders, Black media and traditional Black institutions to pledge their collective, meaningful engagement in a national drive to ensure that all Black Americans know their HIV status.

■ Develop a national AIDS strategy. President Obama should follow through on his campaign pledge to develop and implement America's first national AIDS strategy. The national strategy should be developed in consultation with people living with HIV, affected communities, traditional Black institutions, state and local health departments, medical associations, private industry and relevant federal agencies. The national strategy should delineate and prioritize a comprehensive national plan to increase testing rates in Black America, with specific focus on community-driven testing campaigns, multi-sectoral engagement in testing promotion, and optimal coordination among diverse federal agencies.

■ Fix reimbursement policies. President Obama should direct the Centers for Medicare and Medicaid Services to provide adequate coverage for HIV testing services and linkage of patients who test HIV-positive to follow-up medical and supportive services.

Recommendations for Joint Action by Congress and the Obama Administration

■ Fund a national testing campaign. The Obama administration and Congress should work together to provide targeted funding for a major, national, multi-year campaign to make knowledge of HIV status a social norm in Black America. This program should build on—and give more vigorous life to—CDC's recently announced Act Against AIDS Leadership Initiative. Under this program, CDC should be required to establish and adhere to specific, time-bound milestones to increase HIV testing among Black Americans. This new national initiative should include broad-based, state-of-the-art advertising efforts, as well as funding for locally tailored testing promotion campaigns in Black communities across the U.S. Funding for the initiative should provide for rigorous, independent evaluation and documentation of lessons learned.

■ Swiftly pass legislative initiatives. Congress should expeditiously approve and send to President Obama pending legislation to strengthen HIV testing efforts in Black America. Proposed legislation that deserves swift passage includes the Routine HIV/AIDS Screening Coverage Act, the Stop AIDS in Prison Act, and the National Black Clergy for the Elimination of HIV/AIDS Act.

■ Fully fund the Minority AIDS Initiative. Congress should appropriate at least $610 million in funding for the Minority AIDS Initiative in FY2010 and continue in subsequent years to ramp up funding for this program.

Recommendations for the CDC and State and Local Health Departments

■ Target funding for testing promotion. The CDC should increase funding to Black-serving organizations, traditional Black institutions, and state and local health departments to increase utilization of HIV rapid-testing technologies.

■ Build capacity for local testing coalitions. CDC should provide substantial, targeted financial and capacity-building support for the development, maintenance and support of community-driven HIV testing coalitions in Black communities across the U.S., with particular focus on the 25 cities with the largest number of Black people living with HIV.

■ Launch anti-stigma campaigns. In furtherance of the objectives of the Act Against AIDS Leadership Initiative, the CDC should work with marketing experts, community-based organizations and traditional Black institutions to develop and implement a multi-component strategy to alleviate HIV stigma and discrimination in Black America. The strategy should build on international best practices in anti-stigma programming and include funding to support community-based cultivation of celebrity spokespeople to fight HIV stigma. The anti-stigma strategy should specifically address homophobia and encourage tolerance and acceptance of sexual diversity.

■ Build HIV science literacy. The CDC should provide major new funding for capacity-building initiatives to build HIV literacy in Black communities.

■ Implement CDC guidelines. All states should review their laws—and where necessary, revise them—to ensure their alignment with CDC's 2006 guidelines for HIV testing. All state legislative frameworks should require private insurers to reimburse medical providers for HIV testing services. State medical regulators should review their policies and practices to intensify uptake of routine HIV testing in medical settings, with particular attention to settings that serve large numbers of Black patients.

■ Increase clinicians' ability to diagnose acute HIV infection. The U.S. Public Health Service should collaborate with state and local health departments and professional medical associations to develop and implement clinical guidance and training programs to improve clinicians' ability to diagnose acute HIV infection.

■ Link HIV-positive individuals to care. The CDC should collaborate with state and local health departments and with its partners in the U.S. Public Health Service to improve the effectiveness of referral and linkage for all individuals who test HIV-positive. Demonstrated improvement in service linkage should be a meaningful criterion for HIV prevention and Ryan White funding for states and localities.

Recommendations for the Private Sector

■ Promote HIV testing in the workplace. Companies and government agencies that employ large numbers of Black workers should energetically promote HIV testing and educate employees regarding venues where testing is available.

■ Develop media campaigns. Diverse media outlets should collaborate in developing and implementing high-profile media campaigns that promote HIV testing in Black America. Experts on marketing products and services to Black consumers should be integral partners in the development and monitoring of these campaigns. Local media outlets should provide public service support for local HIV testing campaigns in Black communities.

■ Endorse CDC's guidelines. All relevant professional medical associations should endorse CDC's 2006 testing guidelines and should incorporate testing promotion modules in their medical training programs.

■ Pay providers for testing. All insurers should adequately reimburse medical providers for HIV testing services, including pooled RNA testing for antibody-negative specimens. Such policies would recognize CDC's finding that routine HIV testing is a fundamental component of proper medical care.

NAACP executives Bruce Gordon, president and CEO; Roslyn Brock, vice chair; and Julian Bond, chair take an HIV test July 14, 2006 on the opening day of the organization's 97th annual national convention.

By the Numbers

Black HIV Infection, Testing and Transmission in America

Map of the Black AIDS Epidemic in America

Black HIV Infection in America

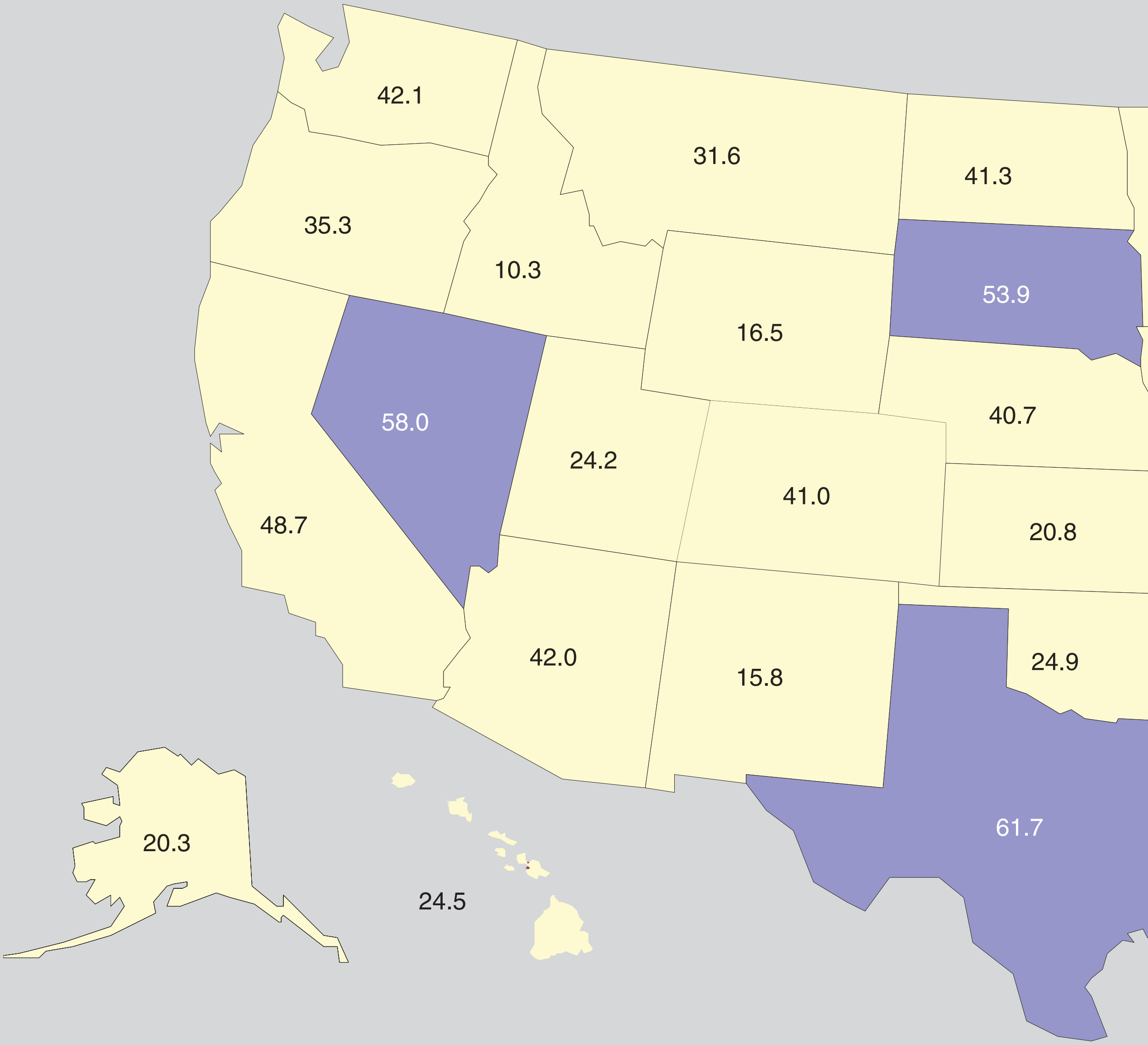
The State of Awareness
Know Someone with AIDS
Race of Newly Infected
Race of All HIV-Positive
Rate of Infection
Infection Over Time
How STDs Help HIV
Among Women
Among Men
How Black Men Get Infected
How Black Women Get Infected
Among Gay and Bisexual Men
Undiagnosed Gay and Bisexual Men
Where Newly HIV-Positive Live

Black HIV Testing and Transmission in America

Race of Americans Tested
Lifetime Testing Rate
Views on Testing and Stigma
Impetus of HIV Test
Timing of HIV Test Decision
Reasons for HIV Test
Health Care Provider Suggested HIV Testing
Got HIV Test in Last 12 Months

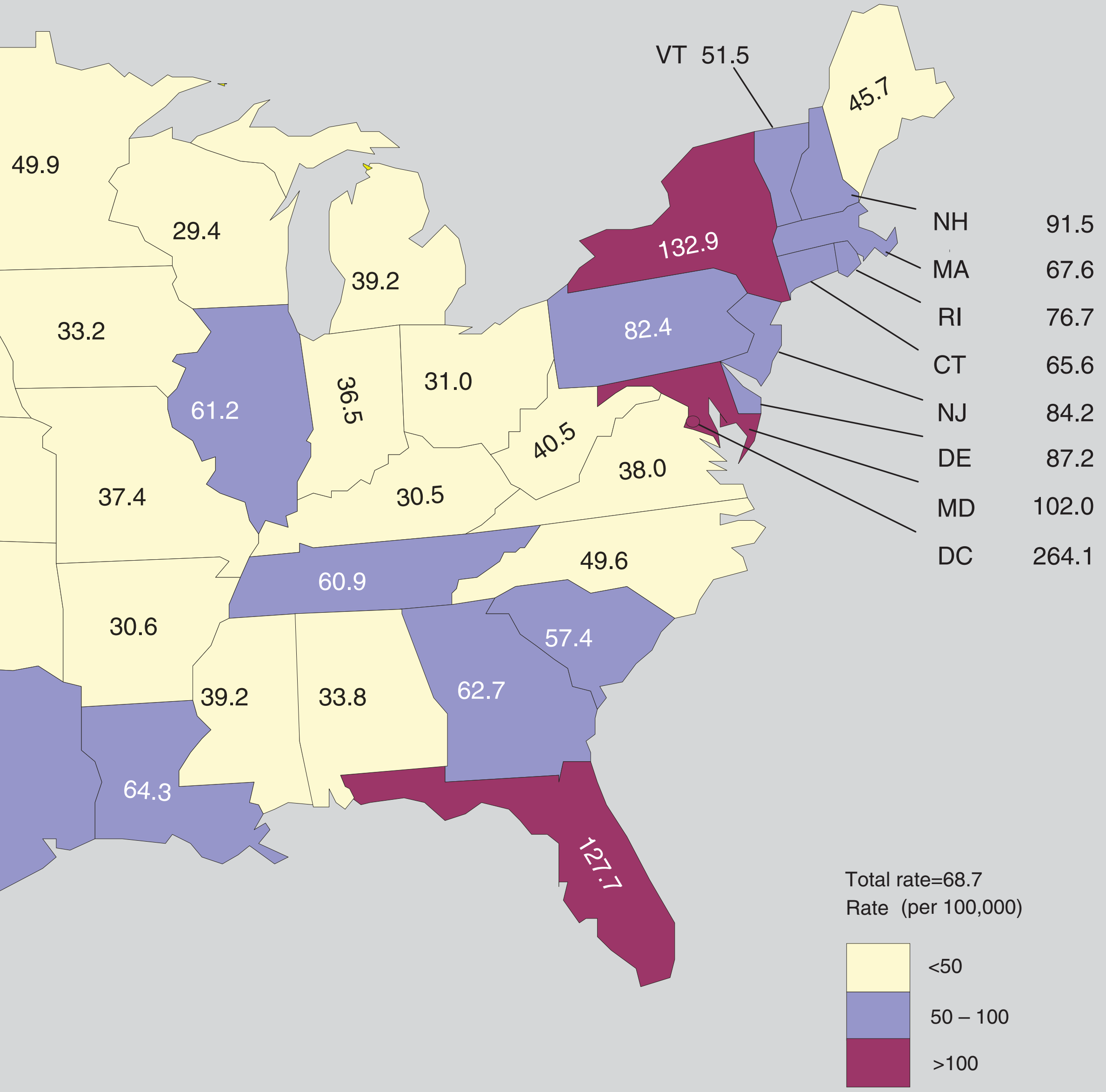
By the Numbers

MAP of the Black AIDS Epidemic in America



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.*

Sources: CDC, HIV/AIDS Surveillance by Race/Ethnicity, slide set, accessed December 17, 2008, at http://www.cdc.gov/hiv/topics/surveillance/resources/slides/race-ethnicity/index.htm.
***CDC, HIV Prevalence Estimates—United States, 2006, MMWR, 57(39);1073-1076.**



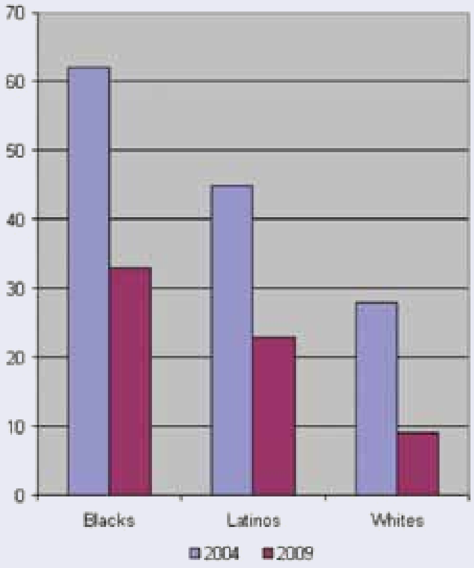
By the Numbers

Black HIV Infection in America

The State of Awareness

Percent of men saying they have seen, heard or read “a lot” about the problem of AIDS in the United States during the last year.

Blacks	2004	62 percent
	2009	33 percent
Latinos	2004	45 percent
	2009	23 percent
Whites	2004	28 percent
	2009	9 percent

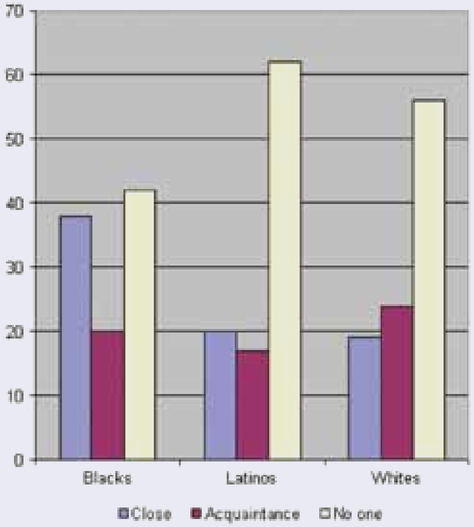


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Know Someone with AIDS

More Black Americans than any other racial/ethnic group report knowing someone close who has AIDS, has died from AIDS or who is HIV-positive.

	Percentage		
	B	L	W
Close friend or family member	38	20	19
Acquaintance, co-worker or someone else	20	17	24
Don’t know anyone	42	62	56

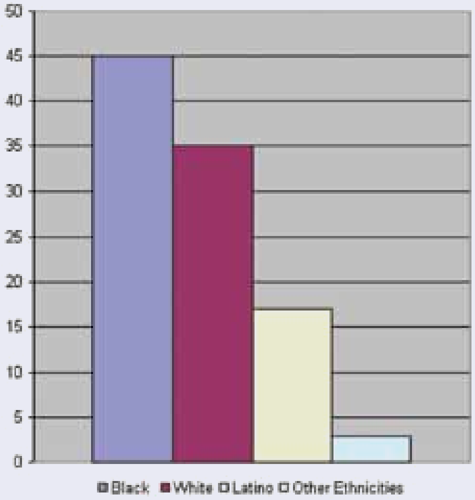


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Race of Newly Infected

An estimated 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

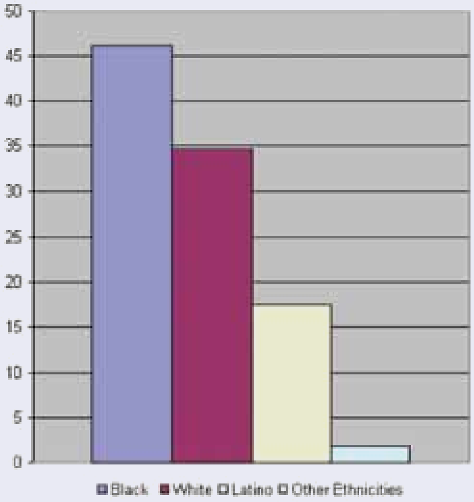


Source: Hall HI, Song R, Rhodes P, et al. Estimation of HIV Incidence in the United States. JAMA. 2008;300:520–529.

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

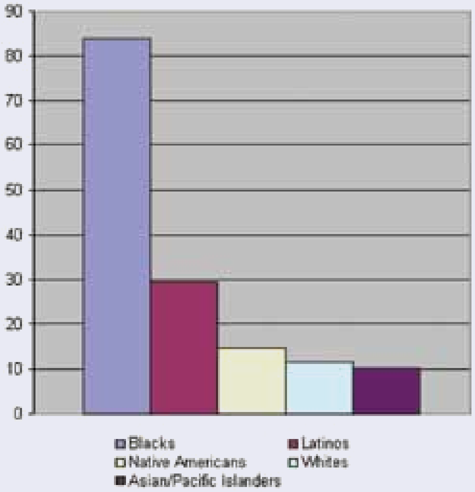


Source: CDC, HIV Prevalence Estimates—United States, 2006, MMWR, 57(39);1073-1076.

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

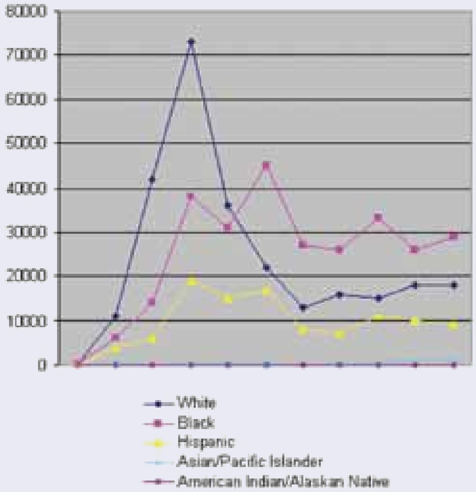


Source: Hall HI, Song R, Rhodes P, et al. Estimation of HIV Incidence in the United States. JAMA. 2008;300:520–529.

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:



Source: Hall HI, Song R, Rhodes P, et al. Estimation of HIV Incidence in the United States. JAMA. 2008;300:520–529.

How STDs Help HIV

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

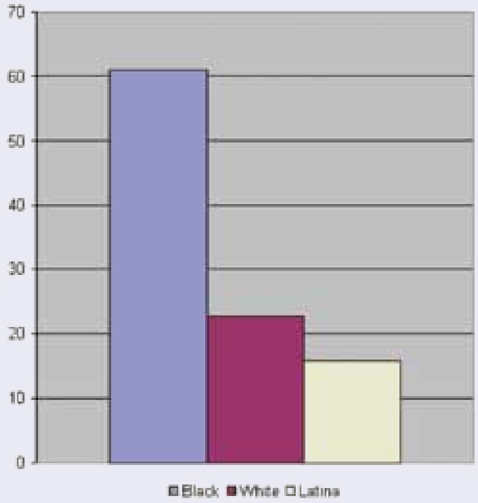
Sources: CDC, Sexually Transmitted Disease Surveillance, 2006. November 2007.

***CDC, The Role of STD Detection and Treatment in HIV Prevention—CDC Fact Sheet, accessed on December 17, 2008, at http://www.cdc.gov/std/hiv/STDFact-STD&HIV.htm#MoreInfo.54(24);597-601.**

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

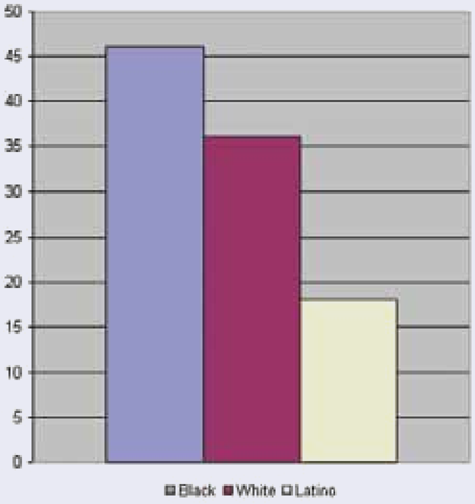


Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989. Data not available for any other ethnicity.

Among Men

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

Black	46 percent
White	36 percent
Latino	18 percent

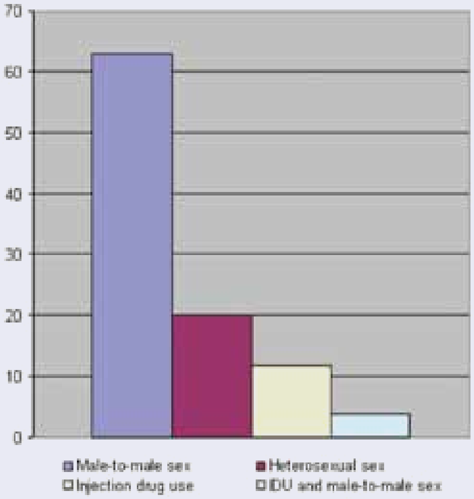


Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989. Data not available for any other ethnicity.

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

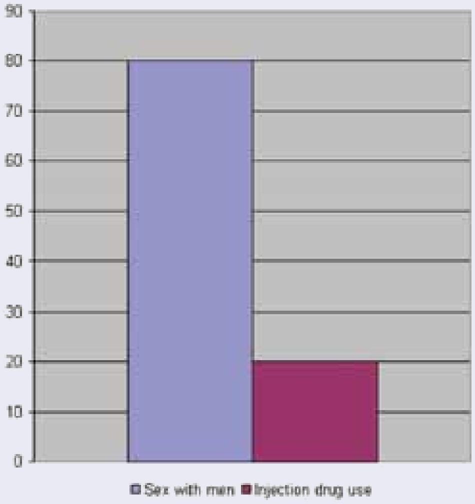


Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989.

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

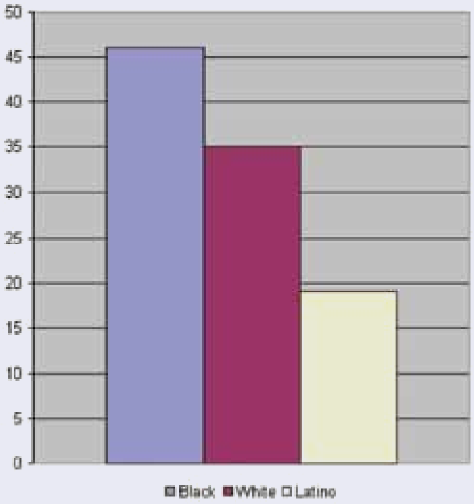


Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989.

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:

Black	46 percent
White	35 percent
Latino	19 percent

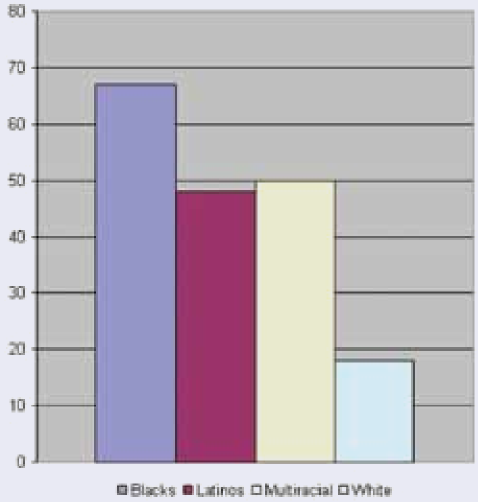


Source: CDC, Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006, 57(36);985-989. Data not available for any other ethnicity.

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

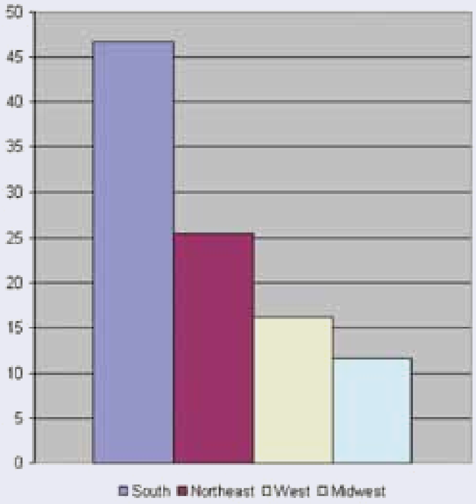


Source: CDC, HIV Prevalence, Unrecognized Infection, and HIV Testing Among Men Who Have Sex with Men—Five U.S. Cities, June 2004-April 2005, MMWR, 54(24);597-601.

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:

South	46.7 percent
Northeast	25.4 percent
West	16.1 percent
Midwest	11.6 percent



Source: CDC, HIV/AIDS Surveillance in Urban and Non-urban Areas, slide set, accessed December 16, 2008, at http://www.cdc.gov/hiv/topics/surveillance/resources/slides/urban-nonurban/index.htm.

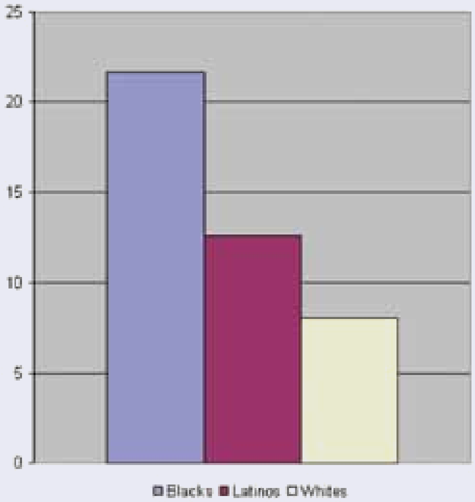
By the Numbers

Black 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

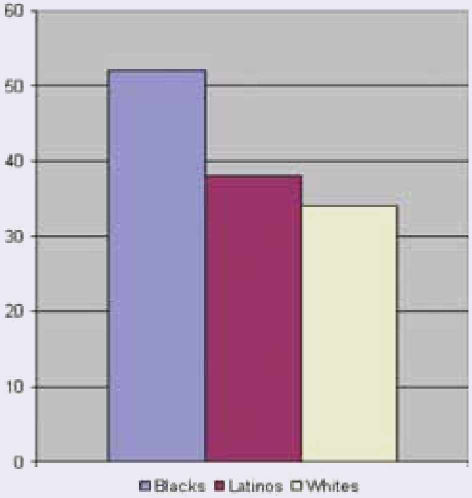


Source: CDC, Persons Tested for HIV—United States, 2006, MMWR, 57(31);845-849. Data not available for any other racial or ethnic group.

Lifetime Testing Rate

In 2009, more than half of all Black Americans over the age of 18 report having been tested for HIV at some point in their lifetimes. That's a significantly higher testing rate than any other racial or ethnic group.

Blacks	52 percent
Latinos	38 percent
Whites	34 percent

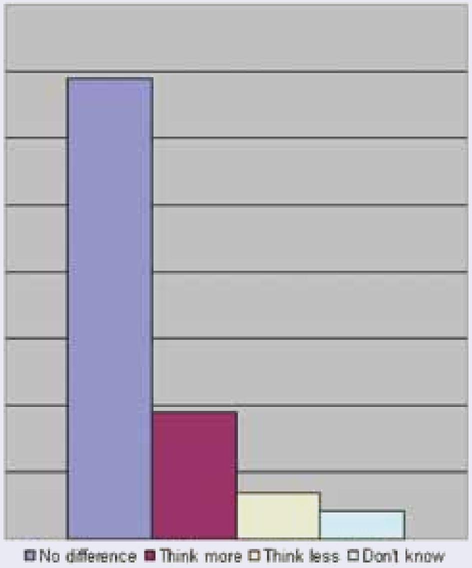


Source: CDC, Early Release of Selected Estimates Based on Data From the 2007 National Health Interview Study, June 2008.

Views on Testing and Stigma

Most Black Americans in 2009 say they think testing would not lead to stigma.

Would make no difference in how people think of you	69 percent
People would think more of you	19 percent
People would think less of you	7 percent
Don't know/refused	4 percent

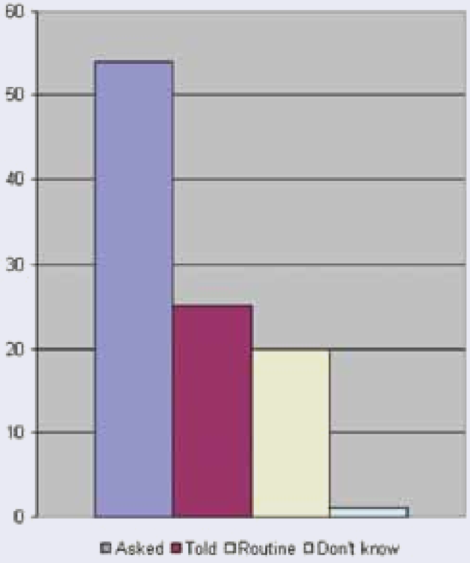


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Impetus of HIV Test

Most Black Americans who take an HIV test say they specifically ask for it.

Asked to be tested	54 percent
Doctor/nurse told me it was being done	25 percent
Impression it was routine part of exam	20 percent
Don't know/other	1 percent

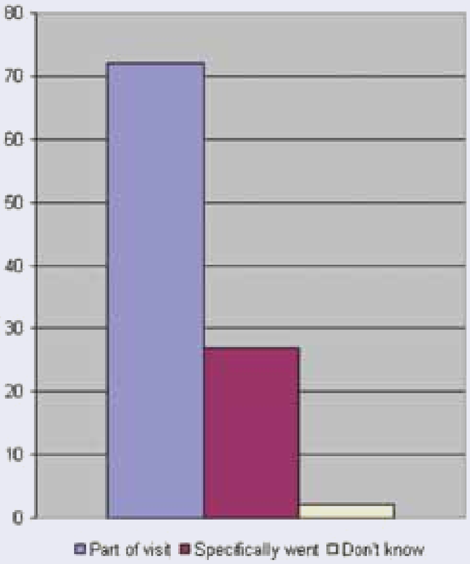


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Timing of HIV Test Decision

Most Black Americans who take an HIV test say they decide to do it as part of another health visit.

As part of another health visit	72 percent
Went specifically to be tested	27 percent
Don't know	2 percent

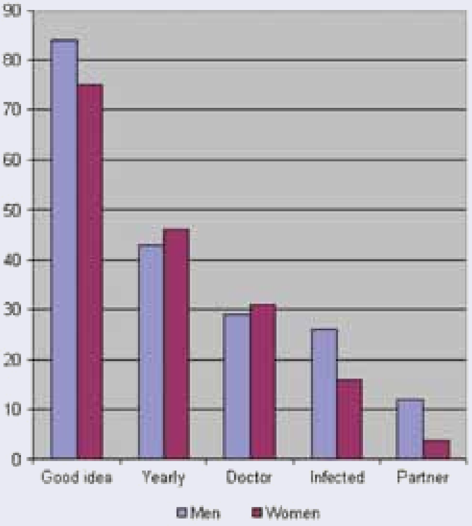


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Reasons for HIV Test

Most Black Americans who take an HIV test say "it just seemed like a good idea." Percentage of reasons stated by Blacks who report being tested, by men and women:

	Percentage	
	Men	Women
Seemed like good idea	84	75
Do it every year	43	46
Doctor suggested	29	21
Possibly infected	26	16
Partner suggested	12	4

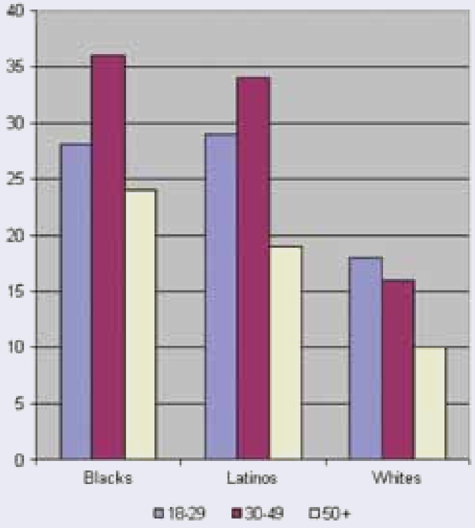


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Health Care Provider Suggested HIV Testing

Among those reporting, Blacks and Latinos more often say they are counseled by health professionals to have an HIV test than whites. Percentages by race and age:

	Percentage		
	18-29	30-49	50+
Blacks	28	36	24
Latinos	29	34	19
Whites	18	16	10

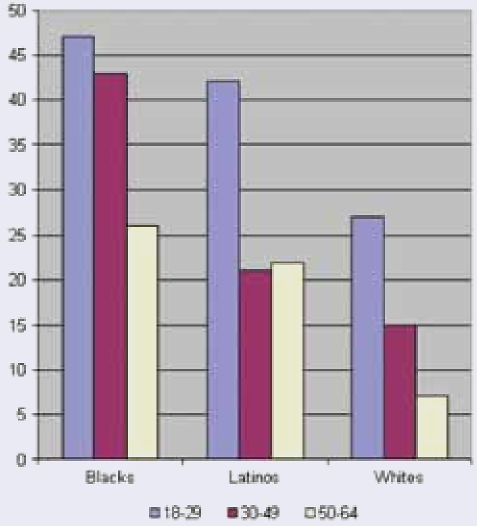


Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.

Got HIV Test in Last 12 Months

Among those reporting, Blacks more often say they got an HIV test in the last 12 months than other racial/ethnic groups. Percentages by race and age:

	Percentage		
	18-29	30-49	50-64
Blacks	47	43	26
Latinos	42	21	22
Whites	27	15	7



Source: Kaiser Family Foundation, 2009 Survey of Americans on HIV/AIDS.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About the Black AIDS Institute

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.

What We Do

The Institute develops and disseminates information on HIV/AIDS policy. Our first major publication was the NIA Plan, which launched a national campaign to stop HIV/AIDS in African American communities by formulating and disseminating policy proposals developed through collaboration with federal, state and local government agencies, universities, community-based organizations, healthcare providers, opinion shapers and "gatekeepers."

■ **The African American HIV University,** the Institute's flagship training program, is a fellowship program designed to increase the quantity and quality of HIV education in Black communities by training and supporting grassroots educators of African descent. AAHU's Science and Treatment College trains Black people in the science of HIV/AIDS. We believe when people and communities understand the science of AIDS, they are better equipped to protect themselves, less likely to stigmatize those living with the disease or at risk of infection, better able to adhere to treatment and advocate for care, and better positioned to influence public and private HIV/AIDS polices. The Community Mobilization College is designed to enhance the capacity of Black communities to address the HIV/AIDS epidemic. Through building the knowledge and networks of community leaders around the country and providing a skills-building internship practicum focused on community mobilization, individuals become capable of engaging traditional Black institutions and other stakeholders in local-level community activities that will increase access to and utilization of HIV prevention services in their communities.

- **The International Community Treatment and Science Workshop** is a training and mentoring program to help people who are living with HIV/AIDS or who are working with community-based and non-governmental AIDS organizations to meaningfully access information presented at scientific meetings. Program updates will be available for the next International AIDS Conference which will be held in Vienna in 2010.

- **The Drum Beat** project is the Institute's Black media mobilization designed to train Black journalists on how to cover HIV/AIDS and tell the stories of those infected and affected. The Black Media Task Force on AIDS, a component of the Drum Beat Project, currently has over 1500 Black media members.

- The Institute publishes **original editorial materials** on the Black AIDS epidemic. Our flagship publication is our *State of AIDS in Black America* series which chronicles statistics, policy and movement activities from year to year. In the past few years, the Institute has published reports on Black women, Black youth, Black gay and bisexual men and treatment in Black America. Our website www.BlackAIDS.org attracts nearly 100,000 hits a month. And our weekly AIDS updates currently have over 35,000 subscribers.

- **Heroes in the Struggle** is a photographic tribute to the work of Black warriors in the fight against AIDS. Featuring elected officials and other policy makers, leading Black clergy, celebrities and entertainers, journalists, caregivers, advocates and people living with HIV/AIDS, the exhibit travels to Black universities, museums and community-based organizations throughout the United States, providing information on HIV/AIDS, raising awareness, and generating community dialogues about what Black people are doing and what we need to be doing to end the AIDS epidemic in our communities.

- The Institute provides **technical assistance** to traditional African American institutions, elected officials and churches who are interested in developing effective HIV/AIDS programs, and to AIDS organizations that would like to work more effectively with traditional Black institutions.

Finally, nearly 30,000 people participated in AIDS updates, town hall meetings or community organizing forums sponsored by the Institute annually.

- **Leaders in the Fight to Eradicate AIDS (LifeAIDS)** is a national Black student membership organization created to mobilize Black college students around HIV/AIDS. LifeAIDS sponsors a national Black Student Teach-In and publishes Ledge, the only national AIDS magazine written, edited and published by Black students. Founded in 2004, LifeAIDS is the nation's only AIDS organization created by Black college students to mobilize Black college students to end the AIDS epidemic in Black communities. LifeAIDS has a presence on more than 70 college campuses nationwide.

- **The National Black AIDS Mobilization** is an unprecedented five-year multi-sector collaboration between all three national Black AIDS organizations in the United States (The Balm in Gilead, the National Black Leadership Commission on AIDS and the Black AIDS Institute) with a goal of ending the AIDS epidemic in Black America by 2012.

BAM seeks to build a new sense of urgency in Black America, so that no one accepts the idea that the presence of HIV and AIDS is inevitable. The campaign calls on traditional Black institutions, leaders and individuals to actions toward ending the AIDS epidemic in Black America.

The project has four key objectives: cut HIV rates in Black America, increase the percentage of Black Americans who know their HIV status, increase Black utilization of HIV treatment and care, and decrease HIV/AIDS stigma in Black communities.

BAM does this in two ways: identifying and recruiting traditional Black institutions and leaders, and providing Black leaders and institutions with the skills and capacity to develop strategic action plans for themselves and/or their organizations. The organizations that have signed on to NBAM are: 100 Black Men of America, American Urban Radio Networks, Congressional Black Caucus Foundation, National Action Network, National Coalition of 100 Black Women, National Coalition of Pastors' Spouses, National Black Justice Coalition, National Council of Negro Women, National Newspaper Publishers Association News Service, RainbowPUSH Coalition, Inc., Southern Christian Leadership Conference, The Potter's House and T.D. Jakes Ministries.

■ **Test 1 Million** is a call to action to engage all of Black America, from individuals to institutions, in a community-wide effort to end the AIDS epidemic. The campaign—a partnership with the Screen Actors Guild, American Federation of Television and Radio Artists, Magic Johnson Foundation, Black AIDS Institute and leading national Black organizations and institutions—is one of awareness, personal responsibility and collective action. The goals of the Test 1 Million campaign are to raise awareness about HIV testing; increase the percentage of Black Americans who know their HIV status; increase the percentage of HIV-positive Black Americans in appropriate early care and treatment; reduce stigma around HIV testing; and create an army of 1 million HIV testing advocates.

Test 1 Million is supported by the Black AIDS Media Partnership, a sustained commitment among U.S. media companies to work together in a coordinated response to the AIDS crisis facing Black America..

For more information or more copies of this report, contact:

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