A close-up photograph of two Black men's faces in profile, facing each other. Their noses are just inches apart, creating a sense of tension or intimacy. The lighting is soft, highlighting the contours of their faces.

We're the Ones We've Been Waiting For

**THE STATE OF AIDS IN BLACK AMERICA
...AND WHAT WE'RE DOING ABOUT IT**

By Gil Gerald and Kai Wright
Black AIDS Institute, September 2007

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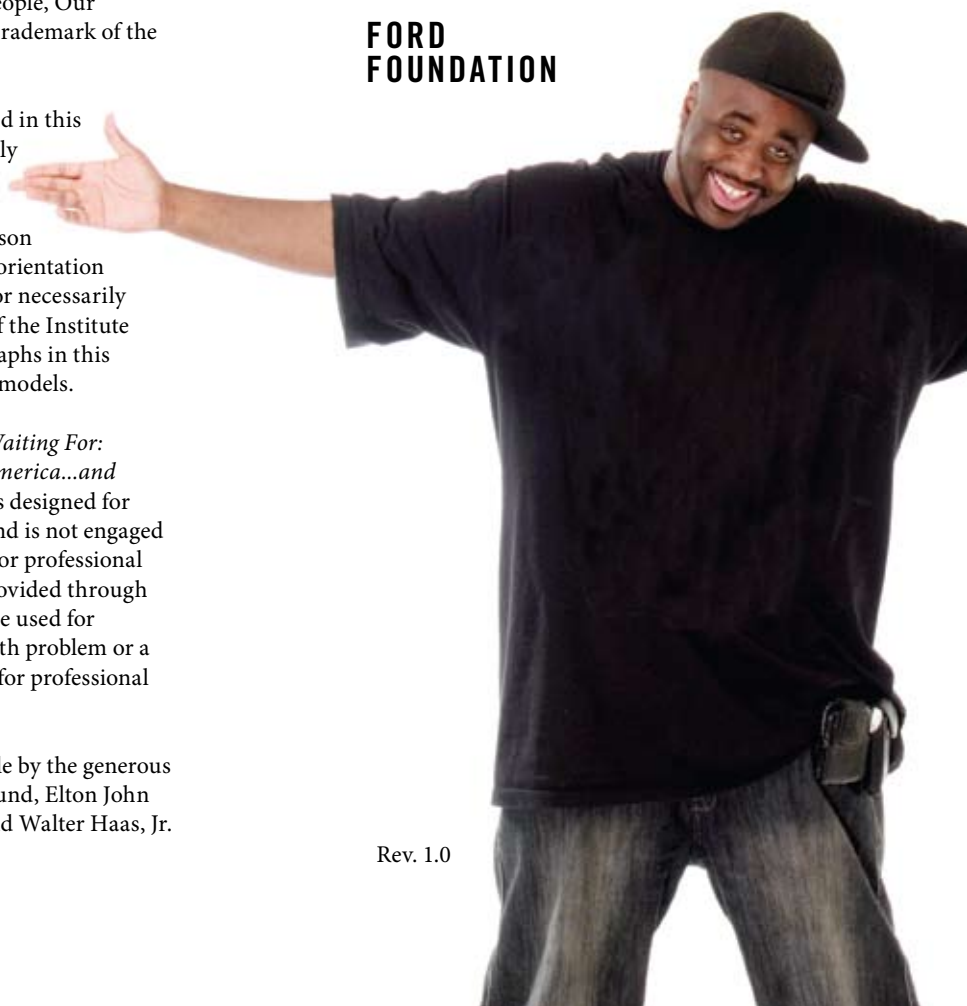


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FROM THE DIRECTOR

We're the ones we've been waiting for

"It is people joining forces in a time of great need. It is hope, it is sharing the burden. It is people caring for their own and finding love, and surviving, and believing in the future even when we are hurting more than we have ever hurt before.

"It is AIDS."

Chris Brownlie—1951-1989

When Hurricane Katrina hit New Orleans on August 29, 2005, I was in Atlanta at an HIV/AIDS consultation for the Centers for Disease Control and Prevention. Upon hearing the news, I rushed to my room and, in a desperate panic, turned to CNN in search of information. Like most Americans I was shocked at the images flooding my hotel room—desperate people standing on rooftops begging for help, dead bodies floating down the streets of a major city in the United States.

But perhaps unlike most Americans, Hurricane Katrina was deeply personal for me. This was happening to my city. This was happening to my family. My oldest niece was a rising sophomore at Xavier University in New Orleans. My family is from Louisiana and Mississippi. My childhood was punctuated with frequent trips to New Orleans for family reunions, weddings and, of course, funerals.

I've walked along the 17th Street levee



with my parents. I remember wandering along the streets of the Lower Ninth at sunset with my cousin Edward, eating crawfish out of a brown paper bag (stolen out of my Aunt Vera's shrimp boil, while the adults weren't looking) and throwing the shells over our shoulders as we went along without a care in the world.

As I watched CNN, I knew my Aunt Vera's old house was gone, as was my Aunt Late's, and my Uncle Jed's. When Katrina hit New Orleans, my family counted over 100 members living in the city. All of them were displaced. As of today, fewer than 10 have returned.

As this report is being released, the world is marking the two-year anniversary of Katrina, pausing to remember the devastating damage the Gulf Coast absorbed and pondering the lack of progress made in the rebuilding efforts. I was recently in New Orleans, and evidence of Katrina is still everywhere you turn. In some parts of the Lower Ninth Ward, it was as if the hurricane had just happened.

But what has struck me most about the new images from New Orleans are not the pictures of the devastation, but the examples of the people of New Orleans rebuilding their own city—the day care center that reopened with little more than the grit and determination of a Black women who refused to give up; the historically Black colleges that are operating out of hotels because students can't wait for the rebuilding to get their education; the judge who decided now is the time to reform the juvenile justice system; and the AIDS service organizations that are making sure that people with HIV/AIDS can still get medication, even if Charity Hospital never reopens.

Like the Katrina story, the AIDS story in Black America is a complex one. The face of Hurricane Katrina was Black. So, too, is the face of AIDS in America today. And like Katrina, AIDS is intensely personal. In this report, our third annual update on the State of AIDS in Black America, we lay out both the highs and the lows of our national and our communal response to this ugly fact.

We've attempted to paint an honest picture of what AIDS in Black America is like today—the good, the bad and the ugly. That means not pulling punches on policymakers. But it means not pulling them on ourselves either. We love, respect and support the organizations discussed in this report, but we've not given anyone a pass.

Ultimately, our review of the State of AIDS in Black America today left us with a clear conclusion: While we've come a long way in dealing with the epidemic, we are not near where we need be to end it once and for all.

That reality is painfully evident as you turn through this report. We open with a chart-book laying out the dimensions of the problem in clear, cold numbers. Don't just read these charts once. Clip them, post them, carry them with you and use them as a resource for getting the startling message out in your community.

The report then explores the latest initiatives, challenges and failures of our national response to the epidemic, first focusing on prevention and then on treatment. Here, Katrina's themes echo most loudly: The levees that are America's HIV health delivery systems are broken—and the rebuilding has been devastatingly slow in coming.

The good news is that the sleeping giant of traditional Black institutions, from faith and civil rights to elected officials, media, the arts and entertainment, have taken notice and, in some cases, made impressive commitments. With their membership and chapters, conferences, conventions, and various communication vehicles, they could change the AIDS landscape in no time.

In a *Washington Post* op-ed on August 14, 2006, Julian Bond wrote, “Almost 40 million people are dead. And most of those who have died and are dying are Black.” He went on to write, “The face of AIDS in the United States is primarily Black. The majority of new HIV infections here are Black, the majority of people who die from AIDS here are Black and the people most at risk of contracting this virus in the United States are Black. AIDS is now in our house. It’s now our problem.”

The bad news is most traditionally Black institutions are not yet ready to respond to Bond’s eloquent call to action.

Last August, 25 Black leaders, led by the Black AIDS Institute, the Balm in Gilead and the National Black Leadership Commission on AIDS, launched the national Black AIDS Mobilization with the goal of ending the AIDS epidemic in five years. The final section of this report—which will be a new dimension of our annual update—reviews the state of the movement we’ve launched.

The reality it describes is that, even with our awakened awareness and new commitment, we still don’t have the one thing that will truly end the AIDS epidemic in our communities: a national, coordinated, mass movement. While there are many examples of meaningful individualized efforts, they remain sporadic and haphazard. None of our national Black institutions have developed a strategic action plan for ending AIDS, either in their individual work or as a collective.

As Danny Glover put it, “Black America can no longer afford to trifle with the politics of America’s culture wars, whether they come from the left or the right. It is time for Black people to take ownership of the AIDS epidemic and responsibility for ending it.”

There are many reasons why Black institutions have not yet delivered the sort of detailed plans needed to seriously pursue ending AIDS in our community. One reason is certainly both benign and malicious neglect on the part of governments, corporations and foundations that have done little to provide traditional Black institutions with the resources they need to do the job. No institution in Black America has received the sort of government, corporation or foundation support that AIDS organizations serving white gay men found in the mid-1980s and early 1990s.

Having said that, it still comes down to us. Corporations, governments and foundations could and should do more. But if they don’t, we *still* have to find a way to end this epidemic. Ultimately, the white gay community rallied to demand the resources it needed—both from within and from outside of its own ranks. We must also understand that government can’t write our national plan. Corporations can’t build a groundswell in our communities. Foundations can’t make those most at-risk for HIV/AIDS feel welcome in our communities. We have to do that.

We’re the ones we’ve been waiting for.



The Black Epidemic By the Numbers

A Statistical Snapshot of Today's
African American Epidemic

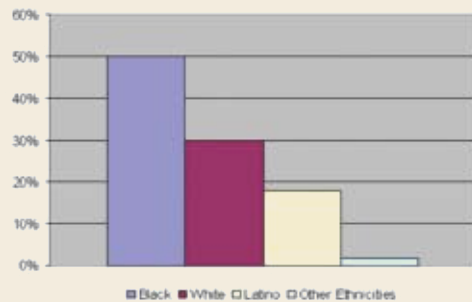


Who's Getting Infected in America

By Percent

Racial/Ethnic Percentages of New HIV/AIDS Diagnoses in 2004

Black: 50 percent
White: 30 percent
Latino: 18 percent
Other Ethnicities: 2 percent

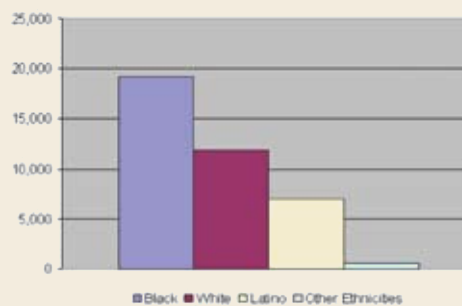


Source: CDC. HIV/AIDS Surveillance Report, 2004. Vol. 16, Table 1. Data based on 35 states with long-term HIV tracking systems that count infections by recording patients' names.

In Numbers

Number of New HIV/AIDS Diagnoses by Race/Ethnicity in 2004

Black: 19,206
White: 11,806
Latino: 6,970
Other Ethnicities: 602
Total: 38,584

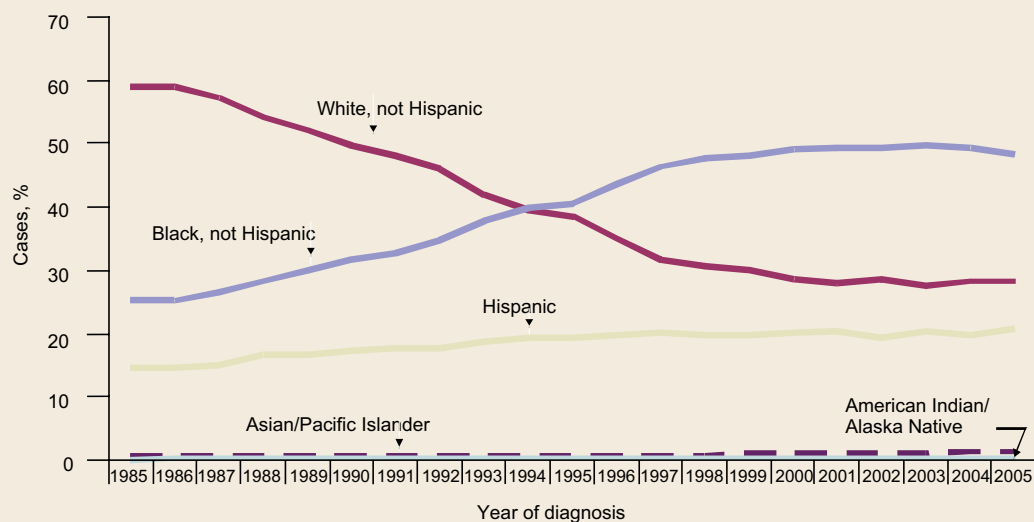


Source: CDC. HIV/AIDS Surveillance Report, 2004. Vol. 16, Table 1. Data based on 35 states with long-term HIV tracking systems that count infections by recording patients' names.



20 Years of Diagnoses

Racial/Ethnic Percentages of Annual AIDS Diagnoses, 1985-2004

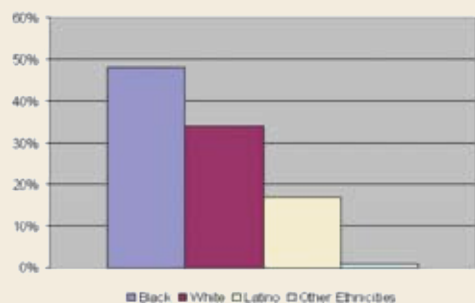


Source: CDC. HIV/AIDS Surveillance by Race/Ethnicity. Online slide set at www.cdc.gov/hiv/topics/surveillance/resources/slides/race-ethnicity, accessed September 3, 2007.

Positive Americans

Racial/Ethnic Percentages of All People Living with HIV/AIDS (as of 2004)

Black: 48 percent
White: 34 percent
Latino: 17 percent
Other Ethnicities: 1 percent

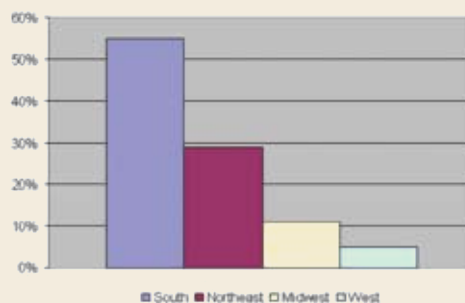


Source: CDC. *HIV/AIDS Surveillance Report*, 2004. Vol. 16, Table 9. Data based on 35 states with long-term HIV tracking systems that count infections by recording patients' names.

Where Newly HIV+ Live

Regional Percentages of New HIV Diagnoses, 2001-2004

South: 55 percent
Northeast: 29 percent
Midwest: 11 percent
West: 5 percent



Source: CDC. *Trends in HIV/AIDS Diagnoses – 33 States, 2001-2004. Morbidity and Mortality Weekly Report*, Nov. 18, 2005.



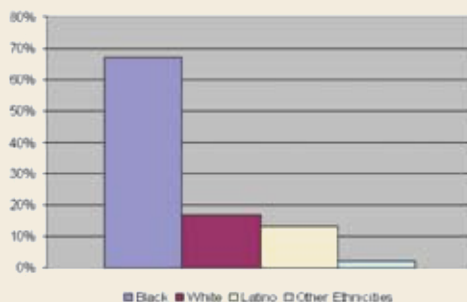
An Up-Close Look at Today's Infections



Women

New HIV Infections Among Women in 2004

Black: 67 percent
White: 17 percent
Latino: 13 percent
Other Ethnicities: 2 percent

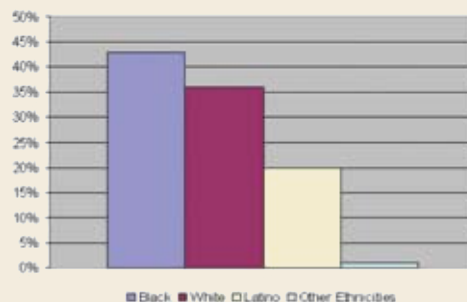


Source: CDC. HIV/AIDS Surveillance by Race/Ethnicity online slide set, Slide 16. Data based on 33 states with HIV tracking systems that count infections by recording patients' names since at least 2000.

Men

New HIV Infections Among Men in 2004

Black: 43 percent
White: 36 percent
Latino: 20 percent
Other Ethnicities: 1 percent

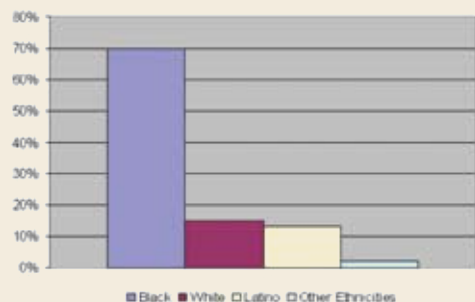


Source: CDC. HIV/AIDS Surveillance by Race/Ethnicity online slide set, Slide 15. Data based on 33 states with HIV tracking systems that count infections by recording patients' names since at least 2000.

Youth

New HIV/AIDS Cases Among Teens in 2004

Black: 70 percent
 White: 15 percent
 Latino: 13 percent
 Other Ethnicities: 2 percent



Source: CDC. *HIV/AIDS Surveillance in Adolescents and Young Adults* online slide set, Slide 6. Data based on 33 states with HIV tracking systems that count infections by recording patients' names since at least 2000.



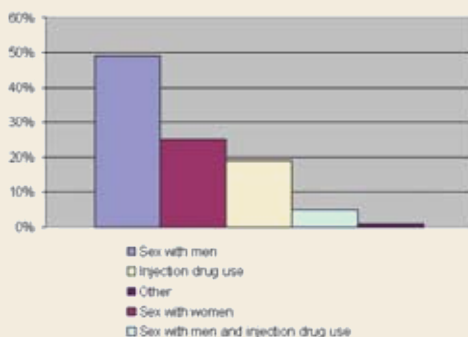
How Black Americans Get Infected



Men

Transmission Routes of HIV Diagnoses Among Black Men, 2001-2004

Sex with men: 49 percent
 Sex with women: 25 percent
 Injection drug use: 19 percent
 Sex with men and injection drug use: 5 percent
 Other: 1 percent

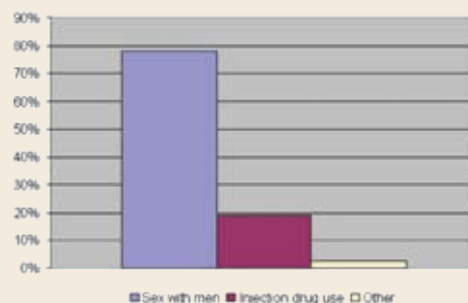


Source: CDC. *Trends in HIV/AIDS Diagnoses – 33 States, 2001-2004. Morbidity and Mortality Weekly Report*, Nov. 18, 2005.

Women

Transmission Routes of HIV Diagnoses Among Black Women, 2001-2004

Sex with men: 78 percent
 Injection drug use: 19 percent
 Other: 3 percent



Source: CDC. *Trends in HIV/AIDS Diagnoses – 33 States, 2001-2004. Morbidity and Mortality Weekly Report*, Nov. 18, 2005.

Unanswered Questions

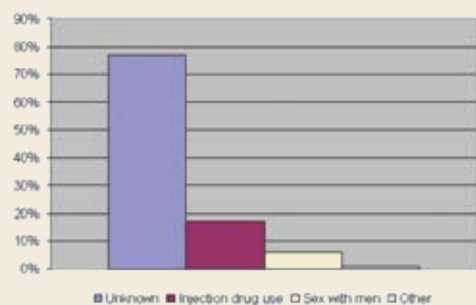
HIV Risk of Male Sex Partners of Black Women Who Tested Positive in 2004

Unknown: 77 percent

Injection drug use: 17 percent

Sex with men: 6 percent

Other: Less than 1 percent



Source: CDC. *HIV/AIDS Surveillance Report*, 2004. Vol. 16, Table 22. Data based on 42 states with long-term HIV tracking systems that count infections by recording patients' names in 2004.



Who's Still Dying of AIDS in America

A Record of Lives Lost

Annual AIDS Deaths by Race/Ethnicity, 1985-2004

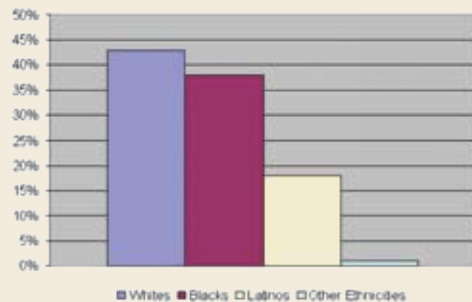
Year of Death	White, not Hispanic	Black, not Hispanic	Hispanic	Other Ethnicities	All Groups	Percent Black
1985	4,005	1,757	1,021	36	6,819	25.77%
1986	7,011	3,029	1,807	74	11,921	25.41%
1987	8,886	4,554	2,492	106	16,038	28.40%
1988	10,930	6,108	3,500	199	20,692	29.52%
1989	14,452	8,028	4,625	143	27,328	29.38%
1990	16,434	9,107	5,208	238	30,987	29.39%
1991	18,719	10,939	6,173	319	36,150	30.26%
1992	20,157	13,205	7,064	326	40,752	32.40%
1993	21,300	15,278	7,604	413	44,595	34.26%
1994	22,538	17,806	8,759	516	49,477	35.99%
1995	21,968	19,062	9,136	539	50,705	37.59%
1996	14,558	15,894	6,904	386	37,742	42.11%
1997	7,351	10,464	4,079	231	22,125	47.02%
1998	6,082	8,997	3,371	186	18,636	48.28%
1999	5,620	8,860	3,232	184	17,896	49.51%
2000	5,310	8,560	3,010	159	17,039	50.24%
2001	5,184	8,962	3,188	178	17,512	51.18%
2002	5,205	8,929	3,103	175	17,412	51.28%
2003	5,081	8,905	3,529	154	17,669	50.40%
2004	4,309	7,939	3,212	173	15,633	50.78%
Cumulative	225,100	196,383	91,017	4,770	517,270	37.96%

Source: CDC. Deaths among Adults and Adolescents with AIDS by Race/Ethnicity, 1985-2004, United States. Black AIDS Institute requested data.

Blacks' Share

Blacks as Percentage of Total AIDS Deaths (as of 2004)

Whites: 43 percent
Blacks: 38 percent
Latinos: 18 percent
Other Ethnicities: 1 percent



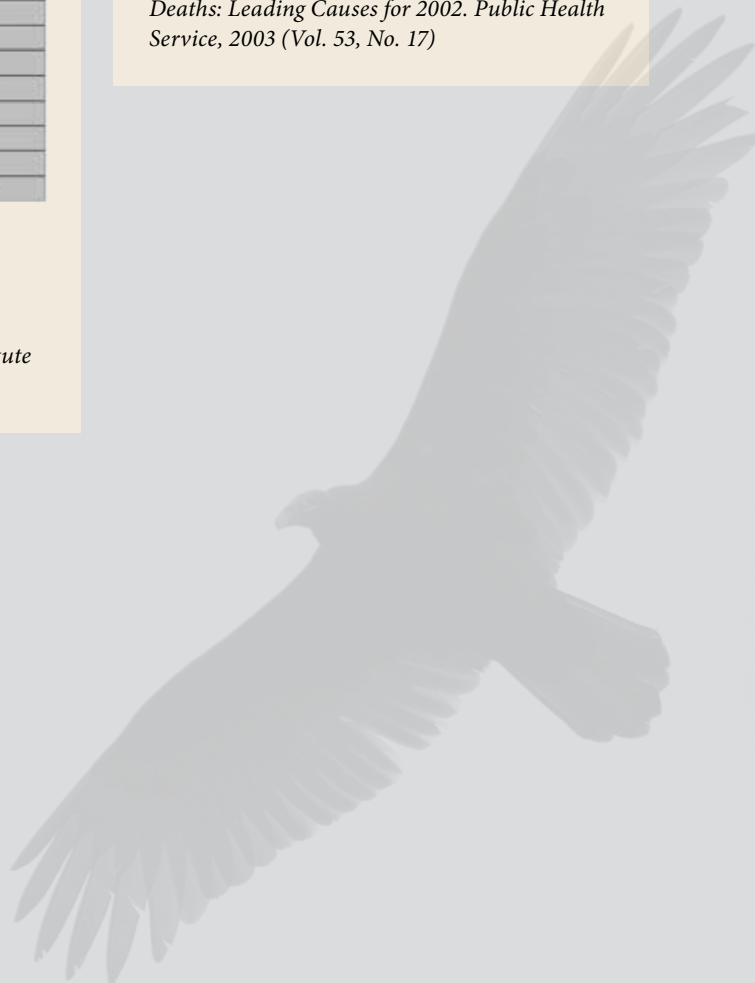
Source: CDC. *Deaths among Adults and Adolescents with AIDS by Race/Ethnicity, 1985-2004, United States*. Black AIDS Institute requested data.

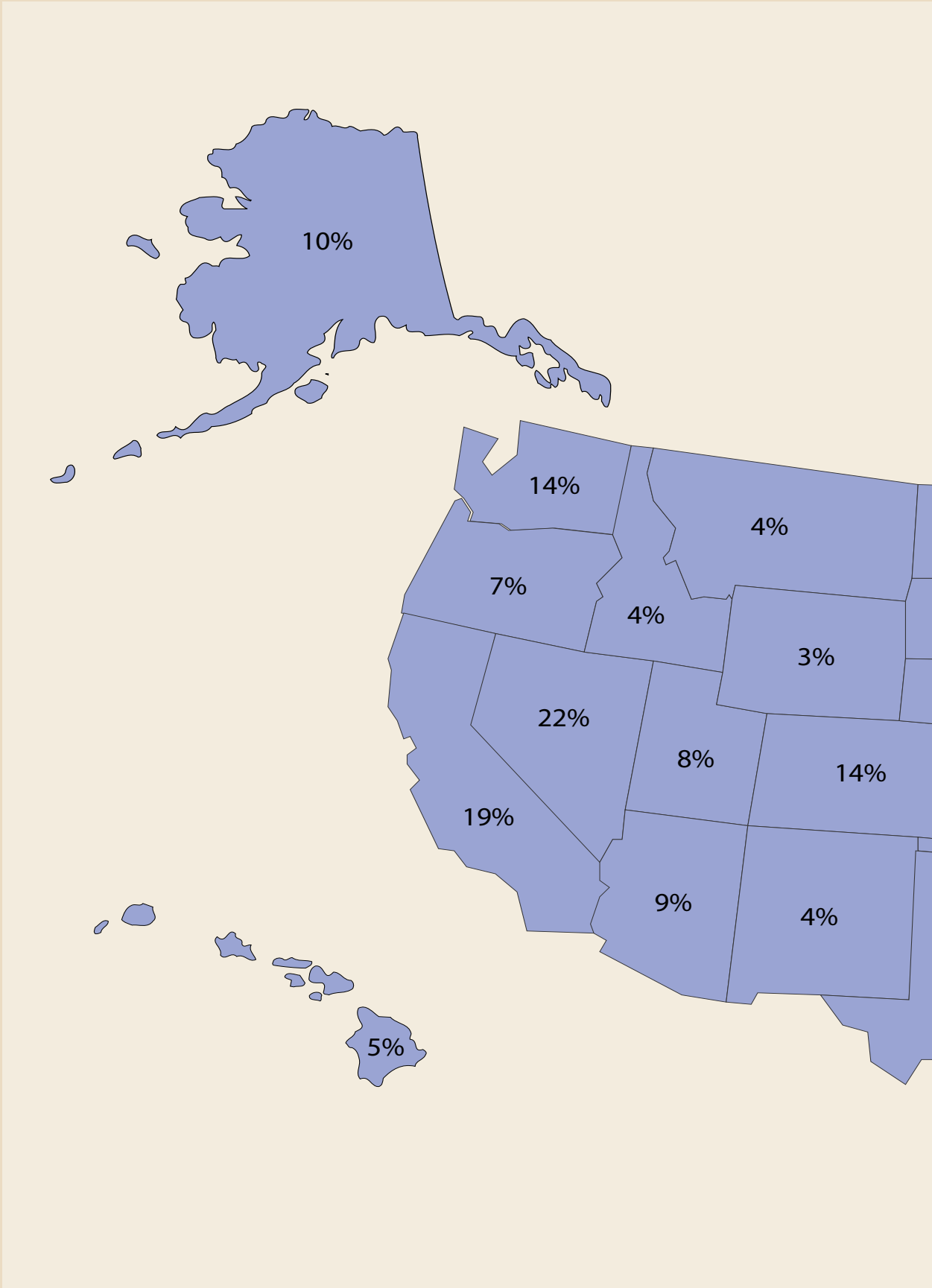
No. 2 Cause

Five Leading Causes of Death Among Blacks, Ages 25-44 (as of 2002)

1. Heart Disease
2. HIV Infection
3. Unintentional Injury
4. Assault
5. Malignant Tumors

Source: CDC. *National Vital Statistics Reports, Deaths: Leading Causes for 2002*. Public Health Service, 2003 (Vol. 53, No. 17)



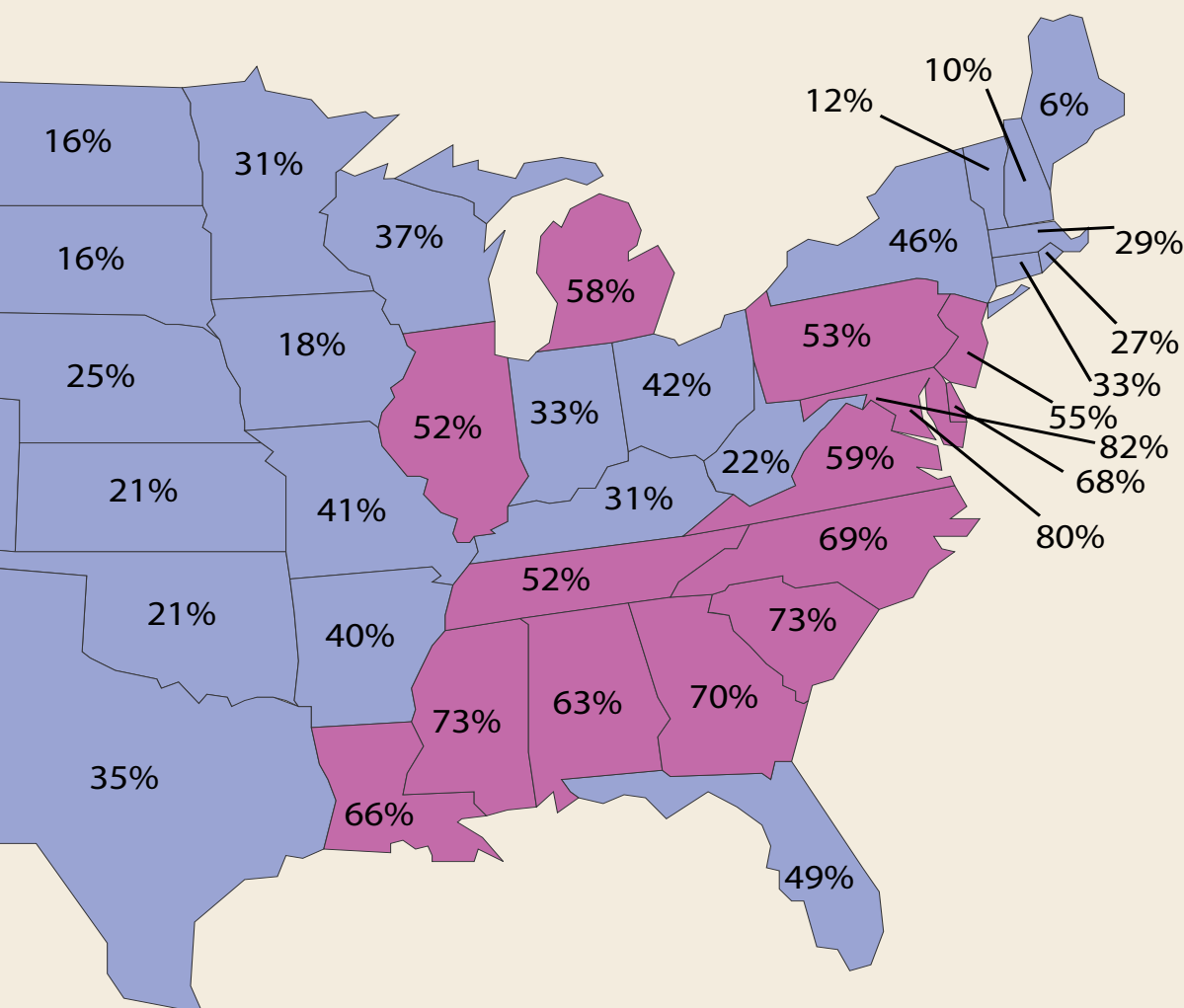




The National Picture: Black AIDS State-by-State

Percentage of people living with AIDS in each state who is African American, as of 2004. In 15 states, more than half of the population of people living with AIDS is Black.

Source: Statehealthfacts.org. All percentages have been rounded.





State-by-State Black AIDS Rates vs. Black Census Figures

	% of AIDS Cases	% of Black Pop.		% of AIDS Cases	% of Black Pop.
Alabama	63%	26%	Missouri	41%	11%
Alaska	10%	3%	Montana	4%	<1%
Arizona	9%	3%	Nebraska	25%	4%
Arkansas	40%	16%	Nevada	22%	7%
California	19%	6%	New Hampshire	12%	1%
Colorado	14%	4%	New Jersey	55%	13%
Connecticut	33%	9%	New Mexico	4%	2%
Delaware	68%	19%	New York	46%	15%
District of Columbia	82%	57%	North Carolina	69%	21%
Florida	49%	15%	North Dakota	16%	1%
Georgia	70%	29%	Ohio	42%	12%
Hawaii	5%	2%	Oklahoma	21%	7%
Idaho	4%	<1%	Oregon	7%	2%
Illinois	52%	15%	Pennsylvania	53%	10%
Indiana	33%	8%	Rhode Island	27%	5%
Iowa	18%	2%	South Carolina	73%	29%
Kansas	21%	6%	South Dakota	16%	1%
Kentucky	31%	7%	Tennessee	52%	16%
Louisiana	66%	32%	Texas	35%	11%
Maine	6%	1%	Utah	8%	1%
Maryland	80%	27%	Vermont	10%	1%
Massachusetts	29%	6%	Virginia	59%	19%
Michigan	58%	14%	Washington	14%	3%
Minnesota	31%	4%	West Virginia	22%	3%
Mississippi	73%	37%	Wisconsin	37%	6%
			Wyoming	3%	1%

Sources: Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention-Surveillance and Epidemiology, Special Data Request, November 2005. Urban Institute and Kaiser Commission on Medicaid and the Uninsured. Estimates based on the Census Bureau's March 2004 and 2005 Current Population Survey (CPS: Annual Social and Economic Supplements).

THE FOUR GETS

FOUR STEPS YOU CAN TAKE TO FIGHT AIDS IN YOUR COMMUNITY:

1 GET INFORMED. What you don't know *can* kill you. Knowledge is a powerful weapon against HIV/AIDS.

2 GET TESTED. The vast majority of Black Americans infected with the AIDS virus don't even know it. You can't protect yourself or your partner if you don't know your status.

3 GET TREATED. 70 percent of HIV-positive people in America are not in proper treatment and care. AIDS is not the death sentence it once was. Early treatment can prolong your life.

4 GET INVOLVED. AIDS is spreading through our communities because not enough of us are involved in efforts to stop it. There are many ways to get involved in the fight:

- Volunteer
- Make a donation
- Become a regular contributor
- Join a board
- Deliver a meal
- Talk to your neighbors, friends and family about HIV/AIDS
- Write a letter to your Mayor, Governor, the President



**Black Voices
ON AIDS**



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got AIDS?

The State of Prevention

Testing, Testing

Not long ago, getting an HIV test could be a real pain. Even after setting aside all the accompanying anxieties and fears and stigmas, it was just a hassle.

First, you'd come in for the test—and unless you went to a private doctor's office, this often meant an uncomfortable and nerve-racking wait in a lobby full of nervous people. Then you had to sit through a talk with an HIV counselor, who would ask all kinds of personal questions about what you'd done to put yourself at risk for contracting the virus. Then there was the poking and prodding with needles to draw your blood.

But that wasn't the end. There was still the agonizing wait—as long as two weeks—while your blood shipped off to a lab to get tested. Then you had to go *back* to the doctor or clinic and, once more, sit in a waiting-room purgatory before finally getting your test results.

It was a lot to deal with.

And a lot of people never made it through the process: The U.S. Centers for Disease Control and Prevention has long estimated that a third of all people who get tested never claim their results.¹

So for years, health departments and testing-technology developers have been working to ease this process. Gradually, new technologies have become available and, in turn, public health officials have adapted guidelines to streamline HIV testing in America. But in 2006, the CDC approved reforms that may represent the most significant overhaul of HIV testing the United States has ever seen.

The agency's move was greeted with a mixture of praise and damnation. Few challenged its overarching goal of making HIV testing an easily accessible, routine part of health care. But many, including the Institute, have questioned whether the CDC's initiative goes too far and, thus, misses a crucial point: testing is not a silver bullet to slay AIDS. Without a similarly robust commitment to the far broader and far more difficult prevention work needed to help individuals and communities make healthy choices, no amount of testing will stop the virus' spread.

Left page: Jimmy Jean-Louis (of the TV show "Heroes") at the 2007 BET awards.



How HIV Monitoring Works

In summer 2005, the CDC announced a multi-pronged plan to more closely examine its much-cited estimate of 40,000 new HIV infections each year. As a result, we'll be hearing a lot of new numbers in the coming years, some of which are bound to be controversial. With our minds on that proverbial demon lurking in the details, we give you a brief snapshot of how the CDC's gonna do its math.

What they want answered: How'd you get it?

How they'll answer it: The National Behavioral Surveillance System, already up and running, has generated one of the most shocking stats in the epidemic's history: 46 percent of Black men who have sex with men may already be infected, and two thirds of those folks don't know they've got it. The idea is to take a closer look at those who are most statistically at-risk, asking what they are doing and how they are interacting with services.

The system is tracking people who fit three behavioral categories: Men who have sex with men, injection drug users and what the prevention wonks have started calling "high-risk heterosexuals." Yes, the scintillating CDC jargon is distracting, but try to focus—this is the important part. In alternating 12-month cycles, researchers will focus in on one group and study their behavior, so that they'll get a fresh batch of information on each group every three years.

What they want answered: How many are infected each year and who are they?

How they'll answer it: The HIV Incidence Surveillance System is the agency's tool for getting past its annual 40,000-newly-infected estimate. CDC has chosen 34 sites around the country to focus on each year. In those places, researchers are drilling down on every newly-diagnosed infection to get,

among other things, the person's demographics and clinical info on that person's virus. Importantly, they will also run newly-developed tests to determine how recently the person has been infected.

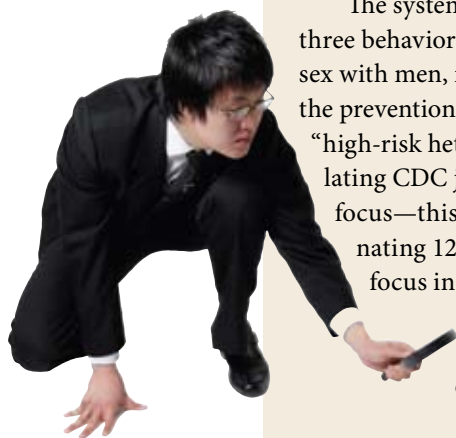
What they want answered: What's the total number of infected?

How they'll answer it: HIV Prevalence Estimates are nothing new. CDC takes data from the 33 states that track HIV by recording names of those infected, runs it through two statistical modeling processes (in order to factor in those who may be positive but have never been tested) and comes up with its total number. In June 2005, CDC updated the current estimate, saying between 1,039,000 and 1,185,000 Americans were living with HIV as of 2003, with anywhere from 24 percent to 27 percent of those folks unaware they're infected. It is the first time CDC has put the positive tally above one million.

The AIDS Case Surveillance system will continue to be a tool for building this sort of big-picture data. This is the original surveillance system, which tallies the number of newly diagnosed AIDS cases and deaths reported by all states each year. As of 2003, around 400,000 of the one million HIV-positive folks had an AIDS diagnosis.

What they want answered: If you're positive, how are you doing in treatment?

How they'll answer it: The Morbidity Monitoring Project will not only tell CDC how people are faring in treatment, it will also figure out what's happening to those who are not in care. Why aren't they getting treated? And are they doing something harmful to themselves—or others—in the meantime? Researchers have selected 26 sites in 21 states from which to pull medical records of those in care and ask some questions. They will also interview both people who are in care at those sites and those in the area who are not.



Check Everybody

The federal government maintains a wide range of official public health guidelines that, while not legally binding, offer care providers detailed recommendations on how a given procedure should be handled and carry the weight of the government's approval—which, in some cases, is needed to access federal funding. There are guidelines for stuff ranging from diagnosing fetal alcohol syndrome to prescribing anti-HIV medicines. And since 1985, there have been guidelines for how HIV tests should be conducted. In September 2006, the CDC completed a rewrite of those guidelines as part of its ongoing campaign to boost the number of people who know their HIV status.² (See “Standardized Testing Revisited” on page 26.)

The percentage of American adults who have gotten HIV tests in their lifetime has steadily grown since 1987, according to surveys. However, the share of adults who have been tested in the previous 12 months has slowly declined since 1996, when life-saving drugs hit the market and reports about the epidemic's supposed end became widespread.³ Today, CDC estimates as much as one quarter of the 1.2 million people believed to be HIV positive don't know they are infected.⁴

Data strongly suggests that these quarter million undiagnosed infections fuel the estimated 40,000 new infections logged in the U.S. each year. The CDC has long cited studies showing once people know their HIV status, they are overwhelmingly likely to take steps to prevent passing it on to their sex or injection drug-using partners.

Research shows more African Americans are getting tested than whites—41 percent of Blacks in a Kaiser Family Foundation survey report having been screened in the past 12 months, compared to 16 percent of whites.⁵ But CDC nonetheless estimates that more

than half of all infections among African Americans remain undiagnosed.⁶

Blacks also appear to be at greater risk for getting tested too late, uncovering the virus only in the final stages of its development towards full-blown AIDS. Forty-two percent of positive Blacks are diagnosed within two months to a year of the infection developing into AIDS.⁷ Once an infection reaches this endpoint, treatment is far less likely to succeed, a fact which CDC surmises is at least part of the reason for the American epidemic's racial death gap. African Americans who contract HIV are now as much as eight times more likely to die from it than their white counterparts.⁸

One reason for delayed testing is that people don't think they are at risk. Indeed, mounds of research show just how safe many believe themselves to be, even when they're not. In one CDC study, 60 percent of Black women didn't know whether their male sex partners were positive or negative, yet 70 percent believed themselves to be risk-free.⁹ This assumed security exists despite the fact that Blacks account for nearly 70 percent of new HIV infections among American women. (See “The Black Epidemic: By the Numbers” on page 8.)

The perceived lack of risk runs even higher among self-identified Black gay and bisexual men. In one study, nine out of 10 young men who tested positive didn't consider themselves to be at risk for contracting the virus.¹⁰

In order to right all of these wrongs, the CDC has set about an aggressive campaign to promote testing over the last several years. The revised guidelines are a major component of that push. “The overarching goal is to maximize opportunities for those persons who are currently unaware of their HIV infection to learn their HIV status earlier,” the CDC's Bernard Branson wrote in a March 2006 letter requesting public comment on the new guidelines. He cited studies that

show “with current HIV testing practices, many persons with unsuspected HIV infection currently access health care services, but because they are not tested, their infection goes undiagnosed.”

That’s in part because doctors and patients alike have long engaged in a dizzying and often self-defeating game of trying to determine who should and should not get tested. The CDC’s new guidelines dramatically simplify the formula: Anybody between the ages of 13 and 64 who comes into care should be offered an HIV test.¹¹ Period. No more guessing about who is more or less at risk, reading the tea leaves of their sexuality, their race, their neighborhood or job. Just test everyone. Further, the test is to be made a standard part of the bevy of prenatal tests

given to pregnant women. These aspects of the new guidelines have received near-universal praise.

Making It Too Easy?

But the CDC didn’t stop with universal testing. The new guidelines go on to make two far more controversial changes to the testing procedure.

First, the guidelines shift the burden of consent from the doctor to the patient.

Previously, patients had to expressly agree to an HIV test and sign a written waiver declaring their consent. That precaution grew out of real need: After HIV tests were first developed in 1985, patient advocates



Standardized Testing Revisited

In September 2006, the CDC issued its new guidelines for health care providers conducting HIV tests. The new guidelines aim to get more people into testing by streamlining the process, and they mark a dramatic shift in how HIV testing is conducted in America. Here are the big changes:

Everybody gets tested. For years health care providers and patients alike have groped for a reliable formula to determine who needs to get tested when. The old rules urged testing for certain “high-risk individuals”—injection drug users, people who have anal sex, etc.—and in geographic areas that have higher HIV prevalence. The new guidelines toss all of these maddening calculations out. Now, the CDC says, everybody aged 13 to 64 who comes in to a health care facility should be given HIV tests as part of their routine medi-

cal care.

It’s on you to say no. Because of the stigma associated with HIV and the discrimination that was rife when HIV tests first became available in 1985, public health has always gone out of its way to soothe the anxieties of people getting tested. So for years health care providers were urged to obtain explicit, written consent before testing someone for HIV. But providers complained that this process was cumbersome and expensive, particularly in emergency rooms. So now, the CDC says, getting the patient’s consent for providing care in general covers HIV testing, too, although, patients should still be informed that they’ll be tested in advance, so that they may turn it down if they wish.

Seek counsel elsewhere. HIV testing has always been closely linked with HIV prevention counseling. Whenever someone got tested, he or she first spoke with a counselor about HIV risks and how to reduce them. But, again, providers fretted that this process proved unwieldy for their operations and, moreover, discouraged people from getting tested. So while the new CDC guidelines still stress the import of counseling, they no longer urge that it be part of the testing process.

justifiably feared discrimination. They sought and won a range of protections, including not only strict consent procedures but also limits on how health departments tracked HIV infections.

The new guidelines signal federal officials' belief that we've entered a new era. Now, simply agreeing to overall health care is sufficient consent for an HIV test, and that consent need not be obtained in writing. Patients should be notified they will be tested beforehand, so that they have an opportunity to opt out of it if they chose, but the burden is on them to do so.

Second, and perhaps even more controversial than the consent changes, the CDC's new guidelines break the longstanding marriage between testing and counseling. All of those difficult conversations you once had to sit through before and after getting a test were the result of the old CDC recommendations. They urged that anyone getting an HIV test also be offered HIV-prevention counseling sessions designed to determine the person's risk; to offer prevention information; and to discuss the meaning of the test's outcome, whether it be positive or negative. While the CDC continues to urge that patients have access to such counseling, it no longer recommends that it be linked to the testing process.

The CDC's recommendations are not legally binding upon state and local laws and regulations, but they heavily influence how local officials design their own rules, in part because of the implicit threat of jeopardizing federal funding by failing to comply. Some states have already begun altering their procedures. Most notably, New York is debating many of the same proposals, with health officials from the administration of New York City Mayor Mike Bloomberg aggressively pushing new state laws mirroring the CDC's proposed new guidelines.

But critics argue that consent and counseling requirements are key steps in the

testing process because they help counter one of the epidemic's most lasting prevention problems: Stigma.

Battling Stigma

Stigma surrounding HIV remains strong in many Black communities in particular, and those that have opposed streamlining the consent and counseling processes fear it will actually worsen the problem. They argue that by stripping away consent precautions, whether they be needed to protect against discrimination or not, public health risks driving people away from testing altogether. It's not an irrational concern. Particularly in the South, service providers continue to report patients being so fearful of stigma that staff must answer phones without using the word AIDS, hand meds out of clinic back doors, and arrange clandestine off-site rendezvous in order to perform discreet HIV tests.

Moreover, critics argue, weakening the counseling guidelines wastes a chance to battle stigma. That's because counseling serves not only to prepare patients for the test results, but also to educate them about the basics of HIV prevention and treatment. Particularly among African Americans, HIV literacy remains dangerously low—and that illiteracy both fuels stigma and blocks individuals from taking action to get healthy. The National Association of People With AIDS' Paul Feldman told Housing Works' *AIDS Issues Update* that changing the guidelines "misses a golden opportunity" to fix that problem.

"HIV continues to be highly stigmatized," says Feldman. "An HIV test is not like a basic blood count or other lab tests. The results can be life changing, and people need to know what they're getting themselves into. A general consent that you sign at the front desk on the way into the hospital or doctor's office does not do the job."

For its part, the CDC counters that “routine” HIV testing is just what’s needed to fight stigma. By making the test a regular part of receiving health care rather than ghettoizing it, the agency argues, providers chip away at fears that drive stigma of both testing and the virus itself. (See “Q&A: CDC Explains Its Testing Reforms” on page 30.)

New Challenges

One aspect of the broader testing push that everyone’s concerned about is whether we’re at all prepared for what will happen if it succeeds. There are real questions about whether the AIDS care safety net can even continue to serve those already in it, let alone absorb tens of thousands of new cases unearthed by more aggressive testing.

“One of the things that this program will do is identify people, but it is not really addressing the shortage of experienced and knowledgeable clinicians to take care of you once you find out you are positive,” warned Dallas’ Dr. Keith Rawlings, medical director of the Peabody Health Center. “I think that is an issue—particularly in the Black community—that we need to be looking at.” Additionally, Rawlings notes, “Once you get to an experienced clinician, you need the medication. If you can’t get to the medication or can’t afford the medication, you are not going to get the particular outcome you want.”

The CDC’s also not alone in its drive to make HIV testing easier and more accessible. Drug makers and medical device manufacturers are onboard as well, developing and refining their technologies for the brave new world of HIV testing.

Today, oral swabs have largely replaced painful needles for HIV testing. And now, through a technology known as “rapid testing,” those swabs can crank out HIV test results right before your eyes, in much the same way as a pregnancy test.

Since the first rapid HIV tests won Food

and Drug Administration approval in 2003, they have done their own part to drastically reshape the testing experience.¹² Nowadays, when you go for an HIV test you will likely be handed a stick with a cotton swab attached to the end (not unlike a Q-Tip), which you will then be directed to wipe across your gums. The technician places the wiped swab in a solution and waits for results. Twenty minutes later, a color-coded reading indicates whether you’ve contracted the virus. (If the rapid test indicates you have the virus, a confirmation test must be done the old-fashioned way—drawing blood and sending it off to the lab.)

Rapid tests are addressing one of the most glaring problems in HIV testing: the once-lengthy wait between taking the test and getting the results. Because an estimated third of those who took the old blood test didn’t voluntarily come back to pick up their results, a quarter of all positive test results never got delivered.¹³

Now, one of the leading makers of rapid test kits, OraSure Technologies, is seeking FDA permission to sell its test, OraQuick, over-the-counter. If ultimately given the go ahead by the FDA, the OraQuick test will be the first HIV test the FDA has approved to be administered entirely without a healthcare provider. According to news reports, OraSure plans to petition the FDA after completing a series of clinical studies scheduled through 2008. Among other things, those studies are examining how to link consumers with mental health services if they test positive.¹⁴

Medical device makers have been trying to sell HIV tests over-the-counter since the beginning of the epidemic. The FDA first nixed the idea as far back as 1988. And in 1996, the agency actually approved two home tests, but both products required customers to draw blood and send it in to a lab, waiting a week or more for results.

Critics of take-home tests have always

lodged many of the same complaints they have directed at the CDC's new streamlined testing guidelines—primarily, finding out you're HIV positive, even 25 years into the epidemic, is not the same as discovering you're pregnant or being diagnosed with any other disease.

HIV is still associated with other equally loaded and socially divisive issues—such as sexual orientation, spousal fidelity and drug use—and the medical realities of the virus remain widely misunderstood. By allowing people to learn their HIV status alone and without any trained health providers to educate and support them, not to mention connect them with appropriate care, home HIV tests could create as many problems as they solve.

The challenge of today's testing push, then, is how to make it widely accessible without stripping it of meaning. Knowledge is power, but only if you have the tools to use it.

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Q&A

CDC Explains Its HIV Testing Reforms

Kevin Fenton has been the director of the CDC's National Center for HIV, STD and TB Prevention since November 2005. As a Black gay man, he knows too well the stakes of the epidemic he's working against. He spoke with the Black AIDS Institute in January 2007 to explain how and why the CDC has changed its recommendations for HIV testing in America.

What are the new guidelines setting out to achieve?

What we're really recommending is that all Americans aged between 13 and 64 years should be aware of their HIV status. So the guidelines put into place structures for facilitating this.

And what is at the core of those structures?

The guidelines call for voluntary screening of everybody between the ages 13 and 64. It calls for all patients to be informed that an HIV test should be a part of the routine diagnostics, and that they should have a clear option to decline. The recommendations also simplify procedures to obtain consent for testing as part of

routine care. It says that basic information should be provided on the test and the risks and how to avoid infection. And finally, it focuses on counseling for individuals who test HIV positive, to ensure that those individuals are linked to treatment and services.



Why test everybody? Why not say who is more or less at risk?

There are two reasons why we are moving away from offering HIV tests based on risk.

The first is really from a providers' perspective. Often times it's really difficult for a provider to truly assess if an individual is at risk, in part because discussing some of the issues regarding risk is very sensitive, and in the context of a clinical consultation there may not be enough time to share or explore this information. And many studies have shown individuals are less likely to divulge true risk to their practitioners, especially if they feel like this might be stigmatized behavior. Or that their physicians may judge them.

The second reason why moving away from risk is important is that it really begins to bring HIV testing into the routine health care of all individuals, whether they're sexually active or not. So in the same way that individuals have their blood checked or have their urine checked for diabetes as part of their general health care, so too our hope is HIV testing over time will become more routine and part of the package of health screening that individuals do.

And what's gained by it becoming part of the routine?

It's absolutely vital when we think about the current HIV/AIDS epidemic in the United States.

Currently, we know that there are more than a million people living with HIV and a quarter of these individuals remain undiagnosed. And we know that those who are undiagnosed are more likely to be of a minority background; they're more likely to be young, especially young men who have sex with men; and they're more likely to be heterosexual minorities, as well. So we know that there are a number of people who are HIV infected but who are unaware of their

status. So all of our efforts must really be geared toward encouraging earlier diagnosis of HIV, to link those people who are HIV positive to HIV care, and for those who test negative to use the opportunity to reinforce messages around safer sex, prevention and protecting themselves and their loved ones against acquiring HIV infection.

So it's really important that as we think about the next few years—we're now 25 years into the HIV epidemic—as we think about the next five and ten years, we really need new strategies to meet the new challenges.

You mention that minorities are more likely to be undiagnosed. Why?

Part of it may reflect higher prevalence of the disease.

Importantly, though, undiagnosed infections may also reflect differential access to testing services. It may also reflect different attitudes toward HIV testing. People may have good access to HIV testing services but do not want to have their HIV status diagnosed, because of fears of discrimination, fears of having to disclose to sexual partners or to family members, or the stigma associated with being diagnosed HIV positive. People may not want to deal with that.

One of the criticisms of the new plan is the part about simplifying the consent. People say that given the stigma, don't we want to make sure people know what they're getting into? Speak to the reasons for simplifying the consent process and why you're not concerned about it being a problem.

We held a number of consultations with a wide range of stakeholders, and we looked at some of the barriers to HIV testing as it exists today. And some of the most common barriers were that physicians consistently reported that the requirements for separate consent and pretest counseling really posed

major barriers for them undertaking an HIV test.

Other studies really showed that patients in fact do prefer to have an opt-out approach to consent, because we're offering an HIV test to everyone and there's no finger pointing, as it were. Patients can feel like this is just a general health check.

So contrary to some of the criticism, your studies show that people say, "I want it offered to me, because if it's offered to everybody then I don't feel like I've been singled out."

Absolutely. And there've been other studies that show that differential consent procedures are probably unnecessary now, 25 years into the epidemic. More people know about HIV. They know that there are effective treatments for HIV. It's not like the beginning of the epidemic, where we knew so little. People

are starting to see benefits to getting tested and knowing their HIV status.

But I do want to underscore that we are not doing away with consent, and we are not saying that individuals should be tested without their consent. In fact, the guidelines make it explicitly clear that individuals who are HIV tested must be done so with their full knowledge. So this is not about testing individuals without their consent. But what we're doing is insuring that the consent procedures are rolled into the part of obtaining general consent for health care, and there's not a separate or explicit consent for HIV testing.

Why are the guidelines pulling away from the link between counseling and testing?

Just to be clear, these recommendations are for clinical settings.



And spell out what you mean by that distinction.

The recommendations really are for emergency departments, for infectious disease clinics, for STD clinics—for clinical settings. They're not for testing which may be undertaken in community settings, for community-based organizations doing work in local communities. We are revising our guidelines for those settings and recommendations will be produced for those settings subsequently.

But to get back to your question about counseling, as I said earlier, evidence suggests that counseling for individuals who test HIV positive has been demonstrated to be effective in terms of assisting in reducing risk behaviors, facilitating partner notification, and making sure those individuals who are HIV positive are linked to care.

Evidence of the effectiveness of counseling for individuals who test HIV negative is less robust. And the impact of the counseling may not be as long lasting for the individuals who test HIV negative. The guidelines however do state that individuals who are high-risk and test HIV negative could still benefit from prevention counseling, in order to prevent them from acquiring new STIs or becoming HIV positive in the future.

So what we're really trying to do is, yes, unlink the counseling from the testing, but secondarily ensure that the counseling is applied to where it is most effective.

But why is that change necessary?

In a recent study 76 percent of professionals in emergency departments reported never or rarely encouraging HIV testing. And among the reasons were lack of qualifications for counseling and that they felt the process was too time-consuming. So three quarters of persons said, "Listen, I know this person could benefit from an HIV test, but I really can't do it because it's too time-consuming, because of the counseling and the

need to have specialist training, etc."

So if that is the case, we are missing a number of individuals who are passing through our doors day in and day out and are not being able to access HIV testing. So now with these revised recommendations, what we're really doing is encouraging HIV testing and ensuring that counseling is applied to those who are in greatest need—either those who test HIV positive or those who have high risk behaviors who would benefit from intensive counseling.

Are you concerned about success? If the goal is to get more people tested, what about having the capacity to get care and treatment for these people?

Whichever way you look at it, we're going to have to deal with this epidemic in real ways. If we have 250,000 people in our population who are undiagnosed, then they are at very high risk of transmitting that HIV to others. And so therefore the long-term costs of not diagnosing these are going to be tremendous, because of all the transmission of the disease and the high cost of being diagnosed late.

So, yes, in the short term it may be that there will be costs associated with higher numbers of HIV testing and higher numbers of individuals who are diagnosed with HIV. But once these individuals are diagnosed, then the benefits of early diagnosis will accrue.

So I think we need to unpack the different things that are going on. One question is: Is this a cost-effective strategy? Yes it is because of the benefits of early diagnosis. Will this result in immediate pressures on the system? It will. But the hope is that by doing this and by demonstrating the effectiveness of this, this will be another tool for us to encourage greater investment into HIV and AIDS in the United States.

Left page: Bruce Gordon (then CEO, NAACP), Roslyn McCallister Brock, (Vice President, NAACP Board), Julian Bond, (Chair, NAACP Board) take HIV test at NAACP convention, while Twana Tibbs (Mrs. Gordon), Willis Edwards (Board Member, NAACP), Actress Sheryl Lee Ralph (Board Member, Black AIDS Institute), Phill Wilson (Executive Director, Black AIDS Institute) and Pamela Horowitz (Mrs. Bond) watch in background.

Next page: Henry Simmons (of the TV show "Shark"), Vanessa Williams (of the TV show "Soul Food") and Robi Reed (casting director and producer) take HIV test in connection with SAG and AFTRA on June 25, 2007.







The State of Treatment

A Domestic Crisis

They were needless, nameless deaths. And of the hundreds of thousands of people who died from AIDS worldwide in 2006, they were among both the least expected and most predictable: In November 2006, South Carolina's health department confirmed that four people had died while waiting for access to AIDS treatment.

These people didn't die in some poor country on the other side of the globe, where expensive medicines and support systems don't exist. They died right here in the United States, where we spend nearly \$2 trillion a year on healthcare, and where many consider the epidemic to have ended ten years ago.

Thousands of people still die of AIDS in the U.S. every year, under a wide range of circumstances. Certainly, none of those deaths have to occur, given what we know about preventing infection in the first place and treating it once it happens. But these four deaths were particularly appalling because they appear to represent people who were taking the necessary steps to live—and had turned for help to the very system we set up to stop AIDS deaths in America. They stand as damning evidence that the system is broken.

Public information about the four lives

lost in South Carolina is scant. But what we know is enough to shame the nation. We know they neither qualified for Medicaid nor had enough resources to buy health insurance on their own, and we know that put them among the ranks of an estimated 47 million uninsured Americans.¹ We know they were stuck on a hundreds-deep waiting list for the state-run program that subsidizes HIV meds for the uninsured.² And we know that this waiting list, like the deaths it spawned, was neither a secret nor a surprise to the policy-makers who go on allowing it to persist today.

In fact, at the time South Carolina confirmed the deaths, it was among six states in which uninsured people with AIDS were waiting to get into the local AIDS Drug Assistance Program (ADAP).³ These programs, which are jointly funded by federal and local money but administered by each state, were created in 1990 as part of the Ryan White CARE Act—the nation's first comprehensive response to the AIDS epidemic. They subsidize for low-income, uninsured patients the cost of wildly expensive antiretroviral drugs, which can run up to \$20,000 a year for just one pill in a combination of meds needed to stave off death.

“The meds are only half of it—poor people living with AIDS work until they’re too sick to work anymore,” South Carolina AIDS activist Stephanie Williams told the Housing Works newsletter *AIDS Issues Up-*

date. “They’re living in substandard housing or going back to live with mom and dad. Parents are dying, and old folk are raising their grandkids and great grandkids. This affects whole communities, and the federal government must fully fund the Ryan White CARE Act to even begin solving the problem.”

Sadly, AIDS safety net watchdogs have been saying that same thing since 2001—and Washington has yet to listen.

Pennies from Washington

Ever since the advent of the “AIDS drug cocktail” in the mid 1990s, the ADAP program has struggled to keep up with demand.

Antiretroviral drugs don’t provide a cure, but they do keep people alive—and, therefore, in ongoing need of expensive medicines and services. So with new infections still coming at an estimated 40,000 a year and those already infected living longer, the ranks of Americans living with HIV/AIDS has swelled to an estimated 1.2 million people, according to the U.S. Centers for Disease Control and Prevention.⁴ Those who can’t pay for their own meds land in Medicaid and ADAP, and both programs grow weaker every year as state and federal funding fail to keep pace.

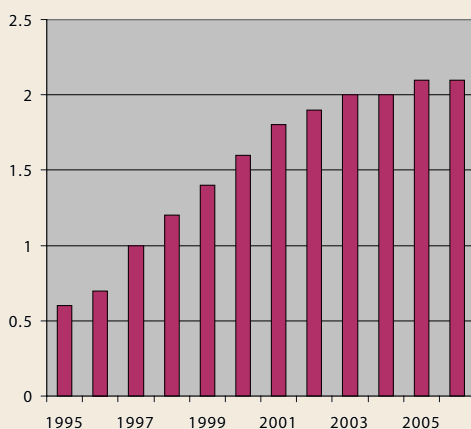
According to the National Alliance of State and Territorial AIDS Directors, the \$1.4 billion a year program spent more than \$100 million on AIDS drugs in June 2006 alone.⁵ Year after year, states run out of resources and implement a host of cost-cutting measures—creating waiting lists for services, boosting income caps for qualifying, restricting medicines that are available.

Waiting lists have been particularly persistent in states in the South, where a burgeoning epidemic continues to outpace both state and federal response. As of March 2007, South Carolina still had 463 people on

Falling Behind

Since 2001, the federal AIDS care budget has failed to keep pace with the epidemic. The Ryan White CARE Act is the primary federal vehicle for funding AIDS care programs, supporting services ranging from support groups and mental health counseling to drug rehab. But while federal health monitors announced in 2005 that there are more Americans living with HIV or AIDS than ever before (over a million), Congress has kept the Ryan White budget essentially flat since 2003.

Ryan White CARE Act funding, fiscal years 1995 to 2006 (in billions):



Sources: Kaiser Family Foundation. *Trends in U.S. Government Funding for HIV/AIDS, Fiscal Years 1981 to 2004*. Fig. 4. March 2004. And, U.S. House of Representatives, Appropriations Committee. *Highlights of the Fiscal Year 2006 Labor, HHS, Education & Related Agencies Appropriations Conference Report*. Nov. 16, 2005.

its waiting list.⁶ In previous years, states like Alabama, North Carolina and Kentucky have been standouts for lengthy waiting lists.⁷ In 2004, the number of HIV positive Americans in line to get drug assistance through ADAP topped 1,600.⁸

The program is uniquely relevant to people of color, who account for almost two-thirds of its clients; 33 percent of ADAP clients are Black.⁹ And most enrollees live both in deep poverty—more than 80 percent had incomes at or below 200 percent of the federal poverty level in 2006—and in real danger of getting sick—half had CD4 counts at or below 350,¹⁰ the point at which federal treatment guidelines recommend patients begin considering treatment.

ADAPs around the country are jointly funded by federal and state coffers, and as the federal money has failed to keep pace with the epidemic, many states have been unable or unwilling to make up the difference. States decide for themselves how much money to kick in to their programs to augment the federal allotment, and the amount varies greatly. Overall, the state contribution is by far the fastest growing share of the budget, but some of the states with the biggest ADAP crisis are as lax as Washington in funding the program. South Carolina, for instance, contributed a mere \$500,000 to its struggling \$15 million program in fiscal year 2005. Indiana, another state that has had waiting lists, didn't contribute a dime to its \$7.2 million ADAP.¹¹

But ADAP's troubles are part of larger problems with the AIDS safety net. The CARE Act, which governs not just ADAP but a range of care and support services for low-income and uninsured patients, has similarly fallen into disarray in the 21st century. Since 2001, the Ryan White CARE Act budget has grown by a mere \$300 million, to \$2.1 billion in fiscal year 2006.¹² As of January 2006 we were spending \$200 million a day on the war in Iraq, according to the Congressional Budget Office—which means the monthly

war budget nearly tripled what we spent on AIDS all year.¹³

Meanwhile, the U.S. government estimates an additional 200,000 Americans have contracted HIV since 2001. (See “Falling Behind” on page 38.)

Fighting Over Scraps

In addition to allotting money for the CARE Act each year, Congress must re-approve the entire program every five years, updating it to make sure it continues to meet the epidemic's current realities. Rarely has the AIDS community found itself as divided as it has been surrounding the most recent CARE Act update, which was completed in the final hours of the outgoing Republican Congress in late 2006.

Southern AIDS service providers have argued that Ryan White must be drastically rewritten to remove a built-in bias that funnels money to the large metropolitan areas where the epidemic began. Today, they note, 41 percent of people living with HIV/AIDS reside in the South; in 2004, Southern states boasted 7 of the 10 highest rates of AIDS cases per capita, nationally.¹⁴ And the South's burgeoning epidemic is uniquely Black. All told, eight of the nation's 10 Blackest epidemics are in states in the South, at least in part due to the region's racial demographics.¹⁵

Those southern states are clearly struggling to keep up with the building crisis. In addition to ADAP waiting lists, southern states often have far too few care providers to meet their epidemics' unique dynamics. The dispersed geography means people often must travel across counties to find an AIDS service provider for counseling, medical care, substance abuse treatment and other services. Clearly, these states need greater help from the federal government in combating this epidemic. Access to quality AIDS care should not depend on where you live in a nation as wealthy as ours.



How the Safety Net Works

Public funding for HIV/AIDS services in the U.S. comes from both federal and state coffers, and is spent at the city level. State money is added to an annual allotment dished out by the feds through the Ryan White CARE Act. Unlike most social safety net programs, the CARE Act is not an entitlement program, which means it is budgeted in one lump sum payment that must be renegotiated every year. Since the Bush administration took office, CARE Act funding has failed to keep pace with the rapidly expanding epidemic. Since fiscal year 2003, in fact, the CARE Act's budget has remained largely flat.

The CARE Act is divided into several "titles," with the bulk of the money spent on Titles I, II and III.

TITLE I pays for a range of emergency support and medical services, including primary care, mental health, cash assistance, case management and more. The CARE Act divides the nation into 51 major metropolitan areas, and disperses these funds to community boards that work with local health departments to spend it.

Title I money funds nearly three million health care visits a year. **About two-thirds of the people who use these services are people of color and nearly a third are women.**

In FY2004, Washington cut funding for this title of the program, causing several metropolitan areas to restrict access to some

services, scale back the scope of others, and simply stop offering others altogether. The FY2005 budget flat-funded this title, leaving the previous year's budget cuts in place.

TITLE II funds states to provide treatment for people with AIDS who are uninsured, including paying for the AIDS Drug Assistance Program, or ADAP. **More than 30 percent of people with AIDS who are in treatment are paying for it through ADAP, and 60 percent of those people are of color.**

Three quarters of the money states use to pay for this treatment comes from Title II. And every year since the discovery of combination therapy states have faced funding shortages, in many cases leading them to limit or discontinue services.

TITLE III directly funds over 300 community-based clinics and health services centers in 41 states, plus Washington, D.C., Puerto Rico and the Virgin Islands. These funds are meant to support health care providers that are working in communities with the greatest risk for HIV—Black neighborhoods, low income areas and among women. But this title is also the primary route for funding services in rural areas; half of the grantees work in rural communities. **Seventy percent of their clients are people of color.**

In addition to providing healthcare, Title III clinics test more than 400,000 people for HIV every year.

At the current funding level, 30 percent of the agencies funded by Title III say they are unable to provide services to everyone seeking them, according to a survey conducted by the CAEAR Coalition.

Source: The CAEAR Coalition, an umbrella organization representing AIDS service agencies funded by the Ryan White CARE Act.

The White House and many congressmembers have signaled their support for such reforms, and proposals floating in both the House and Senate during the 2006 CARE Act debate would have reshaped the program to funnel more money to rural areas.

New York Sen. Hillary Clinton angered many AIDS service providers and activists in southern and rural states by blocking those proposals, arguing the reforms would have dangerously cut New York's funding. Members of New York's House delegation

echoed Clinton's concerns, as did a chorus of congressmembers from other states with old epidemics, such as Illinois and California.

Sen. Clinton and her colleagues are right to insist that help for rural states not come at the expense of the large metropolitan areas that have spent decades working to bring their own epidemics under control. AIDS service providers in places like New York City, Chicago and Oakland are having just as much trouble keeping up with the grimly growing demand for their services as those in the rural South.

But the dilemma these two realities present is a false one. It is possible to meet both new and old challenges—our government has simply chosen not to do so. Ultimately, no matter how the Ryan White CARE Act gets rewritten, it will fail to meet the needs of people with HIV/AIDS all over the country if it is not adequately funded.

The Compromise Plan

Senators Ted Kennedy (D-Mass.) and Mike Enzi (R-Wyo.) stepped into the CARE Act debate in the eleventh hour to hammer out a compromise plan for its reauthorization. The compromise bill reauthorized the CARE Act for just three years, rather than the usual five, and set in motion a process for a thorough review of the program's structures.

The bill assuaged the concerns of states with older epidemics by ensuring that all states must maintain at least 95 percent of their 2006 funding levels over the next three years. It also eased the fears of some states about a new mandate that federal money be handed out based solely on data collected by recording the names of those who test HIV positive, as opposed to using a coded identifier. The compromise bill gives states a penalty-free transition period for moving from coded identifiers to name-based systems.

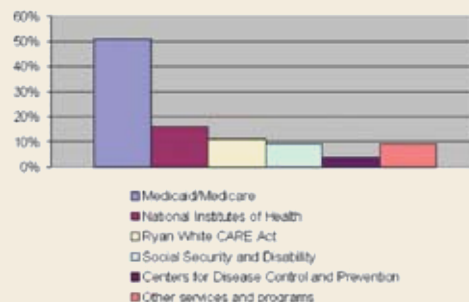
But most importantly, the compromise

bill opens the door for a thorough re-examination of the CARE Act. In January 2007, Kennedy's office began a series of forums and hearings on the CARE Act. Kennedy's office has said it wants to hear from "regular people living with HIV/AIDS" about how the system has and has not worked for them, and that it wants to explore how the CARE Act interacts with other healthcare safety nets, such as Medicaid and Medicare.

Slicing Up the Money Pie

The biggest slice of the federal HIV/AIDS budget goes to Medicaid and Medicare, which account for about half of all the money Washington spends on the epidemic. Here's how the \$17.8 billion allocated in fiscal year 2006 was split up.

Medicaid/Medicare: 51%
National Institutes of Health: 16%
Ryan White CARE Act: 11%
Social Security and Disability: 9%
Centers for Disease Control and Prevention: 4%
Other services and programs: 9%



Source: Presentation by Deborah Parham Hopson, HIV/AIDS Bureau of the Health Resources and Services Administration at Black AIDS Institute briefing, October 13, 2006. Washington, D.C.

Medicaid's Maladies

Medicaid, which shelled out \$6 billion for AIDS treatment in fiscal year 2006,¹⁶ is in its own state of crisis.

Medicaid is the national program designed, as part of Lyndon Johnson's 1965 Great Society, to keep America's poor healthy. Since the early 1990s, progressives have sought to expand it, conservatives have worked to erode federal control over it, and everyone has groped for ways to keep it from bankrupting state governments. Medicaid

expenditures at all levels of government have exploded in the last 15 years. States now spend, on average, 17 percent of their budgets on Medicaid (making it second only to education as a money grubber).¹⁷

State governments are groping for ways to reign in these costs. Though there was evidence of some easing in the budget crunches in fiscal year 2006—Medicaid spending grew by less than three percent, the slowest growth since 1998—all states instituted cost-cutting measures.¹⁸ As Kaiser Family Foundation Executive Director Diane Rowland put it, "This news that revenues are up a little and that spending is down does not mean that states are going to give up on cost containment."

Since 2001, the Bush administration has worked tirelessly to push its own answer for relieving these budgetary pressures: ending the federal government's open-ended commitment to Medicaid and, instead, handing out fixed annual "block grants" that free states from overarching rules and give them wide flexibility to cut costs however they see fit.

In December 2005, Congress handed the administration a significant victory in its campaign to make this vision reality. As part of a massive and last minute budget deal, Congress voted to cut federal Medicaid spending by \$11 billion over the next five years and \$42 billion over the next decade. These savings will come in large part by boosting the fees poor patients must pay from the former \$3 limit to what, for some, could reach hundreds of dollars.

The new Medicaid allows states to charge co-pays of up to 10 percent on each service performed for people living between 100 percent and 150 percent of the poverty level—which is around \$16,000 to \$24,000 a year for a family of three. People above that mark could be charged premiums for the first time ever, and co-pays of up to 20 percent.¹⁹

The only limitation on all of these new fees is that medical bills may not exceed five percent of a family's annual income. But that

Who Needs It?

When the AIDS care safety net frays, who loses out? You guessed it—African Americans.

Number of people the CARE Act serves:
530,000

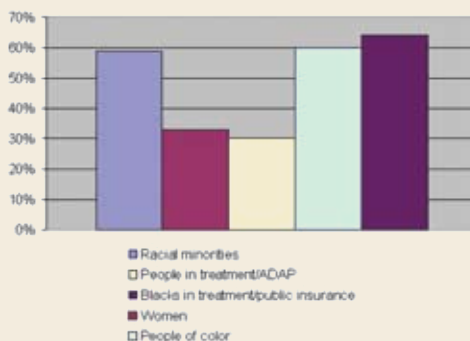
Share who are racial minorities: 59%

Share who are women: 33%

Share of people in AIDS treatment paying with ADAP: 30%

Share of those who are people of color: 60%

Share of Blacks in treatment paying with public insurance: 64%



Source: Presentation by Deborah Parham Hopson, HIV/AIDS Bureau of the Health Resources and Services Administration at Black AIDS Institute briefing, October 13, 2006. Washington, D.C.

restriction provides little comfort for those living so close to the poverty line, because nothing stops a catastrophic event—like a recalcitrant opportunistic infection for someone with an AIDS diagnosis—from eating all of a month's income and driving families into immediate homelessness, or worse.

Medicaid's fate has great consequences for the nation's fight against AIDS. Public insurance pays for half of all people getting treatment for AIDS. A disproportionate share of those people are Black: while 44 percent of whites in treatment for AIDS pay for it with private insurance, only 14 percent of African Americans have that luxury. As a result, two-thirds of Blacks getting AIDS treatment pay for it with Medicaid or Medicare.²⁰

Change Coming?

Many observers have declared the November 2006 elections a watershed moment in modern politics and policymaking: America decided that one-party control of Washington sent the nation down a dangerous path and threw the bums out, as the saying goes. Perhaps. The Democrats certainly stoked that emotion on the campaign stump. And following their victory on November 7, Democrats pledged to bring sweeping change. As Speaker Nancy Pelosi declared, "It's time for a new direction."

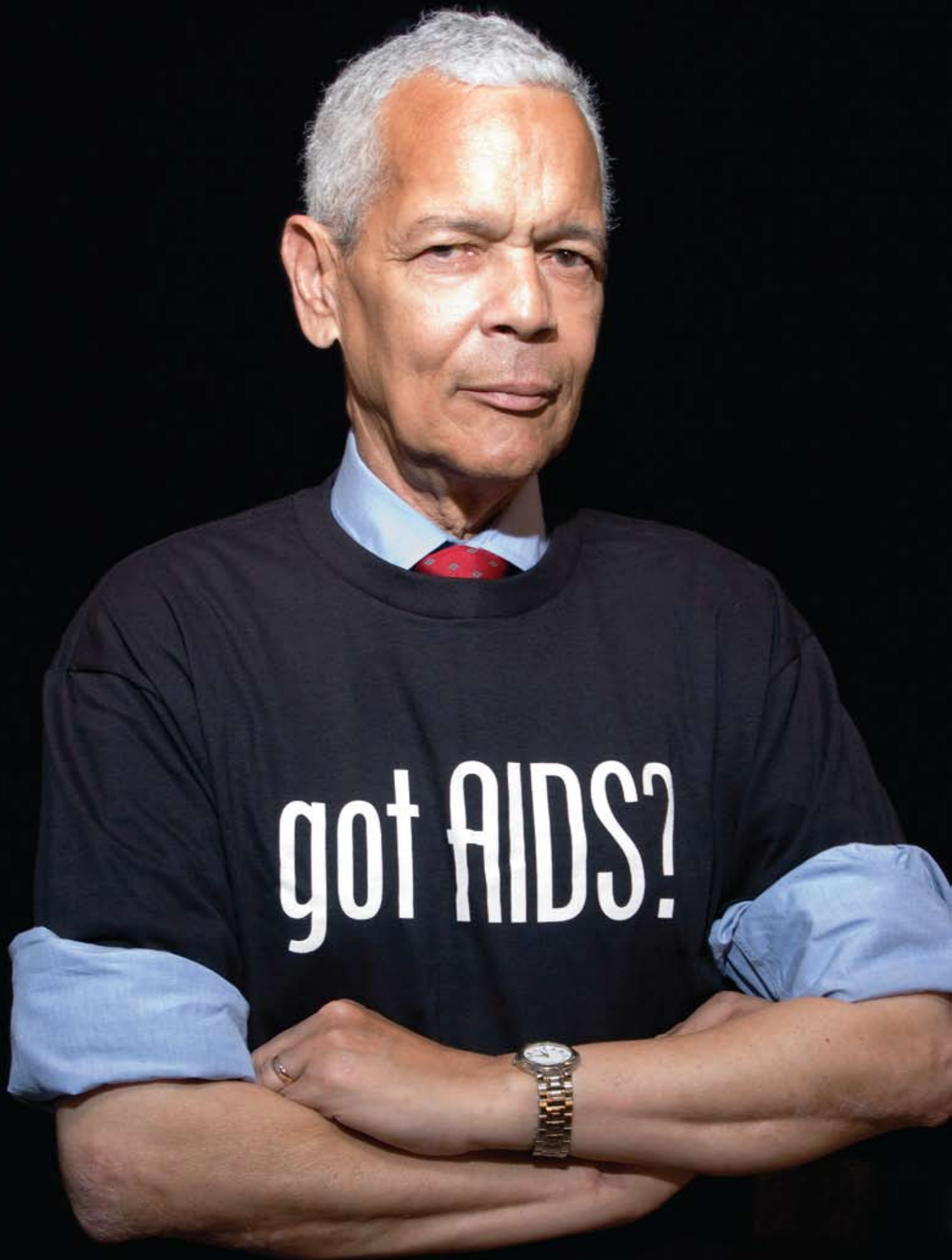
The proof of change will be in the legislating.

If the Pelosi is good for her word, the Democrats must make charting a new course on AIDS treatment and care a priority. A place to start will be this fall's budgeting process. Rather than once again approving a federal budget that pinches pennies for the range of crucial health care safety nets America needs to thrive, Congress must redirect resources from war making and tax cutting to save Black lives. Anything less will be more of the same: needless, predictable

deaths for African Americans at the hands of a wholly treatable disease.

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The State of Our Movement

The Black AIDS Mobilization's First Year

The year 2006 began solemnly, with the death of a movement icon, Coretta Scott King. As hundreds of mourners gathered in Atlanta to remember her sacrifices as first lady of the civil rights movement, we all also reflected on the long road Black America has already traveled. King represented a halcyon era for many, a time when the community came together to stand up and demand its place, to save itself even when few others cared about its fate. But that was not the only movement Coretta Scott King helped nurse from infancy. She was also a foundational leader in Black America's newest movement: the battle to save ourselves from the AIDS epidemic.

In the years following Martin Luther King, Jr.'s death, Mrs. King continued to speak out about and build upon his mission of creating a truly just society. And as she did so, she framed the fight against AIDS as a core part of that mission. During the Southern Christian Leadership Conference's annual meeting in 2001, she marked the epidemic's 20th anniversary with a striking call to action. "AIDS is a global crisis, a national crisis, a local crisis and a human crisis," she told the delegates that August. "No mat-

ter where you live, AIDS is one of the most deadly killers of African Americans. And I think anyone who sincerely cares about the future of Black America had better be speaking out."

Mrs. King would have been proud to watch as her community took those words to heart in the months that followed her death. She would have celebrated as she watched the community's traditional leaders—from civil rights to business, from entertainment to faith—step forward and make dramatic, public vows to end this epidemic in five years.

Sadly, she would also be deeply troubled by the snail's pace at which those leaders have traveled toward making their commitments reality. The task before us is undoubtedly massive. The myriad barriers are no less daunting. But Black America is long past the point when it can accept these challenges as excuses for inaction.


In an ideal world, we'd have time for a slow, gradual windup in our campaign against AIDS. Time, however, is a resource Black America long ago exhausted. We've sat back and watched as the virus has wormed its way deeper into our community. As a result, African Americans now account for

Left page: Julian Bond, Chair, NAACP Board)

half of the epidemic and AIDS remains the second-leading cause of death among Blacks aged 25 to 44. (See “The Black Epidemic: By the Numbers” on page 8.)

Twenty-six years into the epidemic, Black America must now face AIDS as the urgent, life-and-death priority that it is.

Our Problem



In June 2007, the U.S. Centers for Disease Control reported that Blacks again accounted for 49 percent of all HIV/AIDS cases diagnosed in 2005.¹ African Americans, meanwhile, represent just 12.8 percent of the U.S. population.² According to the CDC's June data, the AIDS case rate among African Americans is 10 times that of the rate in the general population.³ These facts are alarming. However, they represent just one dimension of a multifaceted problem.

Our epidemic is not only disproportionately large, it's disproportionately damaging. CDC researchers have found that Blacks are more likely to discover they are infected only after the virus has progressed to an advanced stage, making treatment more difficult.⁴ When Black people gain access to treatment, they are more likely to be dependent upon public insurance programs and publicly financed care—systems that are now teetering on the brink of collapse due to neglect at all levels of government. (See “The State of Treatment: A Domestic Crisis” on page 36.) Ultimately, according to the CDC, “survival, particularly at more than 48 months after diagnosis, [is] greater among Asians/Pacific Islanders, whites, and Hispanics, than among Blacks.”⁵

The treatment challenge is not limited to care for HIV infection. In Blacks, HIV/AIDS is frequently merely one element in a jumble of interlocked health problems ranging from alcohol and other drug use to chronic illnesses like diabetes and heart disease. Often, it all piles up on top of social and economic

challenges such as lack of access to health insurance, poverty and homelessness, not to mention emotional concerns stemming from the stigma and social isolation so many people living with HIV/AIDS continue to face.

Bold leadership and action is needed now within Black America if these deadly trends are ever going to be reversed. National Association for the Advancement of Col-

Calling All Leaders

Excerpts from NAACP Chair Julian Bond's call to arms in an August 12, 2006, *Washington Post* op-ed:

■ “We’re calling on Black America to engage in a coordinated campaign with concrete, measurable goals and objectives and real deadlines ... each of us must identify strategies and activities that match our unique niches and capabilities.”

■ “We must 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.”

■ “We’re calling on Black America to get informed about the science and facts about AIDS ... knowledge is a powerful weapon in this war.”

■ “We’re calling on Black Americans to get screened and find out their HIV status.”

■ “We’re calling for a massive effort to address the disproportionate impact this epidemic is having on Black youth, women, injecting drug users and men who have sex with men.”

■ “We must also pressure our government and elected officials ... to be far more responsible partners than they have been.”

Source: Bond, Julian. 2006. *Black America Must Confront AIDS*. *Washington Post*, August 12.

ored People Chair Julian Bond perhaps said it best in an August 2006 *Washington Post* op-ed, succinctly titled “Black America Must Confront AIDS.” “We’re calling on leaders to lead,” Bond wrote. “The AIDS story in the United States is partly one of a failure to lead.” (See “Calling All Leaders” on page 46.)

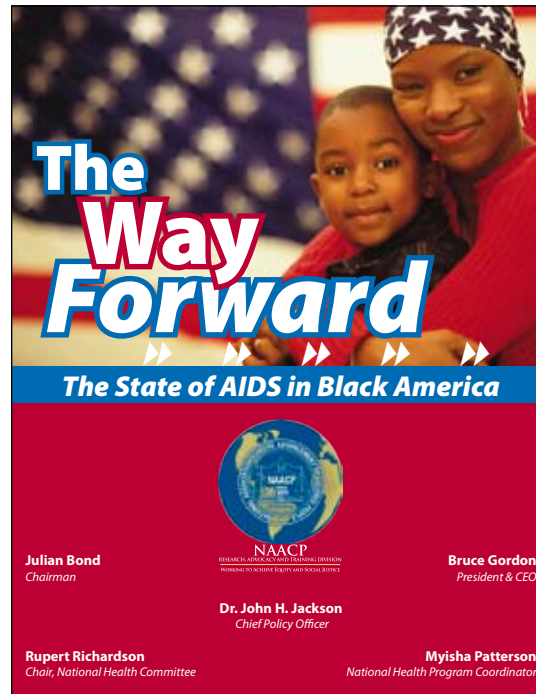
Our Squandered Time

We are now more than a quarter of a century into the HIV/AIDS pandemic, and it’s fair to ask a tough question: Have traditional Black institutions done enough to end HIV and AIDS in Black America? The answer, sadly, is no.

Former President Ronald Reagan is widely derided as having been callously and murderously asleep at the wheel during the epidemic’s first decade, in the 1980s. But the silence and inaction among traditional Black institutions was just as deadly. History has demonstrated that bold Black leadership can force change. Our community’s mass mobilization has beaten back slavery, lynching, Jim Crow and all manner of government-sanctioned brutality and depravity. If we’ve learned nothing else over the years, it is that we can neither expect nor rely upon our government to do its job to save our lives until we demand it. New Orleans and Hurricane Katrina stand as stark modern reminders of the simple fact: We cannot wait for someone else to send the boats or the busses for us.

University of Chicago political scientist Cathy Cohen’s seminal 1999 study of Black America’s response to AIDS remains an invaluable and sobering reminder of our failure to save ourselves in the epidemic’s early years. AIDS has been a uniquely Black problem ever since the CDC’s June 5, 1981, notification that launched the epidemic. In 1985, African Americans already accounted for roughly a quarter of all people diagnosed with AIDS. Yet, as Blacks died of AIDS in large and disproportionate numbers, too

many traditional Black leaders failed to do the minimum: speak up. Cohen notes that the “first article on AIDS to appear in *The Crisis*, the monthly magazine of the NAACP, was not published until 1989 ... years after



the first diagnosed cases and nearly 17,000 Black Americans had already died of opportunistic infections related to AIDS.”⁶

Today, the Black Press is a standout. As most mainstream media has turned away from the epidemic in recent years—having run a host of premature late 1990s stories about its conclusion—Black media outlets have stepped in to fill the void. Magazines, newspapers, broadcast outlets and websites have all begun aggressively covering the epidemic, pumping everything from news to analysis to humanistic features into the communal dialogue.

Essence magazine prominently featured AIDS stories in at least three of its 12 2006 issues, including a massive two-part cover series in November and December to mark the epidemic’s 25th anniversary. December 2006 in fact proved a big month for AIDS and Black Press magazines. In addition to

Actors Speak to AIDS at BET Event

Danny Glover, Harry Belafonte Call on Black Celebrities to Join Mass Black Mobilization to End Epidemic in Black America



HONOR: Actors hold award given to Harry Belafonte at BET Awards show.

LOS ANGELES (June 28, 2006)—Actors and humanitarians Danny Glover and Harry Belafonte, speaking during the 2006 BET Awards Ceremony, called for African Americans and specifically celebrities to join the national Mass Black Mobilization Movement to end the AIDS epidemic in Black America.

Glover, a longtime AIDS activist and humanitarian, made his comments while helping to present Belafonte with the BET Humanitarian Award during the

show held at the historic Los Angeles Shrine Auditorium.

"Following the example of the man we are honoring this evening, let us remember that we are in the 25th year of the HIV/AIDS epidemic," said Glover, a previous BET Humanitarian and one of BET's 25 Heroes in the Struggle Against AIDS. "Please join with BET's Rap-It-Up and the Black AIDS Institute to create a mass mobilization where we all do our part to end this pandemic."

In his acceptance speech,

Belafonte said, "The struggle is long. It hasn't ended. The enemy is tenacious and resilient and we have to be more tenacious and more resilient. Katrina isn't fixed yet. HIV/AIDS isn't fixed yet. Two million men in prison isn't fixed yet. Justice isn't fixed yet. And the only ones who can fix it are those of us who are victims of it. [We] must rise up and make sure that tyranny does not prevail."

Glover's comments follow his participation in a national call to action that was held on June 5 at a news conference hosted by the New York-based Open Society Institute. Elected officials, civil rights activists, entertainers, media personalities and faith leaders issued a call to action and declaration of commitment to end the AIDS epidemic. Conference participants included the Rep. Charles Rangel (D-N.Y.), Bruce Gordon, executive director of the NAACP and others.

"Black America can no longer afford to trifle with the politics of America's culture wars, whether they come from the left or the right. It is time for Black people to take ownership of the AIDS epidemic and responsibility for ending it," Glover said June 5. "Individuals, traditional Black organizations and policymakers must all begin to hold ourselves accountable."

Both Glover and Belafonte are long-time Humanitarians and United Nations ambassadors. Belafonte was a key leader in the civil rights movement of the 60s. He recently joined the board of amfAR (the American Foundation for AIDS Research).

Glover, a Black AIDS Institute board member, said he knows the virus will not be eradicated completely, but an increased effort would help in "dramatically cutting the HIV

rates among Black men and women, increasing the percentage of Black people who know their HIV status, increasing the percentage of African Americans with HIV/AIDS in appropriate care and treatment, and most importantly ending the debilitating stigma that has stymied efforts to stop AIDS in Black America."

Phill Wilson, executive director of the Black AIDS Institute, said, "This is an amazing and strikingly appropriate statement for Mr. Glover and Mr. Belafonte to make at this time. June 27 was National HIV Testing Day. In 2006, AIDS in America is a Black disease. No matter how you look at it, Black people bear the brunt of the AIDS epidemic in America. You can't stop AIDS in America without stopping AIDS in Black America. Getting tested for HIV is a first step."

Said Wilson, "We're calling on every Black institution, leader, media organization and celebrity to make fighting AIDS a top priority. This call to action from these two icons is an important step."

Over a million Americans are living with HIV today—nearly half of them Black. Yet, national policymakers have lost focus. Federal funding for domestic AIDS care programs has remained largely flat since 2001. Approximately 54% of the new HIV/AIDS cases diagnosed in the U.S. are Black. Among women, Blacks account for two-thirds of all new infections. And recent Centers for Disease Control and Prevention studies estimate nearly half of all Black gay and bisexual men in some of America's urban centers are already infected.

The BET 2006 Awards Show, which aired live on Tuesday, will be re-broadcast at 7:30 p.m. ET on Friday, June 30.

Essence, *Heart & Soul* featured "The Fight Against AIDS" as its singular cover story in its December/January issue, proclaiming to its readers that "the face of AIDS in America is becoming decidedly more brown and female." The remarkable package included several personal testimonies and profiles and a lengthy roundtable of women talking about their sex lives and safety in "the age of AIDS." *Ebony* magazine also joined the

parade of December coverage by turning over its monthly editor's letter to the subject and publishing a lengthy profile of four Black women living with HIV.

Meanwhile, American Urban Radio Networks' *Bev Smith Show* features regular, ongoing discussion about the epidemic. AOL's Black Voices website features several AIDS blogs (including one by Institute Executive Director Phill Wilson). And under the lead-

ership of former director George Curry, the National Newspaper Publishers Association's News Service runs a monthly AIDS column by Wilson, along with ongoing, week-in and week-out news coverage of the epidemic for its more than 15 million readers.

Too many traditional Black community institutions, however, are not following the Black Press's lead in getting the word out. An August 31, 2007 examination by the Black AIDS Institute of the home pages of 16 national Black organizations' websites found that only two—the National Coalition of Pastors' Spouses and Rainbow/PUSH—featured any information or links to information about HIV/AIDS.

Our Pledge to Lead

It is, however, important to note the many heartening examples of traditional Black leadership on AIDS in recent months.

As the nation paused to mark the epidemic's 25th anniversary in June 2006, a host of Black leaders gathered in New York City to pledge themselves and their organizations

to helping slow the pace of new Black infections. "For Black America, the moment of truth has arrived," declared actor and activist Danny Glover. "If we are to survive the AIDS epidemic, we are going to have to gather all of our resources and marshal them for the political struggles that lay ahead."

Attendees included top executives from American Urban Radio Networks, BET networks, the Congressional Black Caucus, the National Urban League, the National Association for the Advancement of Colored People, the Congressional Black Caucus, the National Newspaper Publisher's Association, leading Black churches and others.

In August, those leaders were joined by a host of others in convening at the biannual global AIDS conference in Toronto, Canada to draw up a plan for just the sort of resource-marshaling that Glover urged. Leaders from 25 of Black America's most venerable institutions met at the 2006 International AIDS Conference and pledged themselves to a five-year "Marshall Plan" for dealing with the Black epidemic. It was an unprecedented gathering of Black leaders focusing on AIDS,



Black Leaders gather to launch national Black AIDS Mobilization at 2006 International AIDS conference in Toronto Canada.



Black AIDS Mobilization Goals

Each of the 16 traditional Black institutions that have vowed to contribute to the National Black AIDS Mobilization Plan will hammer out the details of making AIDS part of the fabric of their work. But all have agreed to focus on four ambitious goals.

- **Reduce infection rates.** The plan seeks to slash HIV infection rates in our community by half over the next five years.

- **Get Blacks tested.** The plan seeks to boost the number of Blacks who know their HIV status by 50 percent in the next five years.

- **Support appropriate care.** The plan seeks to insure that African Americans who do test positive have access to appropriate care and are personally able to take the necessary steps to live healthily with HIV. It seeks to increase utilization of HIV treatment by Black Americans by 50 percent in the next five years.

- **Eradicate stigma.** The plan seeks to finally wipe out all of the needless, deadly stigmas associated with HIV/AIDS that have for too long blocked Black communities and individuals from saving themselves from this epidemic.

and it created the most significant Black leadership presence ever seen at the massive AIDS meeting.

“This is historic,” said Grazell Howard, program director of the National Coalition of 100 Black Women, remarking on the cooperation across sectors. “Black people don’t talk to each other.”

The meeting also marked the beginning

of the Black AIDS Mobilization. As part of this historic initiative, 16 Black institutions have vowed to hammer out their own plans for integrating AIDS into their organizational agendas. All have agreed to focus on a set of specific goals: cutting infection rates; increasing the number of Blacks who get tested regularly; helping more HIV-positive Blacks get into appropriate care; and taking on stigma associated with the virus. (See “Black AIDS Mobilization Goals” on page 50.)

Each of the organizations has also pledged to appoint a national AIDS director for the campaign, to set annual testing goals and to spotlight the epidemic at their national conferences.

As a whole, these individual plans will inform the development of a National Black AIDS Mobilization Plan, which will incorporate the role of governments, corporations, foundations and healthcare finance mechanisms. The plan will ensure that the pledges our leaders have made in recent months are tied to concrete, measurable goals and objectives—with deadlines. With that tangible end in mind, each participating organization is now at work on crafting plans for eight areas of strategic action:

- Obtaining sufficient full-time, paid staff to mobilize their individual constituencies and evaluate their campaigns;

- Developing and adopting a five-year plan to engage Black Americans in ending the epidemic;

- Creating an internal program for HIV health education and risk-reduction for all of their employees;

- Establishing annual goals for providing HIV/AIDS testing to constituents and employees;

- Including HIV/AIDS information in all communication vehicles at their disposal;

- Disseminating HIV/AIDS information through major plenary sessions at national meetings and conventions;

- Developing an HIV/AIDS policy agen-

da and, where appropriate, educating policy makers on the need to support increased funding and bold initiatives to bring an end to the Black epidemic; and

■ Participating in at least two annual AIDS public awareness commemorations, such as World AIDS Day and National Black HIV/AIDS Awareness Day, designed to raise community awareness about the need for individual and collective action.

The State of Our Movement

The story of the movement thus far is an uneven one—a few outstanding leaders are blazing the way, while the rest are still failing to make the necessary hard work a priority. Many traditionally Black institutions are clearly engaged in HIV/AIDS work of some sort. But that work remains scattershot and sporadic. The vast majority of organizations who have signed onto the Black AIDS Mobilization have not yet made meaningful progress in turning their promises into action.

Few, if any, of our national organizations appear to have devoted sufficient resources to the Black AIDS Mobilization thus far. A key measure of whether sufficient resources are being devoted to the campaign is the amount of staff time set aside for it. The Institute surveyed 16 key organizations who have signed on to the Black AIDS Mobilization about this and other measures of progress. The preliminary results indicate that staffing—where it exists at all—ranges from one-quarter to one-half time person. With that level of commitment, it is not surprising that most of our traditionally Black institutions do not yet have an HIV/AIDS strategic action plan, with clear goals and specific objectives.

In the past, observers within the AIDS community have been quick to point out Black America's slow response to the epidem-

ic, but have been slow to acknowledge the significant barriers that stand in our community's way. If we are to move past talking about failure to planning for success, we've got to identify the roadblocks—and figure out how to remove them.

Perhaps the leading barrier to Black community mobilization on AIDS is the perception that we've already got our hands full with other problems. Cohen's 1999 study highlights the ways in which this reality worked against a meaningful community response for much of the early epidemic. Needle exchange programs offer an ideal example. In the early days of the epidemic, African American community leaders were some of the most vocal opponents of giving injection drug users clean needles, despite the deluge of research identifying such programs as among the most effective way to stop the spread of HIV, worldwide. But for a community that was gripped by the ravages of drug addiction and violent drug trade throughout the 1980s, the idea was a tough one to digest.

Still today, Black America is plagued by a daunting list of intractable problems—high incarceration rates, racial discrimination and injustice, continuing poverty and joblessness, not to mention broader health disparities, to name a few.

While acknowledging the reality of these challenges, to accept them as insurmountable is to also embrace a notion of Black powerlessness. Moreover, it assumes that AIDS exists outside of these existing challenges. In fact, AIDS is the natural consequence of many purportedly more pressing issues, and it insidiously reinforces each of them as well. Families gripped by an expensive, debilitating disease are in no position to contribute to their community's economic, social or political success. The converse is also true: Some of the most remarkable examples community leadership are found in the ranks of former addicts, sex workers, prisoners and other

supposed pariahs who, upon plugging into services for their HIV infection, harnessed their skills and talents to help strengthen their communities.

In sum, the skills, knowledge and experience that a community can develop through mass mobilization to address HIV/AIDS will also be useful in addressing other challenges—the problem of HIV/AIDS in Black America does not exist in a vacuum, it is intricately tied to nearly every other major social and economic challenge we face.

Organizations, however, face real resource challenges in confronting the onslaught of issues Black America must simultaneously address. They need help from both public and private sector players who profess interest in ending AIDS in America at large. That means foundations, pharmaceutical companies and academic institutions must all start providing meaningful support for work traditional Black organizations are gearing up to do on AIDS. It means that corporate America—including Black-owned business—must begin to give back some of the profits it reaps from the \$773 billion Black market it taps.⁷

It also means both federal and state government must make a far greater contribution than it has ever marshaled. Since 2001, the federal budget for AIDS services has held practically flat. Congress and the White House have sat back and watched as their own public health agency has estimated 40,000 new people a year get infected. As the need grows, the money for the domestic epidemic stays the same. (See “The State of Treatment: A Domestic Crisis” on page 36.) This trend must be reversed.

But here again, these resources won't materialize on their own—we've got to go get them. Luckily, we have a road map for how to do so. The Minority AIDS Initiative, which targets federal funds at service providers working in minority communities, stands as one shining example of Black community

leadership in garnering resources.

The initiative grew out of a March 1998 meeting in which the CDC convened Black AIDS leaders to discuss the increasingly divided American epidemic—one white, the other Black and Latino. The agency called the meeting to plot its response, but the assembled leaders left the gathering and sprung into their own action. In a joint statement, they declared HIV/AIDS had reached a “state of emergency” in Black America and began making the rounds in Washington, D.C. to see what could be done about it. The White House Presidential Advisory Council on HIV/AIDS endorsed the community declaration, and in April long-time Black AIDS leader Dr. Benny Primm presented it to the Congressional Black Caucus' Health Brain Trust, led by Virgin Islands congressional Del. Donna Christensen. The CBC, under the leadership of California Rep. Maxine Waters, picked up the ball and ran with it, rallying its congressional colleagues to do something about the crisis.

The result was that in October 1998 Congress passed the Minority AIDS Initiative. The initiative's goal is to build up the often-struggling minority AIDS service groups' capacity to deal with the massive challenge they face. In its first year, the federal government directed \$166 million to the effort.

The initiative was hailed as a crowning achievement, and energized Blacks concerned about AIDS both inside and out of government. But it has significant limitations. The program has been plagued by lingering debates about how exactly the money should be spent—and who should be spending it. Some Black-run service providers complain that large, white AIDS organizations have crowded them out by developing programs that target minorities. The CBC has tried to tailor the language to specify that grants should go to organizations based in minority communities, but some debate lingers about the legality of such rules, given

recent Supreme Court rulings limiting affirmative action programs.

More to the point, however, in the grander scheme of the federal AIDS budget, the Minority AIDS Initiative is a tiny pot of spoils to be tussling over. In 2004, federal funding for the initiative topped out at \$404 million. Traditional Black organizations must now step in and demand Congress do better.

There can be no mistaking the point: Stopping AIDS in Black America will be costly, for everyone. But it will cost far less than allowing the epidemic to continue worsening.

Ending Our Stigma

Sadly, stigma surrounding HIV/AIDS remains a towering barrier to action in Black America—even 26 years and tens of thousands of Black lives after the epidemic began. If we are to save ourselves, it must finally end. Research shows stigma not only frustrates efforts to slow the virus' spread, it discourages people from seeking necessary care.⁸

Luckily, traditional Black leaders have in fact begun stepping up their efforts to wipe out this scourge. Increasingly, our leaders have begun making the sort of strong, no-excuses denunciations of AIDS stigmas that Mrs. King was known for. In an August 2007 report, the National Medical Association identified stigma as an “additional contributor to less-than-optimal outcomes for persons of color living with HIV/AIDS ... these attitudes, coupled with attitudes about homosexuality, and its inherent connection to HIV/AIDS, have frequently left ethnic minorities to conceal their behavior and health condition.”

One could easily add that stigma has also inhibited the exercise of leadership. The late Dr. Herb Nickens, the first Director of the Office of Minority Health at the Department of Health and Human Services, confided in

1987 that when he raised the issue of HIV/AIDS among Black Americans, they wanted to know, “Why are you raising this issue, are you gay?” The condemnation of the people originally considered most at-risk for the virus—gays, sex workers, injection drug users—cascaded into condemnation for anyone seeking to help.

Much has thankfully changed since the days when Dr. Nickens made that observation. While Black gay, bisexual and transgender people continue to be at great risk for HIV, today they are in abundant company in Black America. Nearly 1.2 million Americans are living with HIV/AIDS, and half of them are Black. Now, the “least of us” includes a lot more of us.

Leadership Roll Call

The following 16 traditionally Black organizations had signed on to the Black AIDS Mobilization as of this report's writing:

100 Black Men of America
American Urban Radio Networks
Congressional Black Caucus Foundation
National Action Network
National Association for the Advancement of Colored People
National Black Caucus of State Legislators
National Black Justice Coalition
National Coalition of 100 Black Women
National Coalition of Pastor's Spouses
National Council of Negro Women
National Newspaper Publishers Association
National Urban League
Rainbow/PUSH Coalition, Inc.
The Potter's House & T.D. Jakes Ministries
Southern Christian Leadership Conference
National Medical Association



Our Trailblazers

Although too many traditionally Black organizations are not yet doing enough, a number are already on their way to developing specific goals, objectives and timetables for their contribution to the Black AIDS Mobilization. The following are just a few of these shining examples, which by no means capture the depth of the commitment that is already in play in many more organizations. The Black AIDS Mobilization will be successful only if all of the groups that have signed on to the campaign take similarly bold steps.

The National Coalition of 100 Black Women and **the National Council of Negro Women** have sponsored the groundbreaking National Black Women and HIV/AIDS Conference since 2005. NCBW plans to expand



the annual initiative by adding regional symposia on HIV/AIDS in Black women. NCBW is also planning to vastly expand its national billboard campaign to reach women in all of the 72 communities in which NCBW has chapters. These annual billboard campaigns

will be coupled with a local “Teach, Learn and Outreach” campaign, involving two-day workshops to increase awareness, knowledge and skills in HIV prevention and to provide HIV counseling and testing followed by linkage to appropriate services.

The Potter’s House and **T.D. Jakes Ministries** in 2007 launched a national and international AIDS awareness campaign called It’s Time to Step Up! This campaign will form the foundation of the strategic action plan that The Potter’s House will pursue as part of the Black AIDS Mobilization. Over the next five years, The Potter’s House intends to disseminate information about HIV/AIDS in Black America through nationally televised programming and through its national conferences and meetings; to maintain a Web page dedicated to HIV/AIDS; and to provide structured health-education and risk-reduction sessions at its national conferences, along with HIV counseling and testing.

National Action Network is formulating the initial framework of actions it will engage in over the next five years, including coordinating a national HIV/AIDS education and prevention campaign through its structure of 40 local chapters, each of which will annually develop and provide at least one HIV health education and prevention workshop, and also collaborate with local HIV counseling and testing programs to offer and provide HIV testing and counseling to a minimum of 1,000 individuals per chapter, annually. These efforts will be coordinated with the annual HIV/AIDS public commemoration days.

The National Association for the Advancement of Colored People has been a steady partner with the Institute in launching the Black AIDS Mobilization. The NAACP was among the first organizations to sign a declaration of commitment and call for the creation of a national Black AIDS Mobilization. In August 2006, the NAACP was among a group of Black institutions

that convened at the global AIDS conference in Toronto, Canada to launch a “Marshall Plan” to end AIDS in our community. Like the others present, the NAACP pledged to encourage HIV testing, hold policymakers accountable for treatment access in Black communities, and attack stigma surrounding the virus, among other commitments. It was an historic meeting in which the NAACP played a crucial role. Subsequently, NAACP has put action behind its words. At its annual convention in 2005, NAACP offered onsite HIV testing and hosted several educational and cultural events raising awareness about the epidemic. Both then-director Bruce Gordon and NAACP Chair Julian Bond publicly took HIV tests. In the area of policy, NAACP organized a national petition to reauthorize the Ryan White CARE Act and launched both a national HIV testing campaign and its NAACP Cares campaign to eradicate AIDS across the African Diaspora, including among African Americans.

Magic Johnson Foundation, in partnership with Abbot Laboratories, has launched the Campaign to End Black HIV/AIDS. As described at the I Stand with Magic website,

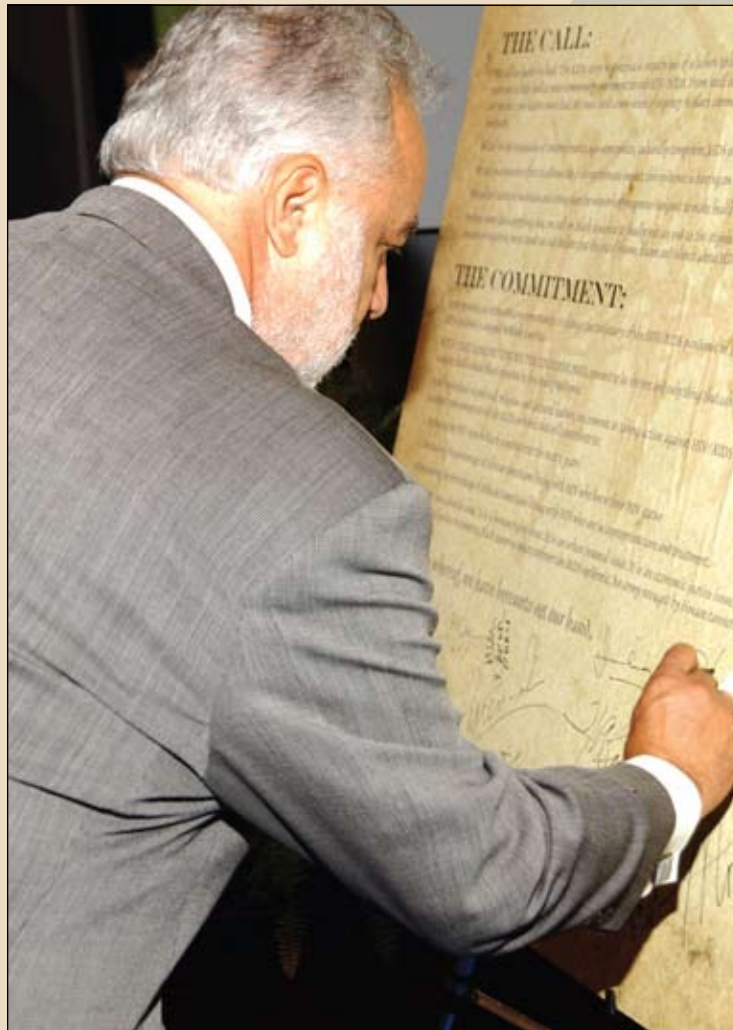
the campaign provides communities with information and resources for prevention and testing, educational materials to share with family and friends and a way to join together to make a difference. Individuals can sign up at the website and get access to the most up-to-date information on key HIV/AIDS issues, including information about safer sex and prevention, regular HIV testing and available treatment.

Notes

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8. Harara, N T, et. al. 2006. Perceptions Towards Condom Use, Sexual Activity, and HIV Disclosure among HIV-Positive African American Men Who Have Sex with Men: Implications for Heterosexual Transmission. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, Vol. 83, No. 4.

National Call to Action and Declaration of Commitment to End the AIDS Epidemic in Black America

*Danny Bakewell,
publisher of the “Los
Angeles Sentinel,”
signing Declaration
of Commitment and
Call to Action.*



Over twenty-five years ago, a strange new disease with no name was identified at UCLA Medical Center. In the intervening years that illness, AIDS, has become the defining health issue of our time, killing 30 million people worldwide, most of them Black.

Today, AIDS in America has become a Black disease. No matter how you look at it, Black people bear the brunt of the AIDS epidemic in our country. Of the estimated 1.2 million Americans living with HIV/AIDS, nearly half of them are Black. African Americans represent over half of the newly-diagnosed AIDS cases in the United States, 47 percent of the new cases among men, 67 percent among women.

We have dithered too long. Our national

policymakers have lost focus. Each year, the epidemic worsens in Black neighborhoods, and each year the national commitment to interrupting its spread and keeping those already infected healthy further lags. AIDS in Black America is a difficult and multifaceted problem—but it is also a winnable war.

Black organizations—from churches to civil rights organization, from media organizations to academic institutions, cultural organizations to policy making bodies—must make fighting AIDS a top priority by setting concrete measurable goals with real deadlines that will help end the AIDS epidemic in our communities.

The Call

- We call on leaders to lead. The AIDS story in America is mostly one of a failure to lead. Whether opinion shapers or industry titans, Black leaders must use their positions to build a mass community movement with a new sense of urgency to end the AIDS epidemic in our communities. No one should accept the idea that the presence of AIDS is inevitable.

- We call for the expansion of comprehensive AIDS prevention efforts.

- We call for a massive effort to address the disproportionate impact this epidemic is having on Black youth, women, and men who have sex with men.

- We call for a strengthening of programs that make HIV treatment accessible.

- Perhaps more than anything else, we call on Black America to finally put an end to the stigma surrounding this disease. Each person in Black America, whether positive or negative, must stand up and declare that the era of shame, blame and silence about AIDS is over.

The Commitment

We have an extraordinary opportunity to change the trajectory of the AIDS epidemic in America. AIDS in America will not end, unless and until the AIDS epidemic is stopped in Black America.

With that admonition, we the undersigned, commit to do the one and only thing that can end the AIDS epidemic in Black America and America as a whole: build a mass Black Mobilization.

The Goal

End the AIDS epidemic in Black America in five years.

The Objectives

1. Reduce HIV rates in Black America by 50 percent.
2. Increase the percentage of African Americans living with HIV who know their HIV status by 50 percent.
3. Increase the percentage of African Americans living with HIV who are in appropriate care and treatment by 50 percent.
4. Reduce AIDS stigma in Black communities by 50 percent.

AIDS is not just a health issue. It is a human rights issue. It is an urban renewal issue. It is an economic justice issue. If we are to have any chance of winning the battle for racial justice in America, Black America must confront the AIDS epidemic. An army ravaged by disease cannot fight. A dead people cannot reap the benefits of a battle won.

In witness whereof, we have hereunto set our hand.



Ujima Principles

1. Sex, drugs and hip-hop.

Since AIDS is primarily a disease of sexual activity, drug use and youth, a new twist on the sixties slogan “Sex, Drugs and Rock and Roll” might be “Sex, Drugs and Hip-Hop.” We have to talk openly and frankly about sex, sexual behavior and sexual orientation in our communities. We also have to deal with the realities of drug use, its relationship to HIV/AIDS prevention and risk reduction. AIDS is rapidly becoming a disease of the young—particularly, but not exclusively, the young, urban and poor. We need to have frank and open discussions with adolescents and young adults. Hip-hop, often accused of being a negative influence on young people, is a powerful medium. If used properly, it can be used to inspire and motivate young people to protect themselves and take leadership roles in the development of HIV/AIDS prevention, care and treatment strategies.

2. Know the enemy. Know the virus.

Knowledge is an incredible weapon in the war against AIDS. The more we know about HIV/AIDS, the better equipped we are to develop prevention, treatment and research solutions that more effectively address the disease in our communities. When we understand the science of the disease, we are better able to protect ourselves from the virus; more likely to get tested and seek treatment; better equipped to adhere to the medical regimens, when positive; and better positioned to influence public policy.

3. Know your status.

Voluntary HIV counseling and testing is the portal to HIV prevention and care. Being HIV-positive is no longer an automatic and immediate death sentence. There are treatments that slow disease progression and they also reduce the risk of transmitting the virus to others. But the benefits of treatment are

unavailable to those who don't know they are infected. Scientific research has shown that people who know their status are more concerned and careful about transmission than those who never get tested. We should advocate for access to free, anonymous, and voluntary HIV counseling and testing designed to meet the unique needs of Black America.

4. Empower women.

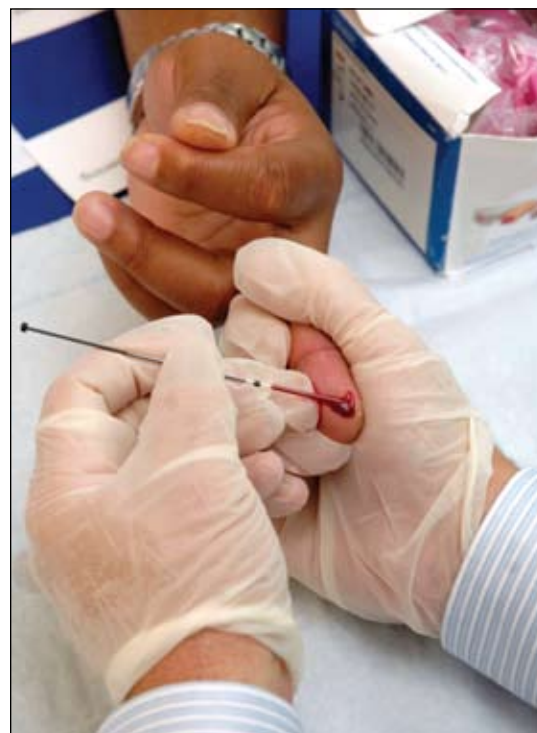
Young women must be taught how to protect themselves and be supported in saying no to unwanted sex. Our community must foster a culture that values women more. Those who are pregnant should have access to early prenatal care and appropriate treatment both for themselves and to reduce the risk of transmitting the virus to their unborn child. We must advocate for comprehensive AIDS prevention strategies for both young women and young men, inclusive of abstinence, delayed gratification, sexual responsibility, safer sex practices, condom use and risk reduction.

5. Black masculinity must be redesigned.

Black men are disproportionately represented among America's incarcerated population. These men return to Black communities, often with HIV. Correctional health facilities must provide appropriate counseling and treatment to inmates, and help in integrating them back into society armed with the knowledge and skills to care for themselves and to prevent further infection. The burden of condom use is often placed on women. This must change. We must expand Black male role models beyond sports and music and encourage academic achievement among Black men. We must teach young Black men that protecting their partner is their responsibility.

6. Provide health care.

Too many African Americans must use emergency rooms as primary care facilities. HIV care requires access to primary care physicians and specialists. Health services



targeting African Americans must also include supportive services. HIV occurs in Black communities against a backdrop of an inadequate health delivery system. We are now facing multiple epidemics of STDs, hepatitis and TB. We must develop Black health promotion messages and public awareness campaigns that acknowledge the relationship between sexually transmitted diseases, hepatitis, tuberculosis and HIV/AIDS.

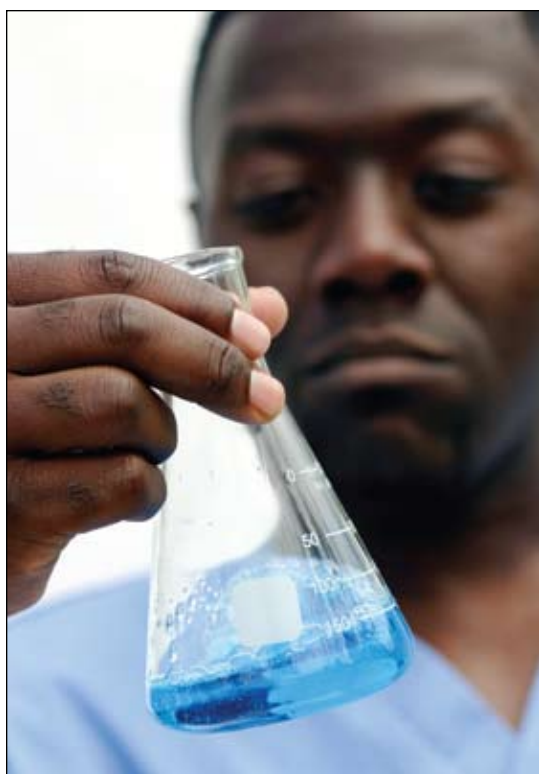
7. Stigma must stop.

In the face of derision, fear, and sometimes even hostility, people won't get tested and seek treatment for HIV. In the face of homophobia and anti-drug hysteria, people won't disclose their risk factors. To fight

the stigmas that perpetuate this epidemic, people living with HIV/AIDS are an invaluable source of information and leadership. By sharing their stories, and giving a face to a nameless epidemic, they can inspire hope and promote prevention.

8. Vaccines must be found.

The ultimate weapon against HIV will be a vaccine. A preventative vaccine is especially critical for Africans, African Americans and other communities of color who are already disproportionately impacted by other chronic illnesses. This is especially true for individuals, communities and countries that cannot



afford expensive HIV therapies; preventive and therapeutic vaccines are essential. Only a vaccine has the potential to eradicate an illness from the face of the earth. To this end, African Americans must participate in vaccine development, trials and readiness. We

must prepare our communities for HIV vaccines by educating them about the benefits of vaccines.

9. You gotta have faith.

The faith community can be an invaluable source of support in the fight against HIV/AIDS in Black America. We must remind faith leaders that “we are all God’s children.” We must demand that our churches be sanctuaries for the least of us. Black clergy and lay people must be included in the development of Black HIV/AIDS policies. Black churches must be called upon to provide services, encourage testing and support prevention messages.

10. Mobilize, mobilize, mobilize!

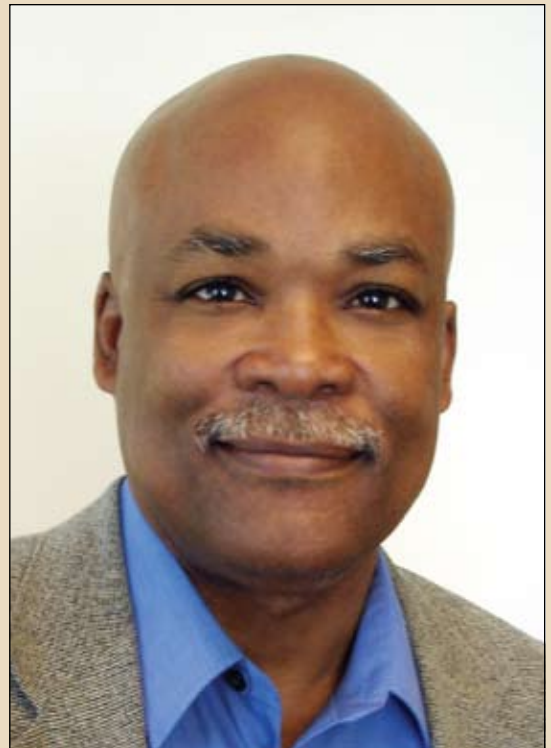
We must build a national mass Black response to the AIDS epidemic in America. As Coretta Scott King said, “Anyone who sincerely cares about the future of Black America had better be speaking out about AIDS.” AIDS will not be over in Black America unless and until Black people develop the capacity and commitment to stop it. Every Black organization in America must make HIV/AIDS a top priority. Black leaders—from traditional Black ministers and civil rights leaders to hip-hop artists and Hollywood celebrities—must join in a national call to action and declaration of commitment to end the AIDS epidemic in our communities immediately.

About the Authors

Gil Gerald is president of Gil Gerald & Associates, Inc., a consulting firm providing technical assistance to health and human services organizations. Gil, a 1974 graduate of Pratt Institute, immersed himself in the 1980s and 1990s in the gay and lesbian civil rights movement and the community-based response to the AIDS epidemic.

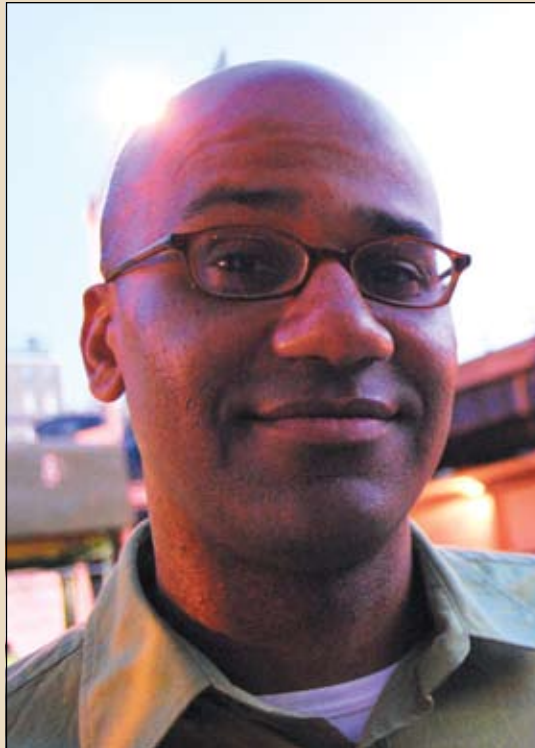
He was a founding board member of the National Minority AIDS Council and the Human Rights Campaign Fund, and served as executive director of the now-defunct National Coalition of Black Lesbians and Gays.

His writing has appeared in *In the Life: A Black Gay Anthology*, *21st Century Sexualities*, *Prevention Education for Young People*, *Journal of the National Medical Association*, *Point of View: the Magazine of the Congressional Black Caucus Foundation*, *Grassroots Fundraising Journal* and *Freedom in this Village*. Gil was also featured in the documentary *After Stonewall*.



Kai Wright is publications editor for the Black AIDS Institute. As a writer and editor in Brooklyn, N.Y., his work explores the politics of sex, race and health. Kai has reported from all over the world for leading independent and community-based publications, ranging from *Mother Jones* to *Essence* magazines, and has received several awards and fellowships for his AIDS writing.

Kai is author of *Drifting Toward Love: Black, Brown, Gay and Coming of Age on the Streets of New York* (Beacon Press, January 2008), as well as two books of African-American history. He has developed, written and edited publications for the Institute since its founding, and has led many of the Institute's media projects, providing technical assistance to Black media in covering HIV/AIDS. He is a native of Indianapolis, Indiana. To check out more of Kai's work, visit Kaiwright.com.





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 communi-

ties 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 peer educators of African descent. AAHU's treatment and science college trains Black people in the science of HIV/AIDS.



to stigmatize those living with the disease or at risk of infection, better able to adhere to

We believe when people understand the science of AIDS, they are better equipped to protect themselves from the virus, less likely

Left page: Black college students gather at annual Black Students AIDS Teach-In at Tuskegee University.

treatment and advocate for care, and better positioned to influence public and private HIV/AIDS policies. The Prevention and Mobilization College prepares Black AIDS workers to engage and mobilize traditional Black institutions in efforts to confront HIV/AIDS and increase 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.

■ The **Drum Beat** is the Institute's Black media project designed to train Black media on how to report accurately on 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. 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. The **Drum Beat** newspaper is a semi-annual tabloid with a distribution of 300,000. It is distributed to Black conventions, barbershops, beauty parlors, bookstores and doctors' offices. The Institute's newest publication is **Ledge**, a magazine produced by and for Black college students and distributed on the campuses of historically Black colleges and universities around the country.

■ **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, HITS 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 do to end the AIDS epidemic in our communities.

■ The Black AIDS Institute and BET, in association with the Kaiser Family Foundation, also sponsors the **Rap-It-Up Black AIDS Short-Subject Film Competition** to highlight the issue of AIDS and HIV infection within the African American community. By showcasing examples of heroism from within Black communities, we can galvanize African Americans to refocus and recommit to overcoming this epidemic.

■ 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 African American institutions.

Finally, nearly 30,000 people participate 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,



Black leaders gather at National Black Leaders' Strategic Planning Summit in Scottsdale, Ariz. in March 2007.

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 **Test 1 Million** campaign is a two-year effort to screen one million people for HIV by December 1, 2008. The campaign began with a celebrity-studded press conference in collaboration with SAG and AFTRA at the Screening Actors Guild. Other events include



an Oakland-to-Los Angeles run where people will be tested along the California coast run route and a national "get a free concert tickets in return for taking an HIV test" program in partnership with leading R&B and hip-hop artists.



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