



# The Time Is Now!

## The State of AIDS in Black America

By Kai Wright  
Black AIDS Institute  
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## OVERVIEW

# The Time Is Now!

**Just being aware of a threat is only the first step in confronting it. In order to interrupt the devastation that HIV has had in African American communities, we must also understand the political and social forces that help shape the epidemic—as well as our nation’s response to it.**

*The Time Is Now!* explains, in plain language, both the history of those forces and the challenges that lay ahead. It begins with the public care and treatment system that policymakers and activists worked together to create in the early stages of the epidemic, explaining how that system works and walking readers through the challenges it now faces. The report then highlights the most pressing prevention challenges for the Black community. It identifies the recurring barriers to stopping HIV’s spread in our neighborhoods, and discusses how political factors both inside and outside of our community have frustrated the search for solutions.

As with all of our publications, this report speaks not merely to AIDS experts, but to those members of our community who may have just become aware of the problem and now need information on how and where to get involved. Getting this information out, and getting African Americans involved, has never been more crucial. **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.** For Black America, the moment of truth has arrived. 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.

## Differential Impact

In the decade since groundbreaking treatments began to slow HIV’s carnage, the epidemic has grown steadily more Black and brown. No matter how you slice the numbers—young or old, male or female, gay or straight—this epidemic is attacking our people most aggressively.

■ African Americans now account for 54 percent of annual new infections, though we are just 13 percent of the population.

- African Americans account for two-thirds of new AIDS cases among teens, but are only 15 percent of the national teen population.
- Black women accounted for 67 percent of all diagnosed female AIDS cases in 2001.
- Studies have shown as much as a third of Black gay and bisexual men under the age of 30 may be HIV positive.

## America's Interest Is Waning

Yet, as the splintering epidemic deepens in Black neighborhoods, America's response to it grows weaker each year. From media attention to government funding for the programs that HIV-positive African Americans overwhelmingly turn to for care and treatment, all signs show the nation moving on from the domestic AIDS epidemic.

- Although there are now more Americans diagnosed with AIDS than ever before—42 percent of whom are Black—funding for the primary federal AIDS program has remained flat for the last three fiscal years. In fact, portions of it have been cut.

- Two-thirds of those programs' clients are people of color and nearly a third are women.

- One study found that the number of news reports on the domestic AIDS epidemic published or broadcast every year decreased by 57 percent between 1997 and 2002. During that time, AIDS death rates and the pace of new infections both dropped dramatically among whites. However, while African Americans and Latinos saw declines, they were not nearly as dramatic and were not sustained.

Meanwhile, substantive efforts to establish or widen the prevention programs most likely to interrupt the epidemic in Black neighborhoods have ceased.

- Nearly 40 percent of all Black AIDS cases could be traced to dirty needles as of 2003.

At least eight major government studies have found that needle exchange programs both efficiently stop the spread of HIV among injection drug users and facilitate their clients' entry into drug treatment programs. Yet, a ban on federal funding for these programs remains in place and 17 states offered no form of needle exchange as of 2000.

- With the astronomical incarceration rates of Black men (an estimated five percent are locked up), the clean separation that public policy assumes between those in and out of prison does not exist in Black neighborhoods. The epidemic is entrenched inside our nation's prisons. Yet, most do little to stop HIV's further spread through drug use, tattooing and sex inside their facilities. And few offer serious transitional services to inmates living with HIV who are returning home.

- Federal research has found that comprehensive sex education successfully reduces sexual behavior that puts youth at risk for diseases. A recent government survey found 97 percent of Black parents believe they should teach their kids about sex. But the federal government is leading a campaign to make abstinence-only education the norm in our schools. Abstinence-only programs omit any discussion of skills and tools to prevent disease transmission during sexual activity.

## Treatment Lapses

Once positive, African Americans are more likely to advance to an AIDS diagnosis, more dependent upon publicly financed care systems, and die sooner than any other group.



■ While AIDS diagnoses continue to decline every year among whites, they have remained at the same level among African Americans. In 2001, the AIDS case rate among African Americans was 11 times higher than that among whites.

■ Nearly two-thirds of African Americans in treatment for HIV depend upon public health insurance. But those public insurance programs are now teetering on the edge of financial collapse. Forty-nine states have recently implemented or stated plans to implement cost-containment measures for Medicaid.

■ HIV-positive African Americans are seven times more likely to die from HIV-related illness than their white counterparts. One study found that African Americans in treatment for HIV were twice as likely as whites to have not received “combination therapy,” which is credited with reducing AIDS death rates.

## A Call to Action

For these reasons, the Black AIDS Institute calls on all sectors of the African American community—from individuals to political, religious and cultural leaders—to engage in a coordinated campaign to renew our national commitment to the fight against HIV/AIDS.

To facilitate that campaign, this report seeks to arm our community with a full understanding of the challenges we face. It then suggests key places where we can begin addressing those challenges.

As a community, we must engage HIV not only as an individual health concern, but also as a political and social struggle. This report highlights seven areas of that struggle in which our community’s participation is urgently needed.

## Funding for Domestic Care and Treatment Programs

The current system for funding care and treatment for low-income and uninsured people living with HIV was designed as a short-term solution to a public health emergency; we now have a long-term, lasting epidemic. In the immediate future, we must demand that federal and state lawmakers adequately fund the current system. But we must also work with care providers and Congress to develop a long-term solution.

## Drug Pricing

For those with private insurance, the exorbitant cost of HIV/AIDS medications are a surmountable hurdle. But only 14 percent of African Americans in treatment for HIV have private insurance. We must engage the national debate over drug pricing, helping to build pressure for solutions that make medicines for all illnesses accessible to everyone without breaking the bank of public health insurance programs.

## The Future of Medicaid

Every state is facing rapidly expanding Medicaid budgets and pressures to reduce costs. But

Congress has not stepped in to relieve that pressure with additional funding, and the Bush Administration is pushing a plan that would end the 30-year federal commitment to paying a share of the costs no matter how high they go. African Americans must participate in the debate about how to reform Medicaid while preserving access and benefits.

## **Support for Needle Exchange Programs**

More than eight major government studies have found that needle exchange programs both reduce HIV infection rates and facilitate entry into drug treatment programs. Yet, 17 states had no such programs as of 2000 and a ban on federal funding for them remains in place. Meanwhile, nearly 40 percent of all AIDS cases diagnosed among African Americans through 2003 were linked to injection drug use. We must demand support for these proven-to-be-effective programs from our local and national governments.

## **Reject Scapegoating in the Black Community**

The recent obsession with men who are “on the down low”—or, Black men who live heterosexual lives but maintain secret sexual relationships with other men on the side—is just the latest boogeyman to distract Black America from the real issues driving this epidemic: injection drug use, the desperate search for intimacy, and the complicated, messy dynamics of human sexuality—even when everyone involved is open about who they are sleeping with. To date, no substantive research exists identifying the number of DL men out there, demonstrating that they are more likely to have unsafe sex, or linking them to increasing infection rates among Black women. Rather than looking for someone to blame, we must begin supporting every part of our community in the effort to stay negative and live healthily with HIV.

## **The Attack on Comprehensive Sex Education**

A quarter of new HIV infections each year are among people under 25 years old, and African Americans account for 56 percent of those infections. Research has shown that by employing comprehensive sex education in our schools over the last decade we have steadily improved youth sexual health. But since 2001, the Bush Administration has tied increasing amounts of federal funding for sex education to states’ use of programs that teach only abstinence, omitting all discussion of ways to prevent disease transmission during sexual encounters. Recent studies have shown these programs not only make little difference in sexual behavior, they also often teach scientifically discredited information and increase the risk of STDs.

## **Sensible HIV Prevention Policies in Prisons**

Despite clear anecdotal evidence of widespread drug use, tattooing and sex in our nation’s prisons, the tools proven to be most effective at stopping HIV’s spread—condoms, clean needles, fresh tattoo ink—are banned in most correctional facilities. Few systems provide adequate HIV education, and still fewer offer substantive services to aid those living with HIV when transitioning back into their home communities upon release. Given the astronomi-



cally high incarceration rates in Black neighborhoods, we cannot afford to ignore the prison epidemic. We must demand more research and genuine dialog between public health and law enforcement on dealing with HIV and Hepatitis C in correctional settings.

## **Support the Search for an HIV Vaccine**

Our best hope for “a cure” to HIV is a preventative vaccine. That’s how smallpox and polio were beaten. Science didn’t find a way to cure infected people; instead, it came up with vaccines that prevent people from getting infected in the first place. As of spring 2004, more than 12,000 individuals had volunteered in HIV vaccine clinical trials, and more than 20 promising HIV vaccines were in various stages of testing. More possible candidates will be studied in the next two years than in the last five years combined. However, the pool of volunteers through which these vaccines are being tested does not nearly reflect the racial and ethnic make-up of the epidemic. Previous studies have suggested a racial differentiation in how well the vaccines work—but the numbers of African Americans in those studies were far too small to draw any real conclusions. We must learn more about vaccine trials and find ways to participate.



## CHAPTER ONE

# The Fraying Safety Net

**“I used for over 40 years,” says Linda, a 56-year-old woman from New York City’s Harlem, looking back on how she became part of a striking upsurge in middle-aged Black Americans who are HIV positive. “I found out I’ve got the virus six months after I got clean. It could have been there all the time, because of my playing around with all those different men. But, like I said, it showed up when I was 50.”**

Like too many African Americans living with HIV, by the time Linda discovered her infection it had already galloped through her body. When she tested positive, Linda was down to 300 “CD4” cells—which are the white blood cells that lead your body’s immune system; HIV kills them, and when you’re down to 200 CD4s you’re considered in danger of contracting life-threatening infections. Ask Linda about her “viral load”—or the measure of how much HIV is in your blood—and she just laughs in amazement: “I should have been on medication the day before.”<sup>1</sup>

Linda had already lost two brothers to AIDS, both of whom had hidden their conditions from her. So she knew it was time to

regain control of her life. “I had cheated myself for so long, to the point where this virus was giving me something to live for,” Linda says, voicing an ironically common sentiment among people living with HIV. “It was like, now or never. I call this virus a squatter—and squatters got rights. So I feed it. I let it have a place to sleep. And I try not to wake it up!”

An HIV diagnosis often sparks this sort of transformative moment; an individual’s resolve to cheat death galvanizes a wholesale life change. Although some do it all on their own, that revival more often occurs when, as in Linda’s case, people who have tested positive plug into a vast network of support services that previously had been beyond their reach.

There are thousands of AIDS service organizations around the country, and they do way more than just connect their clients with HIV treatment. These groups help their clients find stable housing, get into addiction treatment, learn job skills, arrange child-care, plug into emotional and mental health support networks, develop healthy diets and exercise routines, and more. In short, they help their clients fill the range of needs that

all people in working class and low income neighborhoods struggle to get met.

As one client of Harlem United put it, “You know, we go to doctors here. Do you know how many people out there do not go to doctors, and how many things are wrong with other people that they don’t know about? ... If something happens to me, you can guarantee that within the next 30 days a doctor will know about it.”

Linda’s also a Harlem United client. The agency is literally her life: she’s engaged in one or another of its programs from 10 in the morning until three in the afternoon, every day. She does her recovery program, sees a therapist and a nutritionist, and even participates in a mini-worship service with a group that reads scripture and meditates together twice a week. Medically, she finds everything from her ob/gyn to her dentist there.

“I even got my smile here—see,” she beams. “I’m thankful for the life that I have—a second chance at life. ... I thought I would die using. God had other plans for me.”

But the network of service providers that keeps people like Linda alive and healthy is bursting at the seams. Its resources have been stretched to capacity. Yet, tens of thousands of new people are turning to that network for salvation each and every year.

A 2001 survey by the CAEAR Coalition—an umbrella group of 300-plus AIDS service organizations—found that over a quarter of them had developed waiting lists because the demand for services was greater than their resources.<sup>2</sup>

Meanwhile, the American attention span for the HIV/AIDS epidemic has long run out. On one hand, we have slowly begun noticing the global dimensions of this scourge—and none too soon; in sub-Saharan Africa and the Caribbean, in China and India and beyond, HIV went unnoticed and unchecked for too long. But as a nation, from policymakers to journalists to charities, America has embraced a dangerously optimistic myth about

its own epidemic: that HIV has become an easily managed if chronic ailment that everyone now knows how to avoid.

The reality is far different.

## Mission: Not Yet Accomplished

**Few will forget the fear that everyone touched by HIV felt as it first began cutting its path through our neighborhoods in the early 1980s. Its assault was doubly frightening because we knew so little about why people were dropping dead around us, and it turned downright horrifying when scientists figured out people were being killed by a virus spread largely through sex and drugs. Doctors and researchers, activists and the lovers of those killed—everyone involved saw a crisis and mobilized an emergency response.**

That ethos of urgency has surrounded the AIDS epidemic ever since. We’ve engineered treatment, care and prevention programs meant to first and foremost stop the carnage. In 1990, activists convinced lawmakers to notice the crisis that had been plain to everyone else. They pushed through Congress a mechanism to pay for all the new AIDS services, one that is today a \$2 billion program. Its name says everything: the Comprehensive AIDS Resources Emergency Act, also known as the Ryan White CARE Act. It was a stop-gap solution to what we assumed—or hoped—would be a temporary problem. But as we settle into the emergency’s third decade, this frantic response has proven unsustainable.

We are, ironically, imperiled by our own success. In 1996, scientists made an historic breakthrough on HIV: they figured out how to slow the virus’s growth with a combination of aggressive drugs called protease inhibitors.

The new medications, however, are noth-

# A Black Epidemic

Among the 30 states that report the names of people who test positive to the CDC, African Americans make up an astounding share of new infections each year.

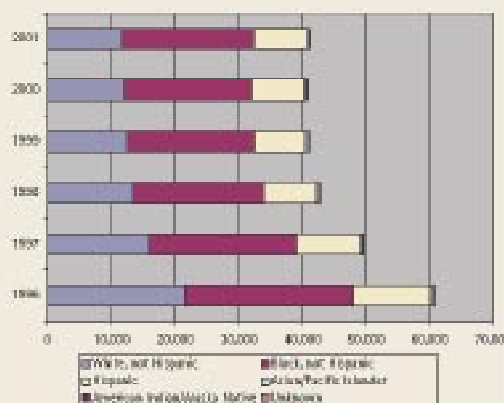
Racial breakdown of new HIV infections in 2002:



Source: CDC. *HIV/AIDS among African Americans*. February 2004.

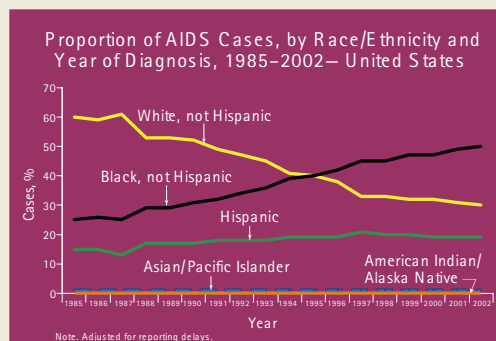
All states and territories report diagnosed AIDS cases to the CDC each year. Since the mid-1990s, the number of cases has steadily dropped among whites; not so for African Americans.

Estimated AIDS diagnoses by year and race, 1996-2001:



Source: CDC. *HIV Surveillance Report*, v. 13, n. 2, table 25.

As a result, Blacks account for a steadily increasing share of the epidemic—half as of the end of 2002.



Source: CDC. *HIV/AIDS Surveillance by Race/Ethnicity L238 Slide Series*. Slide 2.



ing near a cure. They stave off death, but they do not eradicate the virus from the bodies of those infected; they merely slow its progression to AIDS. When people with advanced conditions stop taking the meds, their health deteriorates in just the same way it did throughout the 1980s. That means treatment for the nearly one million Americans estimated to already be living with HIV/AIDS will be an expensive, lifelong process.

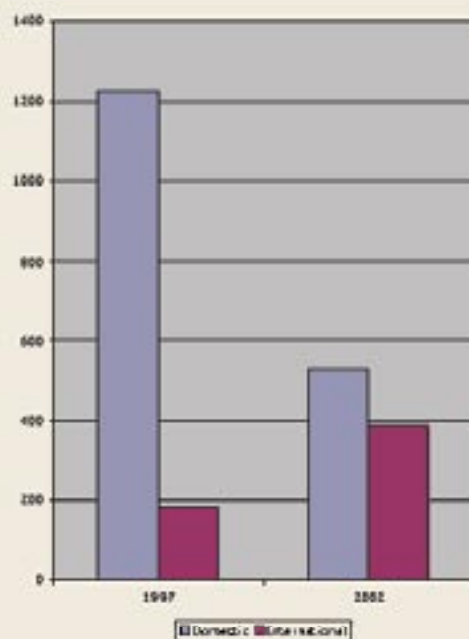
Meanwhile, the U.S. Centers for Disease Control and Prevention estimates that 40,000 people are newly infected with HIV each and

every year. These new infections are overwhelmingly African American. Of the nearly 27,000 people diagnosed with HIV or AIDS in 2002, African Americans accounted for 54 percent; we were just 12 percent of the overall U.S. population.<sup>3</sup> (See “A Black Epidemic” on page 13 and “It’s a Black Thing” on page 19.)

The Ryan White CARE Act already funds some 2,700 programs, serving over half a million people. But based on current trends, the vast majority of the people newly infected each year will rely on that system when they go to look for care and treatment. Today,

**Figure 1**

Domestic versus Globally-focused news reports on HIV:



Source: Brodie M and others. "AIDS at 21: Media Coverage of the HIV Epidemic, 1981-2002." Kaiser Family Foundation. Published in the March/April 2004 issue of *Columbia Journalism Review*.

almost half of those receiving treatment for HIV infection in the U.S. have incomes below \$10,000 and 63 percent are unemployed.<sup>4</sup>

And yet, as the work of CARE Act programs grows exponentially every year, our nation's commitment to them is hardly keeping pace.

Since the Bush Administration took office, CARE Act funding has increased less than \$200 million—from just over \$1.8 billion in 2001 to just over \$2 billion today.<sup>5</sup> In fiscal year 2004, Washington actually cut funding for the portion of the Act that pays for emergency services like counseling and substance abuse treatment. And for fiscal year 2005, lawmakers—led by the White House—flat funded all but one portion of the CARE Act, leaving the budget cuts of the previous

year in place. To make matters worse, Congress mandated that all non-defense programs receive an additional 0.87 percent cut after their final budget levels were set.

The White House had not yet submitted its budget proposal for fiscal year 2006 at the time of this report's writing, but most observers expect the Administration to again call for flat funding of domestic AIDS programs.

Meanwhile, in 2002 there were more people living with AIDS diagnoses than at any previous time in the epidemic, almost 385,000 people.<sup>6</sup> The CDC estimates that another half a million people are living with HIV and that more than half of those people have received no HIV-related care whatsoever.<sup>7</sup> (See "More Need, Less Money" on page 16.)

Culturally and politically, we have declared a premature victory over AIDS in the U.S.

## Lost Focus

**When death rates began dropping as a result of the new drug therapies in the mid-1990s, our policy priorities turned from providing comprehensive care and preventing new infections to aiding the process of getting back to normal. We passed the Workforce Improvement Act, a much-needed law that helped people with disabilities such as HIV return to work without losing the benefits that keep them healthy. Then, what energy remained for AIDS turned overseas.**

A recent study by the Kaiser Family Foundation tracked trends in the news media's coverage of HIV/AIDS. It found that between 1997—a year after combination therapy became widespread—and 2002, the number of stories broadcast or published that focused on the United States decreased 57 percent. In the same time period, the number of stories with at least some global focus grew







## More Need, Less Money

Funding for the Ryan White CARE Act exploded upward after combination therapy emerged in 1995. The drugs kept people alive, which meant larger and more expensive caseloads. Each year, AIDS activists convinced Washington to provide more money, keeping the overwhelmed care and treatment programs that Ryan White funds afloat. In 2001, however, Washington's priorities shifted—and its coffers closed. The steady growth in funding for Ryan White first slowed, and then stopped altogether.

Ryan White CARE Act funding, fiscal years 1995 to 2005 (in billions):

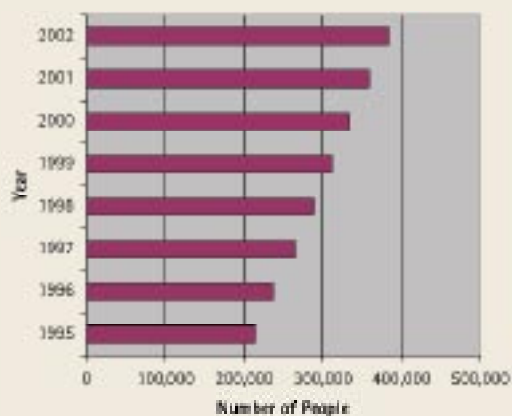


Source: Summers T, Kates, J. *Trends in U.S. Government Funding for HIV/AIDS, Fiscal Years 1981 to 2004*. Figure 4. Kaiser Family Foundation. March 2004.

Meanwhile, the growth of people diagnosed with AIDS, and thus in need of care, has not slowed. **As of 2002, more Americans were diagnosed with AIDS than ever before; 42 percent of them were African American.**

The U.S. Centers for Disease Control and Prevention estimates that another half a million people are HIV positive today, and that more than half of those people have received no HIV-related care whatsoever. In addition, the CDC estimates 40,000 new people are infected with the virus every year.

Estimated number of people diagnosed with AIDS in the U.S., 1995 to 2002:



Sources: CDC. *HIV/AIDS Surveillance Report*, v. 14, Table 10 and v. 13, no. 2, table 29.

by 118 percent. By 2002, 40 percent of stories were at least in part globally focused.<sup>8</sup> (See Figure 1.)

Washington's enthusiasm was similarly redirected. President Bush's FY2005 budget proposal included \$2.8 billion for global HIV/AIDS programs, part of his 2003 pledge to boost global spending by \$15 billion by 2008.<sup>9</sup> The proposal marked an international

spending increase of more than 200 percent since the Bush Administration took office. But the same budget proposal left all but one domestic HIV/AIDS spending category at the same levels as the previous year. (See "Robbing Peter to Pay Paul?" on page 17.)

But in metropolitan areas and Black neighborhoods across the country, AIDS service organizations and free clinics are

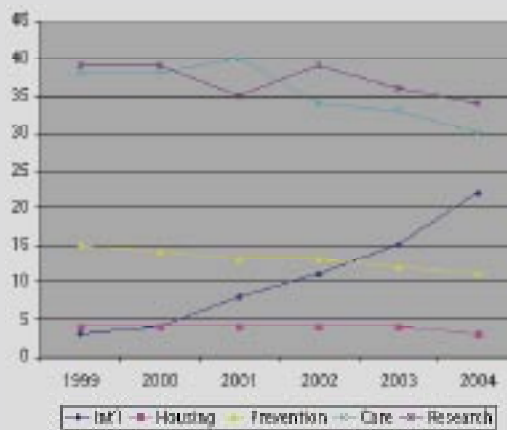
## Robbing Peter to Pay Paul?

Overall federal spending on HIV/AIDS has steadily increased every year since the epidemic began. But in recent years that increase has been driven largely by rising costs of the Medicaid and Medicare programs. Because those are “entitlement” programs, the feds commit to paying a set percentage of each state’s costs, regardless of how high the bill gets. Most federal AIDS programs, including those funded by the Ryan White CARE Act, are instead “discretionary,” which means Congress decides each year how much money Washington will spend.

Within the discretionary pool of money, spending on domestic care programs rose as a percentage of the overall HIV/AIDS budget each year between 1995 and 2001, as providers struggled to keep up with growing demand. In 2001, however, the share of the AIDS budget dedicated to domestic care programs began dropping sharply, while international spend-

ing climbed. It’s a trend driven by the fact that Congress—at the White House’s request—has flat-funded domestic care programs in recent years. And it begs an uncomfortable question about Washington’s newfound interest in the international effort against HIV/AIDS: Are lawmakers robbing Peter to pay Paul?

Distribution of federal discretionary HIV/AIDS funding, fiscal years 1999 to 2004:



Source: Summers T, Kates, J. Trends in U.S. Government Funding for HIV/AIDS, Fiscal Years 1981 to 2004. Figure 3. Kaiser Family Foundation. March 2004.



struggling to serve just their existing clients—never mind the thousands more that will come each year.

The CAEAR Coalition surveyed the local planning councils that oversee how cities spend their federal AIDS grants. Around the country, planning councils testified to having to reduce the level of services they offered last year, thanks to the FY2004 funding cut. (See “How the Safety Net Works” on page 18.)

In Baltimore, local agencies served almost 4,000 fewer clients. Houston expected agencies to develop waiting lists for services and, at the time of the survey, was developing more restrictive qualification guidelines in order to forestall such lines. Newark predicted its safety net would catch 30 percent fewer clients as a result of the funding cut; the city

had to discontinue programs ranging from outreach to residential substance abuse treatment. New Orleans closed enrollment for new patients in its HIV primary care clinics.<sup>10</sup> The list goes on.

Across the country, cities are abandoning HIV/AIDS treatment and prevention programs that have proven to be effective because they do not have the resources to support them. The AIDS care safety net is rapidly fraying even as we blithely take its strength for granted.

In 2005, Congress will have to “re-authorize” the Ryan White CARE Act. Because the CARE Act is not an entitlement program—like Medicaid or Section 8 housing, for instance—lawmakers must not only budget discrete sums for it each year, but also

must re-approve it every five years. At that time, Congress debates what, if any, changes it wants to make to the country's domestic AIDS programs. The African American community should first demand adequate fund-

ing for these vital programs in coming fiscal years. But the crumbling system needs more than additional money; policymakers and the communities affected must also find ways to make a system that was conceived as an

## 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 increased less than \$2 million—from just over \$1.8 billion in fiscal year 2001 to just over \$2 billion in fiscal year 2005.

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. (See Chapter Two.)

**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.*



# It's a Black Thing

- Blacks account for **38 percent of all re-reported AIDS cases** since the beginning of the epidemic.
- The AIDS case rate among Blacks in 2001 was nearly **11 times higher** than that among whites.
- Blacks accounted for **two-thirds of new teen AIDS cases** in 2001, but Blacks are only 15 percent of the overall teenage population.

- Blacks account for **54 percent of all new HIV infections**.
- Black women represent **72 percent of new HIV infections** among women in the U.S.
- Among Blacks with HIV/AIDS, **59 percent rely on Medicaid** and 22 percent are uninsured.
- HIV/AIDS is among the **leading causes of death** for Black men and women in the U.S.
- African Americans living with HIV are **seven times more likely to die** from it than whites.

emergency response to a temporary problem into one that can cope with a lasting and still-expanding epidemic. State and local governments face the same challenge, and several have already begun the restructuring process. Black America must not wait until the end to get involved in these discussions.

## Notes

1. For an easy-to-use guide to understanding the myriad tests and diagnostics healthcare providers use to track a patient's HIV, see POZ magazine's special edition, Blood Simple, Fall 2003. The edition is also available online at [www.poz.com](http://www.poz.com).
2. Hopkins E. Congressional Testimony For Increases in FY 2003 Federal AIDS Funding. San Francisco AIDS Foundation. April 30, 2002.
3. Centers for Disease Control and Prevention (CDC). HIV/AIDS among African Americans [Fact sheet]. February 2004.
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# God's Gift of Motherhood

*Deneen Robinson found the strength to fight her HIV infection by sharing the diagnosis with her young daughters*

**L**iving with HIV has meant many things to me. HIV has meant joy, sadness, medications, doctor visits, health, sickness, life and death. In the midst of all these ups and downs, my children have been a constant and consistent source of strength.

I remember very clearly when I was diagnosed HIV positive. On that day, my first thought was not for me; it was for my children. I said, "Oh my God, my babies. What will happen to my babies?" At that time, my children were two and four years old. I just knew I would not be around another week, let alone the ten years it's been since then.

But the doctor said to me, "People are living a lot longer with HIV. Some people are living six years, maybe longer." In that moment, I thought, perhaps, things would be okay. I'd have time to plant some seeds, so that my children will not forget me. I'd also have an opportunity to begin to instill in them the lessons that would help them grow up to be strong and resilient women.

I have always believed that motherhood is a great gift from God. And for me, being given the blessing to parent meant responsibility too. I knew I had to live up to what I believed that responsibility meant. So in the moment I was given my HIV diagnosis, I decided to work on being both the best me and the best parent that I could be. I will not begin to say it has been easy; it has not. But it has been very rewarding.

One of the greatest rewards came when I decided to share my diagnosis with my daughters. It was in 1994. Their school had given a lecture on HIV/AIDS, and I remember thinking, "What a great opportunity to share my HIV status." I initially asked them what they thought of the school's presentation. My oldest daughter, Emma, said she understood what HIV and AIDS were. She went on to draw a picture of two girls. The girls were identical in every way except that one girl had a smile and the other had a frown. As the parent in this discussion, I was admittedly curious as to the meaning of that difference. Emma explained. "Both girls have AIDS", she said. "The girl with the smile has AIDS and did not tell. The girl with the frown had AIDS and told."

Both of my daughters then began to share what they would do if I had AIDS. My youngest daughter said with disgust, "If you had AIDS, mama, I would run away. I



would pack my things and leave. I do not want to stay with someone who has AIDS. No way!” Then Emma, the oldest, said, “Yeah! I do not want a mama with AIDS. So if you do have AIDS don’t tell us or we will leave.”

Now, mind you, they were five and six at the time. So, I let the opportunity to disclose my HIV status go by, and said simply, “Well, I was just curious. I just wanted to know what you were thinking.” After their comments, there was no way I was going to tell them my HIV status. So I went out and rented a copy of the video by Arsenio Hall and Magic Johnson on living with HIV/AIDS. The video showed all types of people living with HIV. The following Saturday, Emma, Jamie and I watched it together.

After the video, my youngest daughter, Jamie, asked me if I was HIV positive. I said, “Yes.” They both then said, “That’s okay, mommy. We won’t leave you or run away. We still love you.” In that moment, I felt honored to be their mom. I realize now they just wanted me to be honest with them.

I have not forgotten that lesson. My choosing to share my diagnosis with them has changed our relationship as a family. I believe my daughters have learned how important it is to be honest. Their acceptance of me has framed my entire life with HIV. Knowing they love me gives me courage to be open with others. When I am talking to the women who now participate in the social support group I created, I remember the power and permission I have been given by my family.

Today, my family includes an incredible partner who loves me deeply. I daily experience joy when I see their beautiful smiles and hear their laughter. I have a God that accepts me. I have two daughters that show me their love every single day, when they kiss me good night and ask me if I need water so that I can take my meds. I am blessed.

There have been times in the past ten years that I have faltered. I have the courage to try again because I know that my daughters depend on me. I know that I am their example of what it means to be a woman, a fighter, and a survivor. I am so thankful for their love and understanding as I walk through this life. They give me strength to go on day to day.

I can say that I realize how fortunate I am to have the life I do. I know there are readers who are living with HIV but do not have the freedom I experience—this story is for you. I hope you can see the joy that comes from being honest with those you love. That honesty is the first step on the road toward freedom.



GREG McNEAL

*This essay first appeared in BAI's special coverage of the 14th International Conference on HIV/AIDS in Barcelona, Spain. Deneen Robinson is an HIV treatment educator and activist in Dallas, Texas. She has been living with HIV for 12 years.*



## CHAPTER TWO

# We're Still Dying

**“WHEN PLAGUES END” are the words that blared from the cover of the *New York Times Magazine’s* now infamous November 10, 1996 issue. The essay inside announced to the *Times’* nearly two million Sunday readers that HIV had finally stopped killing, that science had turned the virus into a manageable, if chronic ailment.<sup>1</sup>**

Written by conservative gay thinker Andrew Sullivan, the essay is today an iconic example of how white America has moved on from AIDS, of the nation’s false assurance that the worst is behind us.

But despite all the controversy it still causes, Sullivan’s essay was accurate. He perfectly captured the morning-after Zeitgeist that was then sweeping through his community of middle- and upper-middle-class white gay men—people who were not only among those most ravaged by AIDS, but were also among the most vocal leaders in the 15-year-old movement that had forced America to notice.

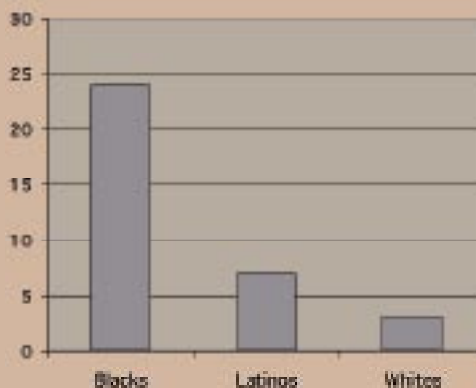
Between 1995 and 1998, Sullivan’s world sighed in collective relief as HIV mortality in the U.S. dropped a staggering 70 percent.<sup>2</sup> Among whites, deaths dropped from more

than 22,000 in 1994 to just over 7,000 in 1997.<sup>3</sup>

**Figure 1**

African Americans are seven times more likely to die from HIV infection than whites.

AIDS Death rate per 100,000 people by race and ethnicity:



Source: Agency for Health Care Research and Quality. U.S. Department of Health and Human Services. *National Healthcare Disparities Report: Prepublication Files. Chapter 3.*

Science had armed doctors with new anti-HIV medicines, and they were using these miracle drugs in groundbreaking “combination therapies” to beat back death—well, at least for those who could afford it.

While the plague slowed in one community, it went on wreaking havoc in others. Death rates declined among Blacks and Latinos, but far more slowly than among whites. In 1996, for the first time since the epidemic began, more Blacks than whites died from AIDS. By 2001, our annual death toll was nearly double that of whites living with HIV.<sup>4</sup>

Since then, we have made slow but steady progress in lowering Black death rates by plugging more and more people into the publicly-funded care system. But still today, African Americans living with HIV are seven times more likely to die from it than whites.<sup>5</sup> And once diagnosed with AIDS, Blacks die faster than any other racial or ethnic group. (See Figures 1 and 2.)

As of 2000, AIDS remained the leading cause of death for Blacks between the ages of 25 and 44.<sup>6</sup> For the country at large, it wasn’t even in the top 15.<sup>7</sup>

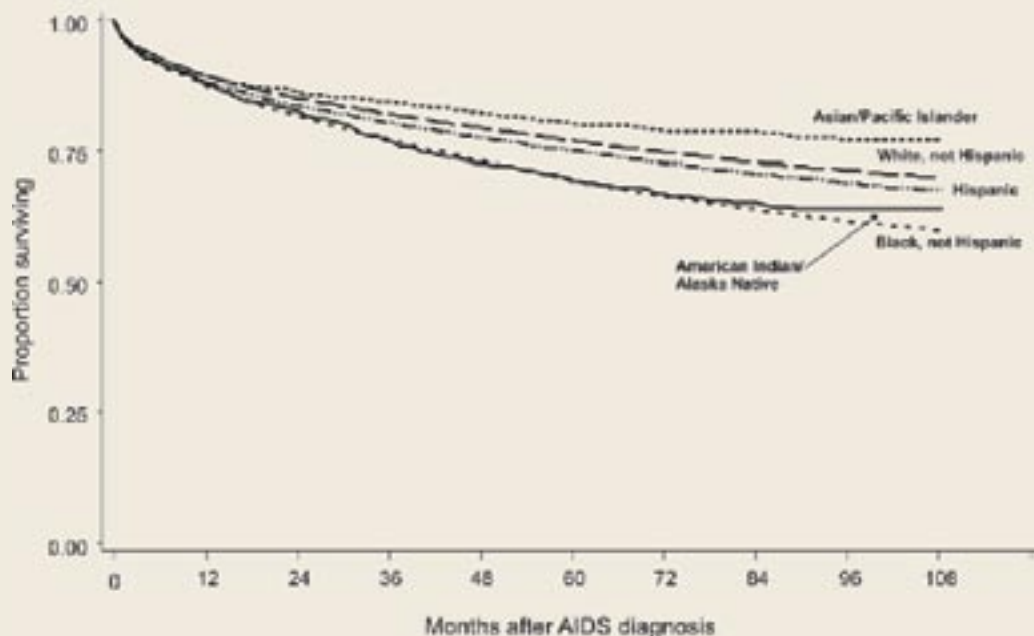
## Less Care, Less Funding

**There are no simple answers to the question of why the death rates have fallen so much more slowly among African Americans than whites. Observers have offered a lengthy and growing list of the potential problems: There are too few Black doctors who specialize in HIV. African Americans discover their infections later than whites, and thus the virus has advanced to its end stages by the time we begin treatment. And of course there are the perennial difficulties patients have in following their treatment regimens.**

HIV drugs are demanding. They require

**Figure 2**

Proportion of people who survive, by months after an AIDS diagnosis



Source: CDC. HIV/AIDS Surveillance Report, v. 15, figure 4.



# Inside the Complicated World of Drug Pricing

The first thing to understand about pricing for HIV drugs is that no one involved in setting the price a consumer pays at the pharmacy checkout counter wants you to understand the pricing structure.

The only price drug companies officially make public for each of their drugs is the **wholesale acquisition cost**. This is the price given to wholesalers, who buy up the drugs in bulk and sell them to pharmacies and care programs that distribute meds themselves. By buying in bulk or exploiting a variety of rebate strategies, large pharmacies typically pay less than this publicly released price. Once obtained, pharmacies then each set their own retail prices, which include mark-ups for their own costs and profits.

State and federal government programs, meanwhile, use a host of complicated formulas to determine what size of rebate they demand from pharmaceutical companies for the HIV drugs they buy. Those formulas are based on the **average manufacturer price, or AMP**, which is a federally-calculated average of prices paid by private sector buyers. It is not

publicly disclosed.

When quoting prices for a given drug, however, most analysts use something called the **average wholesale price, or AWP**. This is an average of the publicly-announced prices wholesalers quote to all buyers. Analysts estimate that the government AMP is around 20 percent below the AWP.

This Byzantine pricing system makes the AWP the best figure for measuring the monthly cost of a given HIV drug. Below are the AWP's for the 10 most-expensive AIDS meds.

Cost of month's supply of meds, based on AWP:

Drug	AWP
Trizivir	\$1,109.96
Norvir	771.54
Viracept	756.66
Fortovase	752.02
Agenerase	735.54
Kaletra	703.50
Combivir	685.28
Invirase	673.91
Crixivan	546.38
Sustiva	449.64

Source: Vazquez E. *Drug Prices. Postively Aware*. January/February 2003. For a more detailed overview of how HIV medication prices are set, see Huff, B. *Paying for Life: The Issues Behind Drug Pricing*. GHMC Treatment Issues, v.17, n. 11.



faithful adherence to a rigid dosing schedule and they cause side effects that disrupt daily routines. If someone has an unstable life or is juggling many responsibilities—from raising children to working multiple jobs—successful treatment requires far more than just having a doctor prescribe the right medicine; both patient and physician must figure out how to make the treatment regimen work within the

context of an individual's chaotic life.

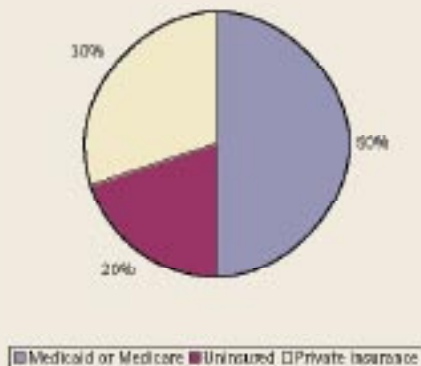
On top of all of these HIV-specific factors affecting the outcome of treatment, there's the increasingly recognized problem of health-care providers giving African Americans lesser quality care in general. In all areas of healthcare, researchers are finding that African Americans, regardless of health insurance status, regularly receive lower quality care



## Breaking Medicaid's Bank

Almost half of people in treatment for AIDS pay for it through Medicaid...

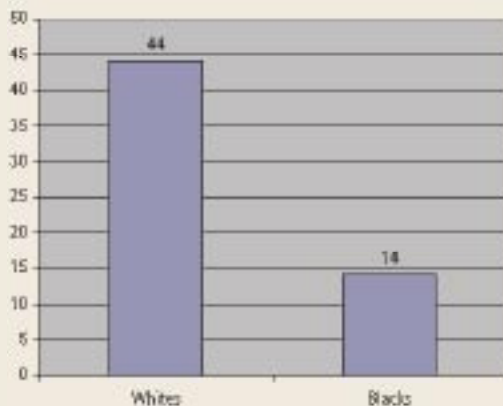
Distribution of payers for AIDS treatment in the U.S. by percentage:



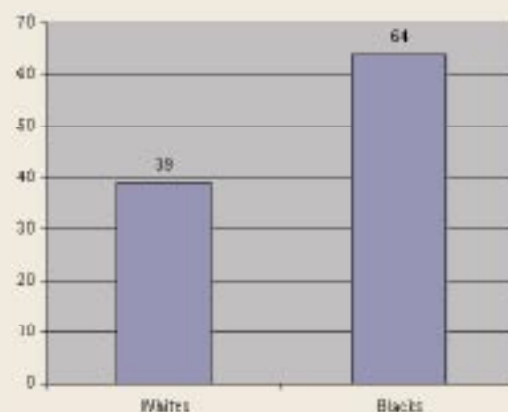
And African Americans with HIV subscribe to public insurance programs in far higher numbers than whites...

Black vs. white financing of HIV treatment by percentage:

Private insurance:

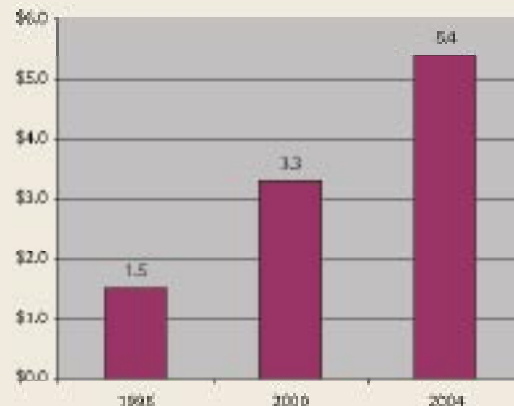


Medicaid or Medicare:



But the program's costs are exploding as the population of people living with AIDS balloons...

Medicaid spending in AIDS (billions):



As a result, state Medicaid programs around the country are buckling under the pressure of caring for people with long term illnesses like HIV/AIDS. Medicaid accounted for 16 percent of all state government spending in FY2002—making it a primary target for cost reductions during the difficult budgetary times all states are facing. **In a recent survey, 49 states said they had implemented or planned to implement Medicaid cost-containment steps.**

Sources: Kaiser Family Foundation. "HIV/AIDS Policy Fact Sheet: Medicaid and HIV/AIDS"; KFF "State Fiscal Conditions and Medicaid, April 2004;" KFF, "Financing HIV/AIDS Care: A Quilt with Many Holes," May 2004.



and have poorer outcomes from their care than whites.<sup>8</sup> HIV is no different.

One recent study found that African Americans who are in treatment for HIV infection were twice as likely as whites to have not received combination therapy in the last year. And almost 30 percent of Blacks in treatment hadn't gotten medications for opportunistic infections in the previous six months, compared to 18 percent of whites.<sup>9</sup>

But even if we could guarantee everyone quality care, we wouldn't be able to pay for it for very long. As soon as protease inhibitors hit the market in the mid-1990s, drug companies began charging astronomical sums for the medicines, driving the price of treatment for an average patient up to \$10,000 to \$12,000 a year. When associated costs are added in, it's more like \$20,000 a year. (See "Inside the Complicated World of Drug Pricing" on page 25.)

For people with private insurance, this high cost of treatment isn't an insurmountable hurdle. But HIV is a virus that preys on poverty, and research shows that only about a third of people living with it have private insurance (compared to three quarters of Americans overall). Half of all people living with HIV are instead enrolled in Medicaid or Medicare, and a fifth have no insurance at all.<sup>10</sup>

Here again, the concern is heightened for African Americans. While 44 percent of whites in treatment have private insurance, only 14 percent of African Americans do. And while only 39 percent of whites in treatment depend on public insurance, 64 percent of African Americans receiving treatment for HIV pay for it with Medicaid or Medicare. (See "Breaking Medicaid's Bank" on page 26.)

## The Collapse of Public Insurance

**In just about every state, Medicaid is on the brink of financial ruin, largely due to the**

**program's burgeoning load of chronically ill and disabled subscribers. The program spends \$5.4 billion a year (not counting state money) to care for people living with HIV, and the number is fast growing.<sup>11</sup> The costs are driven by the care needs of people like Lynaree in Brooklyn's Bedford-Stuyvesant—one of many Black neighborhoods that are still struggling to recover from the neglect of the Reagan era.**

Lynaree has been in treatment for HIV since 1990. Today, she takes a daily combination of antiretroviral medicines. Like many middle-aged Black women, she's also got high blood pressure. So she takes another two pills a day for that condition, along with a water pill. She's been in the hospital three times in the last four years, and both of her conditions require at least bimonthly meetings with a physician.

Lynaree ticks off the different drug combos she's cycled through for both her HIV and high blood pressure with the confidence of a medical school student. "I went back on HIV medications in '95 or '96," she explains, when she enrolled in Medicaid. "I've taken all of the stuff that they were giving out in the '90s. I've had all kinds of side effects. Right now, I just have a bad sinus problem."

But Lynaree's previously undetectable viral load recently jumped to alarming levels. The AIDS virus is so difficult to treat because it mutates rapidly, finding ways to survive each combination of drugs you throw its way. That means that patients are constantly mixing and matching their antiretroviral regimens in an effort to stay a step ahead of their mutating viruses. But when someone is in treatment for many years, she slowly runs out of drugs that her virus hasn't yet seen. So if Lynaree's latest combo of drugs has pooped out, her long treatment history will work against her: Her virus may already have adapted to most drugs on the market. (See "Treating HIV over the Long Haul" on page 29.)



# Treating HIV over the Long Haul

**T**he number of Americans living with HIV who are over 45 years old grew by 60 percent between 1999 and 2002. The epidemic's aging is a sign of our success: We've learned how to keep people alive with HIV. But for African Americans, that success creates a strange conundrum. **As we grow old with HIV, our treatment for the virus will begin to collide with treatment for a host of other health concerns that plague aging Black folks.**

HIV kills by breaking into the white blood cells that organize an immune system's response to infections, taking them over and using them to copy itself. Once HIV has depleted these "T-cells," the body loses its ability to mobilize its natural defenses, and diseases that healthy people easily fend off turn fatal.

There are about 20 antiretroviral drugs available in the U.S. to stop this process. Antiretrovirals work by also breaking into T-cells, then interrupting one or another stage of HIV's replication cycle. But once inside the cells, the drugs often disrupt more than just HIV. People lose muscle and fat in their faces; develop lumps of fat in their stomachs and necks, giving them a hunchback appearance; and get nerve damage in their feet and hands.

But what is perhaps most troubling for African Americans is that protease inhibitors are associated with high blood sugar and cholesterol levels, which means they may

be inflaming the diabetes and heart disease epidemics in Black neighborhoods. They may also be frustrating treatment, since the AIDS drugs can also make people resistant to insulin. "A patient will be on the same insulin dose for a while and then—boom—it's suddenly harder to control the sugar," says Dr. Hilario Organista. "But you want to treat the HIV," he explains. "If you can treat both without side effects, then yes, that's better. Sometimes you get away with it."

The calculus for doctors treating aging African Americans can be dizzying. HIV meds drive up the cholesterol of a patient with heart disease, so doctors give him or her drugs for that problem. But the cholesterol meds can cause liver problems, and that makes it harder for HIV drugs to work.

The liver and kidneys, in fact, are always a flashpoint for long-term HIV treatment. That's where the body breaks the antiretrovirals down, which takes a lot of work. Patients who have used lots of drugs or alcohol are likely to start off with a weak liver or kidneys. In such cases, doctors have to strike the anti-HIV drugs that are particularly hard on those organs off of their list of options. That's something no HIV doc wants to do, because HIV mutates quickly, developing drug resistance.

So far, researchers know only that there's a relationship between all of these conditions and antiretrovirals; they cannot say definitively what the ramifications are. In fact, we know very little about the long-term effects of any of the anti-HIV medications now on the market. Are the current side effects merely early warning signs of deeper problems? How long will they continue to suppress the virus? And what happens as the body ages and becomes less tolerant to such toxic treatments?

Government, academic and drug company researchers are acutely aware of the ironic dilemma Lynaree represents: The more successful physicians are at keeping patients alive without a cure, the harder their success will be to maintain. So researchers are frantically coming up with new curveballs to

throw at the AIDS virus by tweaking existing treatments. The modifications that they are slowly developing have been dubbed "salvage" therapy. The earliest "salvage" drug to hit the market is called T-20, sold under the brand name Fuzeon. But doctors and patients have been as alarmed by its pricing as they

are excited by its treatment potential: It can cost as much as \$20,000 a year.

As HIV patients age, staying in treatment for longer and longer periods of time, Medicaid will not be able to support such drug costs—even when discounted through government purchase programs. Along with the associated costs of long-term care—such as nursing homes and home health aides—drug costs are already killing Medicaid budgets around the country.

But Washington has done little to help states keep their public health insurance programs alive. Last year, Congress offered states an emergency infusion of money to help make ends meet, but no such rescue is on the way this year. The Bush Administration has instead spent the past four years pushing a proposal that would turn Medicaid into a “block grant.” Currently, with the program budgeted as an entitlement, the feds pay an agreed upon share of the costs each year, no matter how high those costs go. Under a block grant system, states would get one, predetermined payment each year and any costs beyond that spending level would be theirs alone.

In return for limiting the federal funding commitment to Medicaid, the Administration’s plan would drop many of the rules that govern how states must run their programs. When starved for resources, states will have little choice but to find ways to limit spending. That will mean limiting the scope of care they can offer their most expensive subscribers—people like Lynaree.

On the other hand, AIDS activists in Washington have for several years been pushing a bill that would expand Medicaid eligibility rules to cover more people living with HIV. Currently, to qualify for Medicaid you must both have an income below a certain level and represent one of a few categories: parents and children, seniors and the disabled. Most people now getting HIV care through Medicaid qualify as disabled because

their infection has advanced to the stage of an AIDS diagnosis. But that means that low-income people living with HIV are not able to get into treatment until they are on the brink of illness—a stage at which healthcare providers widely agree successful treatment is both more difficult and more expensive.

The Early Treatment for HIV Act would allow states to expand their Medicaid systems to cover people with an HIV diagnosis who are not yet disabled, just as a 2000 law gave states the option of covering women diagnosed with breast and cervical cancer. Since the Bush Administration began pushing its plan to reshape Medicaid as a block grant, however, the conversation about Medicaid and HIV in Washington has changed dramatically—from one focused on expansion to one about how to hold onto current benefits.

It’s also unclear just what the new incarnation of Medicare will mean for HIV treatment. Currently, those in Medicare who are poor enough to qualify for Medicaid get their drugs either for free or for a nominal co-pay of around \$1 a month. These individuals are called “dual eligibles” and an estimated 13 percent of people getting HIV care are in that category.<sup>12</sup> But under the new Medicare system, crafted by the Bush Administration and passed by Congress in the fall of 2003, states will no longer be able to use their Medicaid programs to pick up the drug costs for dual eligibles. Instead, Medicare will oversee the drug benefit, but it will cost even the poorest subscribers from \$3 to \$5 a month per prescription—a cost that will go up at what the Congressional Budget Office predicts will be a 10 percent annual rate.

But there is a still more troubling aspect of the new Medicare system for people in treatment for HIV. The program’s new drug benefit will be administered by private insurers, and the rules stipulate only that those insurers must offer one drug per class of medications. Since long-term HIV treatment



means constantly mixing and matching meds within a given class—and waiting on edge for the latest, most expensive “salvage” versions to hit the market—it’s likely that treatment for many Medicare patients will be interrupted, or stopped altogether, when they reach for the next drug and find that their plan does not offer it.

## An Annual Crisis We Never Expect

For the fifth of all people living with HIV who are uninsured, Congress created the

**AIDS Drug Assistance Program, or ADAP. The program is funded through joint federal and state money, and run by each state. It buys drugs from pharmaceutical companies at discounted bulk rates, using a formula similar to that employed by Medicaid, and distributes them to the uninsured. (See “How the Safety Net Works” on page 18.)**

Thirty-three percent of ADAP clients are African American and 25 percent are Latino. Over 80 percent of them earn less than 200 percent of the federal poverty level.<sup>13</sup> Without ADAP, these people would likely be dying at the same rates we saw in the 1980s.

In June 2003 alone, ADAPs around the country filled more than 300,000 prescriptions at a cost of more than \$77 million.<sup>14</sup> But every year since protease inhibitors emerged in the mid-1990s, these programs have spiraled deeper into financial crisis. As the drugs have kept people alive longer (and thus in treatment longer), the program’s costs have grown at a much quicker pace than have either federal or state funding.

As of the beginning of November 2004, more than 800 people in nine states were on waiting lists for treatment due to lack of funding for their states’ ADAP programs. Another 13 states had capped enrollment or set

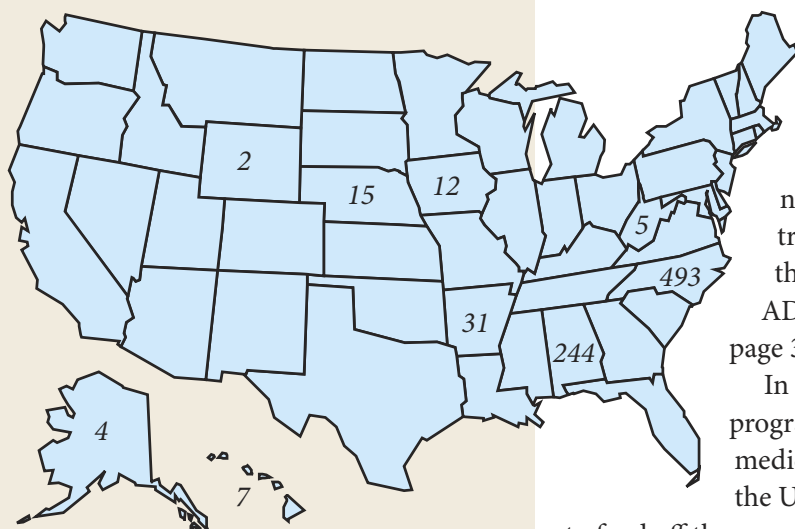
up other cost-containment measures, such as limiting what drugs are available, and six states said they would create new or expanded cost-control measures by the end of this fiscal year.<sup>15</sup> (See “The ADAP Funding Crisis” on page 31.)

In fact, only 17 state ADAP programs offer the full range of medicines recommended by the U.S. Public Health Service

to fend off the opportunistic infections that disable and, ultimately, kill people with HIV. Sixteen states do not offer all antiretroviral

## The ADAP Funding Crisis

As of November 2004, 813 people in nine states were on waiting lists for treatment.



Source: National Alliance of State and Territorial AIDS Directors.



# An Interview with Dr. Anthony Fauci



**D**r. Anthony Fauci has been the federal government's scientific point-person on infectious diseases since 1984. As the head of the National Institutes of Allergy and Infectious Diseases, he leads the effort to find better ways to treat HIV and keep people living with it healthy. The Black AIDS Institute spoke with him in July 2004, during the 15th International Conference on HIV/AIDS in Bangkok, Thailand, about Washington's waning interest in the domestic HIV epidemic.

**BAI: There's concern among African Americans that the domestic epidemic has fallen off the agenda.**

Fauci: That is not the case. That is obviously the concern of some people whose constituencies are seriously impacted by the serious and ongoing epidemic in the United States. There is a very acute awareness in the federal health establishment

that we are not out of the woods with HIV by any means. When I have discussions with [Administration leaders] about the global pandemic, it always comes up that we should not forget the significance of the domestic one.... This is not off the radar screen by any means.

**But are we actually doing enough to stop the epidemic among Black Americans, given the increasing infection rates and disproportionate death rates? Is the administration and Congress doing enough?**

I certainly think we need to pay ongoing attention to the problems in the United States until you have the epidemic

completely under control. I've been to 15 of these conferences, and every time I hear the question, 'Are we doing enough?' There is no such thing as 'enough' until we take care of the problem.

**We know that Blacks living with HIV are seven times more likely to die from it than whites. Why is that? Why do we still see this sort of disproportionate death rate?**

I think the lack of access to drugs—access to drugs, access to counseling, people starting therapy when their virus is more advanced. If you had a situation where young African American men and women could come forward sooner, find out they are infected and get treated earlier [treatment might be more effective]. White or Black, if you treat someone earlier on, it is much more successful than when their immune system is weak.



drugs approved by the Food and Drug Administration.<sup>16</sup>

In June 2004, President Bush pledged a one-time, emergency infusion of \$20 million to eradicate the existing ADAP waiting lists. At the time, more than 1,700 people were on waiting lists. Since then, states have been able to enroll about a third of those people on their own, while the emergency federal money has covered about another third. As of November, most of those still on waiting lists were expected to eventually get care under the president's initiative, but an additional four states had developed new waiting lists that will not be covered by the emergency money. And the lingering question at the time of this paper's writing was: will the White House's budget proposal this year once again inadequately fund ADAP, setting up the same crisis next year?

History does not provide much hope. Despite ADAP's annual budgetary shortfalls, year after year Congress either funds it at the same level or offers small, inadequate increases. The fiscal year 2005 budget offered ADAP only a small funding boost (\$35 million) and flat funded the rest of the Ryan White CARE Act.

ADAP's budget problems will only worsen. As people live longer, churning through drug regimens as they race to keep up with their ever-mutating virus, the demand for the newest and most expensive meds will grow.

Meanwhile, at both the national and local level, public health officials unanimously agree that they must intensify their efforts to get more people living with HIV to learn their status. The Centers for Disease Control and Prevention estimates nearly a third of people living with the virus don't know they have it, and it aims to lower that number by newly testing 30,000 people a year for HIV.<sup>17</sup> But one must ask, to what end? If the CDC's effort succeeds, it will certainly overwhelm the public care and treatment system. Without a real commitment to financing care

and treatment from Congress and the White House, federal health officials are simply working against themselves.

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# Some Call Me a Survivor

*Kwabena Rainey Cheeks has been doing battle with HIV for two decades. He's winning.*

**S**ome call me a survivor because I am a Black 49-year-old gay man that got through the public school system living in Washington, D.C. Oh yes, I have survived racism, classism and homophobia, and, on top of all of that, I have been HIV positive since 1984. Some say I have AIDS; that depends on which month you check. Yes, I AM A SURVIVOR! As the song says, "Ain't got time to die."

I have been in the hospital three times. The first time, in 1990, I was told I would never walk and that I would be dead by Christmas. I asked the doctor who told him this, and he answered, simply, "This is my professional opinion." Everyone has a turning point in his or her life, something that says give up and die or fight back. And at that moment in 1990, I had to make a choice: agree with his professional opinion, lie down, wait for Christmas and die, or, get up and do something that would make things count. If I did die at Christmas, at least I would have made a mark—at least someone would know my name. So I stopped worrying about dying.

Death does not scare me, the truth is everyone is going to face it. All that is important is what we do while we are here. I love life, so I make every moment count for something.

I believe adversity comes into our lives just to help us discover what we truly believe. Do you believe more in the problems or your ability to solve them? Do you believe more in your fear or your faith? I personally believe in God, and my God has prepared me for any and every thing. So the choice of what to believe in is mine—and if I don't have the answer, I know how to find it.

To survive in this world, we have to first believe that we are worth being here, that our lives count. We must love ourselves so much that we won't let anyone or anything take us out. When I look back over my life, and think of the things I have overcome this far, how can I give up? When that's not enough, I think about my ancestors and what they had to survive. My mother never had a computer or a 401k plan. She didn't have a car; she could not even drive. But she worked two jobs everyday, volunteered in the public school for over 20 years and raised six children and eight grandchildren. She was an ordinary Black woman—a survivor.

When I think about what my mother did with what she had, there is no way I can even think about giving up. Does that mean things are any easier for me? Has racism or classism or homophobia or any of the other “isms” been removed for my world? Not at all, that's not the question or the problem. The question is what am I willing to get up and do about it.

You have a choice. You can be on the sideline or in the game. You can always find a reason not to do something—we all do from time to time. But when it comes to your survival, say yes to life! Let go of anyone and anything that does not support you. I know this is not as easy as it sounds, but if it is worth having, it's worth fighting for. The challenge is finding your passion—what makes you happy, what brings you joy—and going for it.

Too often we think of survivors as people that have climbed some exceptionally great mountain, or have crossed some unimaginable ocean. But we all have mountains to climb and rivers to cross in our lives. Before David fought Goliath, he said, I have fought lions and bears, what is a giant? So the next time your Goliath is ready to fight, remember you have already fought lions and bears. Get up and go do battle! The next time you are looking for the survivor, just go to the mirror and look in your own eyes, you will see the greatest survivor of them all—yourself.

*This essay first appeared in the May/June 2001 issue of Kujisource, marking the 20th anniversary of the AIDS epidemic. Kwabena Rainey Cheeks was a founding member of the Unity Fellowship Church Movement, and has been an HIV/AIDS and LGBT issues activist for more than 20 years.*





## CHAPTER THREE

# Drugs and HIV: An Arranged Marriage

**Robert Soto is known as “the polar bear” by folks on the block—that’s the block, an infamous stretch of Brooklyn’s Bushwick neighborhood where the New York Police Department has been trying for a decade to get rid of the drug trade. Since 1992, when the *New York Times* identified the area as one of the country’s most brazen drug markets, the cops have spared nothing trying to bring it under control.<sup>1</sup> None of it has worked.**

Rain or shine, Soto’s out here three nights a week. That’s why they call him the polar bear—he never gets cold. “They got the best heroin over here, so they keep coming back,” Soto says, explaining why police can’t snuff it out. “Even people as far as Rochester know it,” he laughs, shaking his head in marvel. “Knickerbocker and Troutman!”

Sitting hunched over in the door of his van, an unlit cigarette dangling over his graying goatee, Soto comes off like a Latin Tony Soprano. In fact, his whole crew looks and acts like drug dealers. They strut up and down Knickerbocker, moving like they have all the time in the world and tossing knowing head nods at the uniformly Black and brown

faces that roam these streets.

But Soto’s not selling dope; he’s distributing clean needles and condoms and first-aid kits. If you’re going to connect with people on a block this charged, you’ve got to blend in, let them see you’re not an undercover cop. And you’ve got to work just as hard as the drug dealers, pounding the pavement until the middle of the morning in all kinds of weather.

The stakes are high: More than half of all new HIV infections each year in America’s 100 largest cities are contracted through dirty needles.<sup>2</sup> Since the epidemic’s start, 57 percent of all diagnosed female AIDS cases and 31 percent of those among men have been directly related to intravenous drug use (as of 2000).<sup>3</sup>

Moreover, people who contract HIV from dirty needles find out about it later than others—meaning they both are more likely to have unknowingly spread the virus and are more likely to die from it. Of all reported HIV cases in 2002, more injection drug users advanced to an AIDS diagnosis within 12 months after testing positive than any other category. Among male injection drug users,



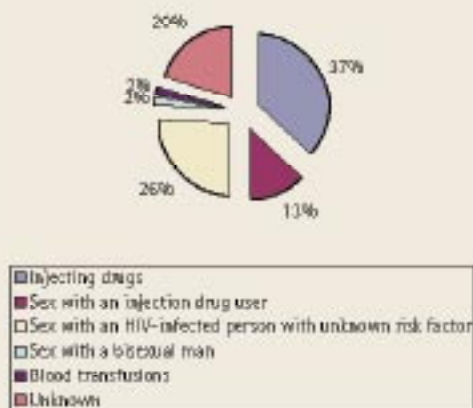


## Needles, HIV and Black America

Percentage of diagnosed Black AIDS cases attributable to needle sharing, cumulative through 2003:



Routes of infection for all diagnosed AIDS cases among Black women, cumulative through 2003:



Source: CDC. *HIV Surveillance Report*, v. 15, tables 19-22.

46 percent developed AIDS inside a year of testing positive; the same was true for 34 percent of female users.<sup>4</sup> So programs like Soto's are not only working to get contaminated needles off the streets, they're trying to

get the folks using them tested and into care sooner as well.

Soto and his coworkers park their outreach van halfway between the area's prostitution and drug markets, which puts it right in the path of sex workers coming to and fro. "Yo, you got condoms?" asks someone in a group passing by. One of the women—though, she doesn't look too far off childhood—wears her long hair in a swoop down the side of her face and neck. Soto guesses she's hiding track marks; when you've been using hard for a long time, you've got to find places to shoot where you can get a quicker, stronger high—like the neck.

Up the street, several of Soto's regular customers are lingering in front of a bodega. One guy's been trying to get his girlfriend into detox through Soto for weeks, but she won't show up for the appointments. They're both waiting for some clean needles and first-aid kits, but Soto can't get them to walk down to the van. This kind of passiveness is why he'd prefer to park right at Troutman and Knickerbocker—a lot of customers can't be bothered to hike the block and a half just for a clean needle.

But the police write the rules around here, and they're gradually shoving the van down the street. Like most law enforcement nationwide, the local precinct worries that letting health workers give out needles will draw users to the area. That's a myth, one that study after study has debunked.<sup>5</sup>

Still, programs like Soto's remain entirely unwelcome in the very communities that most desperately need them.

## Clean Needles Save Lives, Period

Soto works for a group called Afterhours. It's one of about 127 similar efforts—called "syringe exchange programs"—in 35 states

(as of 2000) around the country that try to keep drug users from catching and spreading HIV.<sup>6</sup> Here and around the world, they have consistently proven to be the most effective form of HIV prevention we have available, demonstrably reducing HIV transmission rates by a third or more.<sup>7</sup>

In New York City, which is home to the largest population of injectors in the country, needle exchange programs cut the HIV infection rate among drug users by half in just the first three years of their operation.<sup>8</sup> (See “If You Can Make it Here” on page 40.) Scores of studies have found other local programs to be similarly effective. Needle exchanges are such efficient prevention tools because they literally reduce the volume of HIV that’s circulating in our neighborhoods: In one study, almost 30 percent of used needles returned to an exchange site contained blood contaminated with HIV.<sup>9</sup>

Community leaders and policymakers

who object to needle exchange programs operating in their neighborhoods often fear that by easing access to clean needles public health policy will encourage drug use. Repeated studies have allayed this concern. In fact, multiple researchers from both the public and private sectors have proven that syringe exchange programs are actually an effective way to move people into drug treatment. (See “A Decade of Government Research on Needle Exchange” on page 41.) In one study of a drug treatment program in Baltimore, half of the clients who were referred through a needle exchange actually showed up, and 76 percent of those completed the first 13 weeks. These numbers were comparable to clients who came from other referrals, despite the fact that the needle exchange clients came in with more severe drug use problems.<sup>10</sup>

To quote former Surgeon General David Satcher: “There is conclusive scientific evidence that syringe exchange programs, as part of a comprehensive HIV prevention strategy, are an effective public health intervention that reduces the transmission of HIV and does not encourage the use of illegal drugs.... When properly structured, syringe exchange programs provide a unique opportunity for communities to reach out to the active drug injecting population and provide for the referral and retention of individuals in local substance abuse treatment and counseling programs and other important health services.”<sup>11</sup> (See “Needle Exchange: By the Numbers” on page 42.)

These are successful interventions because people like Soto are essentially street corner social workers and case managers. They dispense not only needles, but basic needs like toilet paper and sanitary napkins. They encourage testing for a range of illnesses. And they help people find everything from healthcare providers to stable housing by linking them with broader AIDS service organizations. In short, they’re frontline

**Figure 1**

The geography of needle exchange (as of 2000):



Source: DesJarlais D and others. 2000 United States Syringe Exchange Program Survey. The Baron Edmond de Rothschild Chemical Dependency Institute. Presented at 12th North American Syringe Exchange Convention. April 12, 2002.



troops not only in the battle against HIV but in the war against urban poverty in general.

Yet, needle exchange programs have long been massively unpopular among Black community leaders and continue to struggle for the political support that would allow them to work on a large, national scale. Washington lawmakers continue to ban federal funding for syringe exchange, and state legislatures around the country still hotly debate whether to allow them to exist at all. (See Figure 1.)

## Public Health Loses to Law Enforcement

The nation's war on drugs has always been

in conflict with its effort to stop HIV.

**Throughout the 1970s, public health actually held sway over drug policy. We discovered methadone—a medical treatment for opiate addiction—and poured federal funding into research for better treatment and prevention programs for drug addiction.**

But in the Reagan era of the 1980s, law enforcement took control of our nation's response to addiction. Pushed by Washington, state legislatures around the country banned first the sale and then the possession of syringes. Suddenly, getting high required you to find not just a bag of dope but a needle to shoot it with as well.<sup>12</sup> Needles became a scarce and valued commodity, and people desperate to feed their addiction began simply sharing used ones among themselves.

## If You Can Make It Here... Needle Exchange in New York

New York City has the nation's largest population of injection drug users—an estimated 150,000 to 175,000 people, or twice as many as that of the next largest population, in Los Angeles. Somewhere between 10 and 20 percent of those people are believed to be HIV positive, which means New York also has more people living with HIV who caught it through shooting up than any other city.

These facts make New York City an ideal test market for needle exchange programs. And even in a drug-using epidemic as intransigent as this one, the local programs have found remarkable success. Here are some facts about the local network of syringe exchanges that the city health department has used to promote its expansion:

- The average annual budget for a needle exchange in NYC is \$200,000; the estimated lifetime cost of treating one person with HIV is \$150,000.

- Collectively, the programs have achieved an estimated 63 percent reduction in needle sharing among users.

- The vast majority of the city's needle exchange clients reside in the same zip code as the program they visit. This means the programs do NOT draw drug users to neighborhoods.

- Within the first three years of needle exchange operation in the city, the rate of new infections among drug users each year was cut by more than half.

- In the first ten years of operation, the prevalence of HIV infection among drug users dropped from 51 percent to 12.5 percent.

*Source: New York City Department of Health and Mental Hygiene. Presentation to Queens Community Board 2. March 4, 2004.*

# A Decade of Government Research on Needle Exchange

For years, needle exchanges have been locked out of community after community based on one paramount anxiety: a fear that making clean needles more accessible will encourage drug use. This was a reasonable enough concern in the late 1980s, given all of the work Black community leaders had put into our collective efforts to stop the flow of drugs into Black neighborhoods. But since that time, countless researchers have found no link between needle exchange programs and rising drug use. In fact, a number of studies have found that needle exchanges are actually an effective way to draw users into addiction treatment. They've also overwhelmingly ruled needle exchanges to be massively effective at preventing the spread of HIV.

Several of these studies were funded by the U.S. government. During the 1990s, Washington funded at least eight major studies on needle exchange, all of which concluded that the programs reduce HIV infection rates without increasing drug use. Despite that fact, Washington maintains its ban on federal funding for the program. What's that ban based on? A fear that needle exchanges will increase drug use.

## 2001

Institute of Medicine. *No Time To Lose: Getting More from HIV Prevention*. 2001.

## 2000

Surgeon General David Satcher. *Evidence-based findings on the efficacy of syringe exchange programs: an analysis of the scientific research completed since April 1998*. March 17, 2000.

## 1997

National Institutes of Health. *Consensus Development Statement: Interventions to Prevent HIV Risk Behavior*. February 13, 1997.

## 1995

National Research Council/Institute of Medicine. *Preventing HIV Transmission: The Role of Sterile Needles and Bleach*. 1995.

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## 1993

Lurie P and others. *The Public Health Impact of Needle Exchange Programs in the United States*. University of California, Berkeley, School of Public Health, 1993. Conducted for the U.S. Centers for Disease Control and Prevention.

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## 1991

National Commission on AIDS. *The Twin Epidemics of Substance Abuse and HIV*. July 1991.

*Source: Day, D. The injection-related AIDS epidemic in the United States. The Dogwood Center. November 1999.*

HIV couldn't have asked for a more hospitable scenario to facilitate its spread.

AIDS activists responded by developing the idea of syringe exchange programs. They

set up storefront locations in neighborhoods with lots of drug use and invited addicts to bring in old needles and exchange them for clean ones. It was a brilliantly simple idea.

But political and religious leaders, *particularly in the Black community*, met it with rage.

As political scientist Cathy Cohen charted in her study of Black America's early political response to AIDS, our communities were so besieged by the drug trade at the time AIDS erupted that our leaders were deeply distrusting of any new policy that appeared to offset their anti-drug efforts. When New York City's health department first pitched a needle exchange program in the late 1980s, one Black leader called it a genocidal plot, the *Amsterdam News* demanded the mayor's resignation, and even lawmakers who are today vocal supporters of most legislation pushed by AIDS activists angrily attacked the idea.<sup>13</sup>

The hostility to needle exchange bubbled up to Congress, and in 1989 legislators unanimously voted to set in place today's ban on federal funding for the programs.

Congress, however, provided that the Department of Health and Human Services (HHS) could lift the ban if it could establish that needle exchanges stop HIV without encouraging drug use. In 1998, HHS Secretary Donna Shalala concluded just that—no surprise, given that several previous government-funded studies had already said the same thing. “A meticulous scientific review has now proven that needle exchange programs can reduce the transmission of HIV and save lives without losing ground in the battle against illegal drugs,” Secretary Shalala triumphantly declared. “It offers communities that decide to pursue needle exchange programs yet another weapon in their fight against AIDS.”<sup>14</sup>

Politics, however, held far more sway than science. President Clinton intervened, declaring that although his administration believed needle exchange to be an effective HIV prevention program it would not lift the funding ban.

The irony is that needle exchange programs are also among the least expensive HIV prevention tools we have available.

## Needle Exchange: By the Numbers

- Share of AIDS cases among Black women tied to dirty needles: 50 percent
- Share of AIDS cases among Black men: 35 percent
- Length of time HIV can live in a dirty needle: >4 weeks
- Average annual cost of needle exchange programs: \$100,000
- Average cost for a lifetime of HIV/AIDS treatment: \$154,000 to \$190,000
- Number of major government-funded studies that have recommended needle exchange programs for stopping HIV and attacking drug use: ≥8
- Number of surgeon generals who have done the same: 3
- Number of states with no needle exchange programs as of 2000: 17
- Amount of federal funding dedicated to needle exchange programs: \$0

A clean syringe costs \$0.07; a year's worth of HIV treatment costs \$20,000. With an average annual budget of just \$200,000, New York City's programs have reduced needle sharing among addicts by 63 percent in the last ten years.<sup>15</sup> Unfortunately, we can only imagine what such programs could accomplish with real financial support and a nationwide reach.

## The Cost in Black Lives

**As politics and the drug war trump science and public health, dirty needles continue to fuel the epidemic: More than a third of**



**all diagnosed AIDS cases since the epidemic began have been the result of sharing needles.**<sup>16</sup>

The real damage is being done in Black neighborhoods. Nearly 40 percent of all AIDS cases diagnosed among African Americans through 2003 were attributable to injection drug use.<sup>17</sup>

Recently, both mainstream and Black community media have highlighted the rising numbers of HIV infections among African American women—rightly so, given the quickening rate of infections among Black women. In 1991, women accounted for just over a fifth of Black AIDS cases; by 2001 they represented more than a third.<sup>18</sup>

But these reports have focused on the sensational story of “down low” men, or Black men who live as heterosexuals but maintain secret sexual relationships with men on the side. (See “Down Low and the Politics of Blame” on page 56.) No significant research exists to prove either the widespread existence of such men or the fact that they are infecting their female sexual partners with HIV. But those facts aside, the deeper problem with this popular storyline is that it obscures a much more important one: Black women are being killed by dirty needles, not closeted bisexual men.

Half of all diagnosed AIDS cases among Black women as of 2003 were attributable to needle sharing—either from a woman sharing needles herself or having unprotected sex with a man who has shared dirty needles.<sup>19</sup> That means that if we stopped HIV transmission through dirty needles we would cut the epidemic among Black women by half. (See “Needles, HIV, and Black America” on page 38.)

Among Black men, meanwhile, 35 percent of all diagnosed AIDS cases as of 2003 were attributable to either sharing needles or having sex with someone who shared a needle.<sup>20</sup> (This number does not include male

AIDS cases in which the person reported both having sex with men and injecting drugs.)

The carnage does not stop with HIV. Since the time when drug war laws made clean syringes scarce, Hepatitis C has sprinted through the drug-using population as well. Today, Hep C has become known as “the silent epidemic,” with 2.7 million Americans chronically infected with the virus—the vast majority of whom were infected through needle sharing.<sup>21</sup> (See “What is Hep C?” on page 44.)

The tragedy is that we know how to stop both HIV and Hep C’s spread through dirty needles—just get rid of them. In places where political and community leaders have shown the courage to embrace public health over politics and fear, needle exchange programs have worked, and they’ve done so with few resources. It’s time for Black America to support these life-saving initiatives and demand that policymakers do the same.

## Notes

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3. U.S. Centers of Disease Control and Prevention (CDC). Drug-Associated Transmission Continues in the United States. March 2002.

4. CDC. HIV/AIDS Surveillance Report, v. 15, table 2.

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10. Brooner R and others. A Drug Abuse Treatment Success among Needle Exchange Participants. *Public Health Reports*, v. 113, supplement 1.

11. Satcher, 2000 report, op. cit.

12. For an overview of federal response to injecting drug use problems, and its relationship to HIV, see

Levenson, J. *The Secret Epidemic: The Story of AIDS and Black America*. Pantheon Books: 2004.

13. Cohen, Cathy. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. University of Chicago Press: 1999.

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15. New York City Department of Health op. cit.

16. CDC. Drug-Associated Transmission Continues in the United States. March 2002.

17. CDC. HIV/AIDS Surveillance Report, v. 15, tables 19 and 21.

18. CDC. HIV/AIDS Surveillance Reports, 1991-2001. Also see Kaiser Family Foundation. HIV/AIDS Policy Fact Sheet: African American and HIV/AIDS. September 2003.

19. CDC. HIV/AIDS Surveillance Report, v. 15, table 21.

20. CDC. HIV/AIDS Surveillance Report, v. 15, table 19.

21. CDC. National Center for Infectious Diseases. Viral Hepatitis C: Fact Sheet. Available online at <http://www.cdc.gov/ncidod/diseases/hepatitis/c/fact.htm>. Accessed on January 11, 20005.

## What is Hep C?

**H**epatitis C is a viral infection that, when left untreated, slowly devours your liver. Over the last three decades it's been a stealthy but virulent sidekick to HIV, reaching an estimated four million Americans, primarily through needle sharing and unsafe tattooing. Not all of those who are infected with Hep C get sick, but the U.S. Centers for Disease Control and Prevention estimates 2.7 million people who are infected with the virus have in fact developed a chronic condition.

For most of those infected—around four out of five—Hep C presents no overt symptoms as it winds its way through the body over the course of several years. Those that do see signs experience debilitating fatigue, nausea and abdominal pain, among other things. However, 70 percent of those infected are barreling towards liver failure; Hep C is the leading cause of liver transplants in the nation.

When mixed with HIV, Hep C becomes

particularly problematic—and lethal. **Nine out of ten people who caught HIV through needle sharing are co-infected with Hep C.** So it is not surprising that the number one cause of AIDS-related death in the United States is liver disease. Hep C's attack on the liver also makes HIV treatment more difficult, because a healthy liver is needed to break down the potent HIV meds.

Hep C can be medically treated and, unlike HIV, there is growing consensus that the virus can actually be wiped out of the body. **The treatments, however, are difficult and fantastically expensive. Hep C is treated with a year's worth of drug therapy, and those meds can add up to as much as \$40,000.**

But as the Hep C epidemic rages unchecked, an already overtaxed market for liver transplants is beginning to crumble. Today, nearly 10,000 of the just over 15,000 people on the national waiting list for liver transplants are there because of Hep C infection.

*For an easy primer on Hepatitis C see POZ magazine's supplement C-POZ, Fall 2002.*







# From Apathy to Action

*For Freddie Allen, the journey began too far from home*

**I**t's over. The drug companies have spit out the last of their fluorescent pens and granny lanyards. The Starbucks-induced frenetic assaults of the global activists are sporadic at best as they shuffle along, forgetting the words to their own passionate chants. Camera-shy researchers and doctors roll posters tight and close PowerPoint presentations, leaving the world of the 10-second sound bite. The XV International AIDS Conference is over and so is the apathy that I've lived with for most of my life.

It was never about the numbers for me, and it's not about the numbers now. At times, I've taken better care of my Timberlands and Polo Sport sweat suits than I have of my own health and the health of my loved ones. It never should have taken a conference in a city so many miles and so many languages from where I live to make me see that, especially when the same issues scream in my face everyday in Washington, D.C.

No, I won't start pacing back and forth in front of the White House slipping banana-flavored condoms to boy scouts and brownies. But I will begin dispelling myths about HIV/AIDS at the dinner table with family or while rushing the weekend at happy hour with my boys. Comfort levels will be cracked, but consider the alternative.

The delegates from Asia didn't need a rousing speech from U.N. Secretary-General Kofi Annan to tell them that 1.1 million people were infected with HIV in 2003 alone. Sub-Saharan Africans didn't need "plenary sessions," "skill-building workshops" or "oral abstracts" to learn that an estimated three million people were infected last year and 2.2 million died. The rest of the world didn't need an international AIDS conference to tell them that their brothers and sisters were dying, and neither do Blacks living in America. All we have to do is walk around the corner.

For so long, many of us have lived with positive male role model replacements—sport superstars selling soft drinks, bad *Cosby* clones, and rappers stunting on MTV's *Cribs*. Now, AIDS is the leading cause of death for African American women aged 25-34. In a few short years, it won't be orphaned children halfway around the world that non-profits will march across the television screen. It will be our American children wading through trash piles.

There's so much work to do. The abstinence-heavy rhetoric of the Bush administration needs fixing. Access to the best drugs needs fixing. Sex education in our schools and in our homes needs fixing.

Many HIV/AIDS grassroots organizations are already engaging the fight. There's Love Life in South Africa, for example, a national HIV prevention campaign for young people. Love Life utilizes the high energy of youth as a driving force, in a country where 35 percent of HIV infections occur before the age of 20. Love Life works because someone cared enough to make it work.

That's all it takes. Someone saying, "We can because we have to." Today, that someone is me. Tomorrow that someone must be you.

*This essay first appeared in BAI's special coverage of the XV International Conference on HIV/AIDS in Bangkok, Thailand. Freddie Allen is a journalism student at Howard University in Washington, D.C. and editor of Ledge, a magazine about HIV/AIDS published by BAI at historically Black colleges every semester.*





## CHAPTER FOUR

# Sex and Mythology: Black Gay Men in the World of HIV

**In December 2002 and January 2003, two young Black men who attended different colleges in the same North Carolina city tested positive for HIV (officials did not release the names of the colleges or the city they were in). The tests indicated that both men had recently contracted the virus and each young man reported that he had had sex with other men.<sup>1</sup> What ensued—both the realities and the dark fantasies that those facts spawned—tells us a great deal about the raging HIV epidemic among gay and bisexual Black men.**

North Carolina's intrepid HIV monitoring division discovered, using a new testing process, that the young men had recently become infected. The process looks for both HIV and the antibodies that mobilize against it; when the virus is present but the antibodies are not, it means HIV has only recently entered the blood stream.

Given the state's relatively few number of reported infections among college students, officials sensed the two new infections in men with similar profiles was more than a

coincidence. They were correct. Through routine follow-up interviews with the young men, investigators identified their recent sex partners and discovered 69 linked cases of HIV infection between 2000 and 2003. All of the infections were among men, and 61 of them were in colleges, largely in North Carolina but with a handful sprinkled in other southeastern schools.

Those 61 men are part of a total 84 North Carolina male college students diagnosed as HIV positive since 2000, 73 of whom are African American. Nearly 60 percent of those 84 men told health officials that they had had sex only with other men, about a third said they had sex with both men and women, and four percent said they had sex with only women.<sup>2</sup>

The cluster of new infections made splashy news when researchers unveiled their data at a 2004 scientific conference. It was particularly attention-grabbing in a population like college students—what one commentator called the “best and brightest” of young Black America.<sup>3</sup> The distortions took off from there.

## Boogeymen and Scapegoats

**Researchers did not ask any of the young men in North Carolina whether or not they were open about their homosexuality. But news reports on the cluster of infections nevertheless described “invisible networks” of homosexual Black men in college. Researchers also clearly stated that they had not found any evidence that the outbreak of infections moved from the men who tested positive to women on their campuses, and they never asked the men whether or not they considered themselves to be gay. Nevertheless, news media breathlessly identified the men as “on the down low.”<sup>4</sup>**

The down low, or “DL” as it’s known in shorthand, has been the domestic AIDS story of the 21st Century. DL brothers are men—necessarily Black—who live perfectly heterosexual lives, except that they quietly have secret sex with other DL men. They do not consider themselves to be gay, and culturally they certainly are not: they have no association with the gay community or its cultural norms.

DL men are distinct from men who are “in the closet” because they do not consider their sexual behavior to be relevant to a sexual identity. Rather, their male sexual relationships are just something they do on the side, more akin to watching the fight with other male friends than having gay sex. “I like girls. I have a girl,” explained one young man who would be considered DL. “But every once in a while, ‘cause women can be very stressful, I might chill with a dude.” For him, that’s a matter of behavior, not identity. “I consider myself just sexual,” he professed.

But some argue that the young man is making a distinction without a difference—hidden sex is hidden sex. And many are concerned that DL men like him are forming an “HIV bridge,” as CDC researchers have put it,

to straight Black women.<sup>5</sup> By not being open, the theory goes, these men are creating risky conditions for both their female and male sex partners.

It’s a tantalizing story, one that has been told everywhere from the cover of the *New York Times Magazine* to the *Oprah Winfrey Show*.<sup>6</sup> Author J.L. King, who professes to have once been a DL man himself, penned a tell-all intended to help Black women ferret his clandestine brothers out; it made it onto the *Times*’ coveted best-seller list.<sup>7</sup>

The problem is that there is no evidence that anything we’ve come to know about the DL man is true. Surely DL men do exist and their sexual dishonesty is just as surely troubling—not only for their sex partners, but for their own emotional and physical health. Yet, no substantive research exists identifying the number of DL men out there. Neither is there any real research indicating that they are more likely to have unsafe sex than anyone else. In fact, one study found that Black men who have sex with other men but don’t disclose that fact have 10 percent *less* unprotected anal sex than Black men who are open about their homosexuality.<sup>8</sup>

Meanwhile, no one has established a meaningful link between DL men and the rise in HIV infection among Black women. The notion that the spike we are seeing in infection rates among Black women is driven by sex with closeted bisexual men is purely conjecture.

Given these facts, one must ask how much of the media frenzy surrounding this topic is actually fueled by both Black and white America’s fears and fantasies about Black male sexuality. (See “Down Low and the Politics of Blame” on page 56.)

The North Carolina outbreak is instructive. More than half of the young men—58 percent—said they had had sex only with men, and all of them caught HIV from sex with another man. Of the 33 percent who said they had sex with both men and women,

there was no indication of whether they had done so secretly, as openly bisexual men, or somewhere in between. And researchers clearly stated that they had found no spike in HIV infections among Black college women in the area—suggesting that even if the bisexual men did conceal their male sex partners from their female ones, they still had safe sex with the women. Yet, in press reports and commentary on the outbreak, the DL monster was once again cast as the vector.

This storyline is so appealing, despite any research validating it, because the DL man is the perfect boogeyman for Black America's problem with HIV/AIDS. He is by definition unidentifiable. And he is decidedly not like anyone *we* know. All of this makes him an easy scapegoat.

Blaming the DL man allows us to avoid dealing with the tough issues that truly are driving infections among both Black women and Black gay men: injection drug use, the desperate search for intimacy, and the complicated, messy dynamics of human sexuality—even when everyone involved is open about who they are sleeping with. Rather than have honest conversations about what drives some Black women to accept less than what they deserve in their relationships with men—both emotionally and physically—we have diverted our attention to the mythical gay monster lurking under the bed.

## Infection Rates on Par with Africa

The obsession with the DL man also obscures a reality of which we have been certain since the first days of the epidemic: self-identified gay and bisexual Black men are getting infected at alarming rates. Gay and bisexual men accounted for nearly half of all Black men living with HIV/AIDS at the end of 2002, and African Americans

represented a third of all gay and bisexual men living with the virus.<sup>9</sup> (See “Black, Gay and Positive” on page 53.)

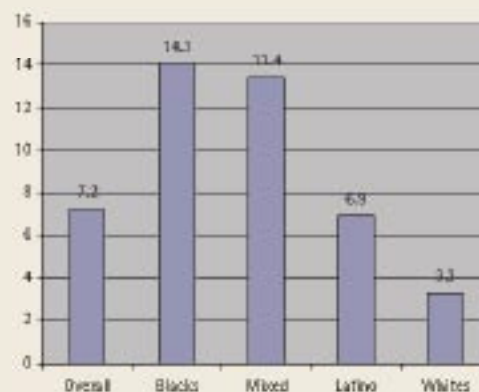
More startling data comes from a series of CDC studies on young gay and bisexual

Figure 1

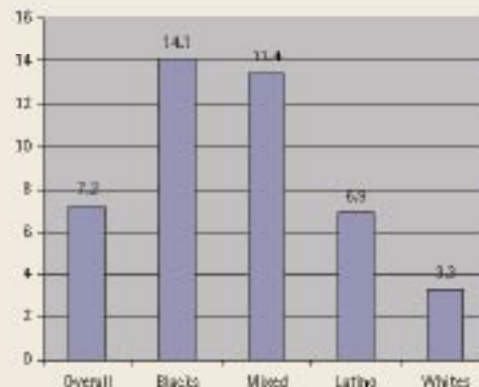
Two federally-funded surveys in the mid-to-late 1990s found HIV infection rates among young, gay African American men akin to those in southern Africa.

Percent of survey participants found to be HIV positive:

Among 15-22 year olds:



Among 23-29 year olds:



Source: Valleroy, Linda and others. “HIV Incidence Among Young Men Who Have Sex With Men—Seven U.S. Cities, 1994-2000.” *Morbidity and Mortality Weekly Report*, v. 50, n. 21.





men conducted in the mid-to-late 1990s. (See Figure 1.)

Between 1994 and 1998, researchers surveyed and tested just under 3,500 gay and bisexual men between the ages of 15 and 22, in an effort to determine HIV's prevalence and the amount of risky behavior young gay and bisexual men were engaging in. They found seven percent of the overall participants were HIV positive. But the rate was twice as high among African Americans (14 percent)—and nearly a fifth of Black 20 to 22 year olds tested positive.<sup>10</sup>

Then, from 1998 to 2000, researchers went back to six of the cities to survey and test just under 3,000 gay and bisexual men aged 23 to 29. Here, they found a startling 13 percent of overall participants were positive. Among African Americans, this time the infection rate more than doubled that of the overall group: 32 percent were positive, or nearly a third.<sup>11</sup> The only place on earth researchers have found similar HIV infection rates is in Botswana.

Later analyses of the data discovered still more troubling trends: Nine out of 10 of the 23 to 29 year old Black men who tested positive neither knew of their infections nor considered themselves to be at risk for getting infected.<sup>12</sup>

In discussing the cause of North Carolina's college-aged outbreak, the state's HIV prevention chief, Peter Leone, offered the explanation that most learned observers point to for these shockingly high infection rates among young Black men. In North Carolina, he posited, if you assume that 10 percent of the state's 33,000 Black male college students are gay, the total population is only around 3,300 people. To Leone, when you introduce HIV into such a small group of sexually active individuals, it will spread like brush fire.<sup>13</sup>

But, more than 20 years into the epidemic, we know woefully little beyond such conjecture about what is driving infections among Black gay and bisexual men. That's

because we've done too little research on the topic.

The federal government's failure to fund adequate research and services for Black gay and bisexual men is as much a result of our community's neglect as it is Washington's. Since 2000, African Americans have accounted for more than half of new AIDS diagnoses among gay and bisexual men each year.<sup>14</sup> Yet, we have continued to ignore the breathtaking epidemic among African American gay and bisexual men—one that was plainly evident as early as the mid-1980s.

## No Place to Call Home

**HIV, of course, is merely a symptom of a larger illness for Black sexual minorities, particularly young people. From hate crime to homelessness, Black gay, lesbian, bisexual and transgender (GLBT) youth are under constant assault in our cities and neighborhoods. Nearly half of the people of color in one survey of GLBT youth reported having been physically attacked because of their sexual orientation. Almost a third of all GLBT youth in that same study dropped out of high school due to harassment from fellow students.**<sup>15</sup>

Another study estimated 25 to 40 percent of all homeless youth are GLBT.<sup>16</sup> And in a Massachusetts Department of Education survey, a third of the state's gay high school students reported attempting suicide in the previous year.<sup>17</sup>

The situation is particularly grim for transgender youth—or individuals who identify with or present themselves as a gender other than that to which they were assigned at birth. In a nationwide study of GLBT youth in schools, two thirds of transgender students reported being the victim of sexual harassment.<sup>18</sup>

There are few large-scale studies on the risks transgender Americans face through-



out their lives. They navigate a culture that is overtly hostile to “tomboy” women and “sissified” men and that, at best, considers transgender people curiosity items for shock television programs like *The Jerry Springer Show*. Many go through puberty and into adulthood without ever meeting people like themselves. The resulting high rates of depression, drug use, violence, and suicidal thoughts are unsurprising. “One of the greatest agonies one can experience is gender dysphoria,” says transgender activist Jessica Xavier. “When your anatomy doesn’t match who you are inside, it’s the worst feeling in the world.”

In 1999, Xavier cajoled the Washington, D.C., health department into financing a survey of around 250 transgender people in the District of Columbia. Forty percent of respondents had not finished high school and another 40 percent were unemployed. Thirty-five percent reported having seriously considered suicide. And a quarter reported being HIV positive. Meanwhile, almost half had no health insurance and reported that they did not see a physician regularly. Seventy percent of the study participants were Black.<sup>19</sup>

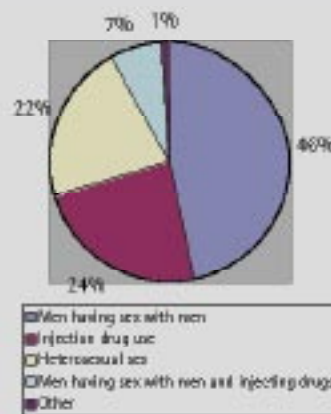
Xavier’s was the latest in a series of similar studies done in cities where relatively-emboldened transgender activists have pushed public health officials to begin considering public policy solutions to their healthcare concerns. These studies have produced disturbingly similar findings: higher rates of just about every indicator of social and economic distress among transgender populations than in the community at large. But we know little about their risk for HIV beyond what we’ve learned from this handful of local studies. That’s because the U.S. Centers for Disease Control and Prevention does not track HIV or AIDS among transgender individuals; rather, it lumps them into the category of infections through male-to-male sexual contact.

Black GLBT people face all of these chal-

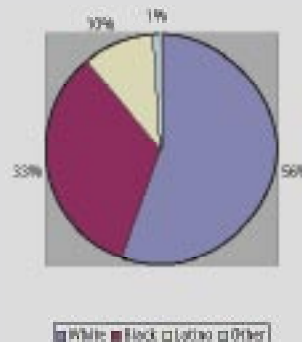
## Black, Gay, and Positive

Commentators often discuss the epidemic as either a Black one or a gay one, pitting one community against the other in a struggle for resources. But the truth of the matter is that no matter how you look at it, African American gay and bisexual men are disproportionately impacted by HIV/AIDS. Since 2000, African Americans have accounted for more than half of new AIDS diagnoses among gay and bisexual men each year.

Modes of transmission among Black men living with HIV/AIDS at the end of 2002:



Racial/ethnic distribution among gay and bisexual men living with HIV/AIDS at the end of 2002:



lenges with little communal backing—neither fully embraced by a largely white-focused gay community nor meaningfully supported by the Black community. For young gay African Americans, this dual and unequal citizenship often manifests itself through the absence of space in which they can navigate puberty and young adulthood, with all of the necessary trials these life stages present for everyone. Like cultural refugees, they surf back and forth between the partial safety of the neighborhoods they call home and that of the less familiar places where they can live their sexuality openly.

Fifteen-year-old Sakia Gunn offers a sad illustration of how tenuous this sort of existence can be. Gunn was a Black lesbian who lived in Newark, New Jersey. Like countless other Black GLBT youth throughout the region, she and her friends migrated every weekend to Manhattan's Christopher Street, where throngs of young, gay people of color come together nightly to be themselves. Following one of these sojourns in 2003, two men made sexual advances towards Gunn and her friends while they waited for a train at a public transit station. When the young women said that they were not interested, and in fact were lesbians, an altercation ensued in which one of the men stabbed and killed Gunn. The tragedy could have been avoided if the teenager and her friends had been able to socialize as themselves in the neighborhoods they call home, rather than traveling to another state to enjoy a few hours of perceived safety.

Neither are these young people actually safe in the gay neighborhoods to which they travel. When they are not being sexually objectified—often by older men who make their Black skin a fetish—they are being shunned by the largely white communities that gay enclaves grow out of. The Christopher Street area again offers a telling example. The young people of color who flock there are not old enough to enter the clubs, so they hang out

in the streets. But this greatly annoys the neighborhood's white condo owners, who have thus chartered an organization to lobby police into harassing the youth. Poignantly, the group is named RID, after a popular brand of rat poison. RID has succeeded in creating a hostile environment for the young people, but it has done little to slow their nightly migration to the area; they have nowhere else to go.

When we consider the lives of Black GLBT young people in this larger context, there is little wonder that they are so disproportionately attacked by a virus that exploits mistakes made during one's search for intimacy. If the estimated infection rates among Black gay and bisexual men under the age of 30 are correct—a third or more believed to be positive—nothing less than genocide is unfolding among our GLBT youth. One doesn't have to conjure the fantasy of a DL man spreading HIV to innocent straight women to understand that fatal illness on this sort of scale hurts all of us. The young people getting newly infected while roaming an unfriendly nation as cultural refugees are our sons, brothers, cousins, nephews and friends; they are future leaders and visionaries that we are now poised to lose a second generation of. African America must come to understand this epidemic's unflinching reality: we will never make real inroads against HIV until we not only accept but embrace every part of our community.

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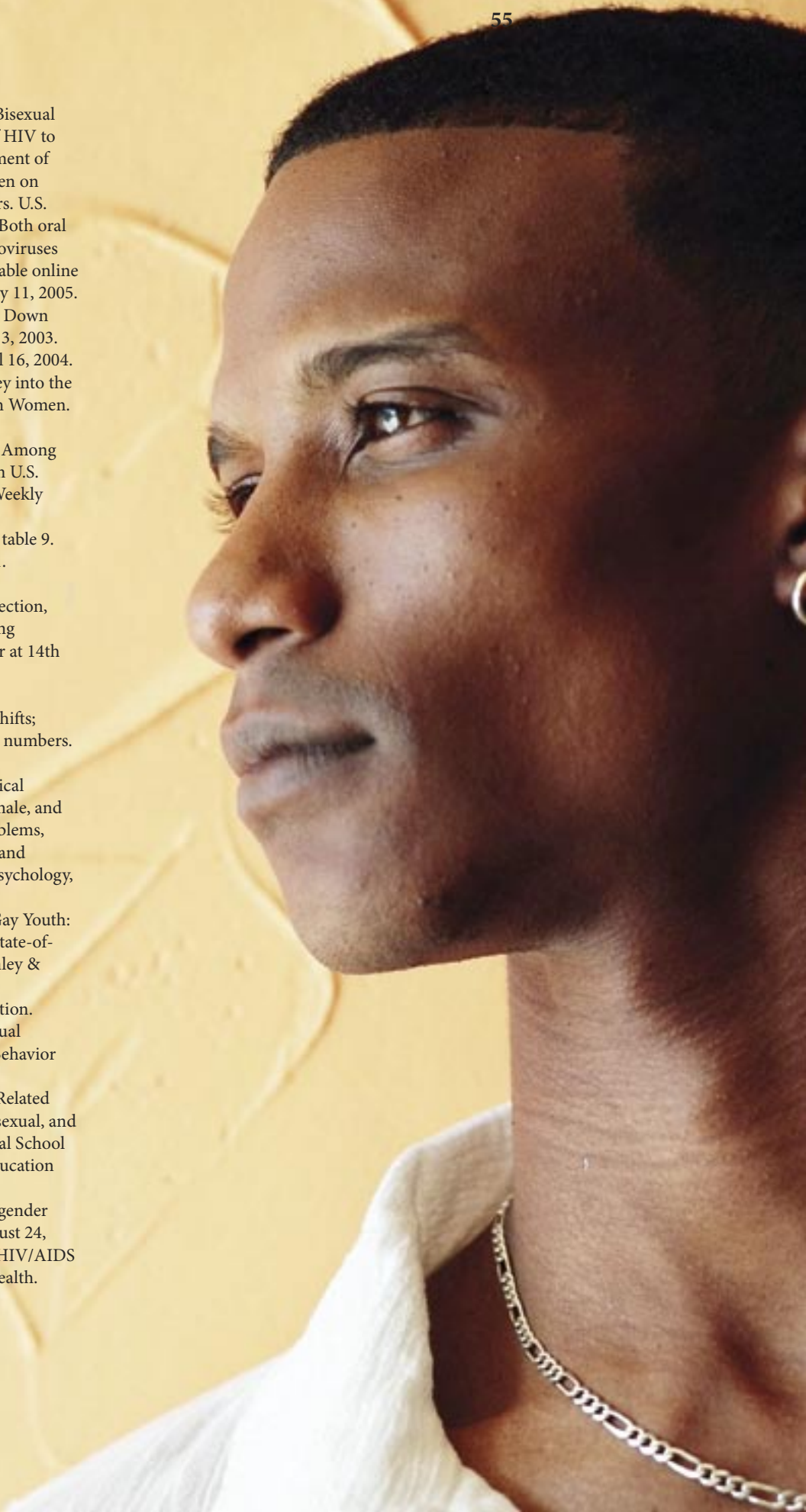
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# ‘Down Low’ and the Politics of Blame

*Dr. David Malebranche explains everything we don't know about Black America's latest HIV myth.*

**D**emonizing Black male sexuality has been a staple of American culture since slavery, where our role was to work and breed, and the Mandingo stereotype of a hyper-sexual Black man with an insatiable appetite for white women was created. That history haunted my thoughts as I watched Oprah Winfrey's recent show about “down low” Black men, or guys who live a “heterosexual lifestyle” (whatever that means) but have sex with other men on the side.

Oprah's April program focused on HIV/AIDS and showcased author J.L. King, launching his new book *On the Down Low*, onto *The New York Times* best-seller list. The show misquoted HIV statistics, offered sensationalistic generalizations, and portrayed down low men as hedonistic predators who carelessly have unprotected sex with men and women. It did all of this in an effort to convince Oprah's faithful audience that the current HIV epidemic among Black women is mainly due to the down low, or “DL,” brothers.



Oprah was just the latest media maven to paint this frightening picture. From articles in *Jet*, *Ebony*, *Essence*, *The Washington Post* and the *Times*, to featured stories on *ER*, *Law and Order: Special Victims Unit* and *Soul Food*, down low men were presented as hyper-sexualized vessels of disease who are so mired in self-hate over their homosexual urges that they have rampant unprotected sex, and don't bother to get tested for HIV. In the process, they infect unsuspecting and "innocent" Black women with HIV, and hasten the virus's spread throughout the Black community.

All of this is just as much of a fantasy as the Mandingo stereotype. The majority of public health research doesn't support the theory that DL men are a "bridge" for HIV to the general Black community. There are no substantive studies on down-low Black men. That's in large part because researchers can't find actual DL men—few of them would be willing to participate in a study discussing the sexual behavior they are supposedly so invested in concealing.

Much of the media hype about the DL comes from a heralded federal study in which researchers in six different cities estimated that a third of 20-something Black men who have sex with other men are HIV positive. Most observers have called the men who identified themselves as bisexual or heterosexual in this study "down low." But the young men were recruited from gay-identified venues—the sorts of places DL men would not frequent.

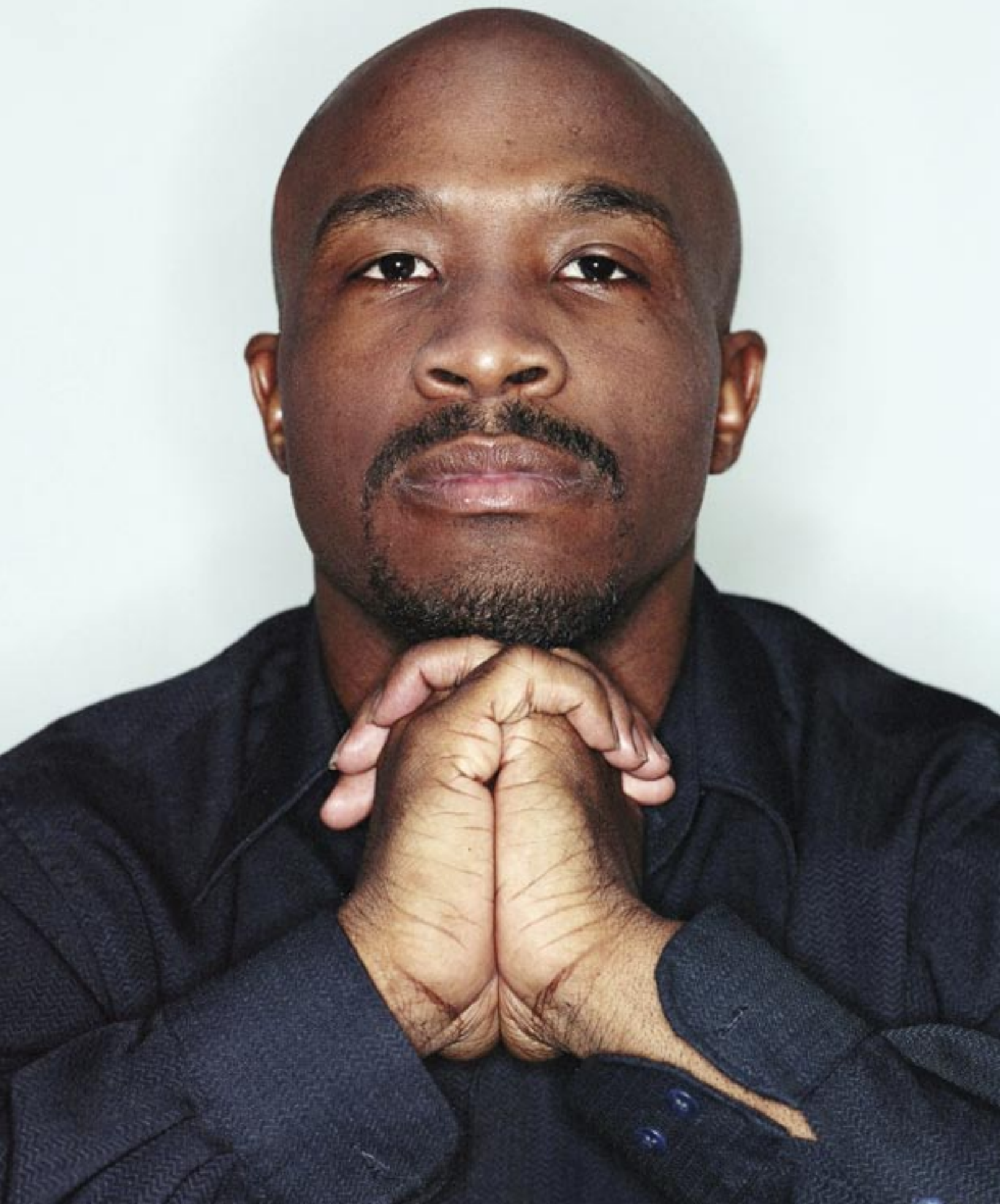
Moreover, here's one of the study's findings that we rarely see cited: Black men who engage in homosexual behavior but don't disclose it have 10 percent less unprotected anal sex than Black men who disclose it.

Despite not having any statistics on the sexual behavior of down-low Black men, the media confidently states that they are the major reason why Black women are getting HIV. What we know is that Black women face a complicated web of risk factors: dirty drug needles, sex with men who inject drugs and sex with heterosexual men infected with HIV. They also have a higher rate of sexually transmitted infections generally, which increases the likelihood of transmitting HIV. It's easier to blame DL brothers for the growing epidemic among Black women than to deal with these issues, or with personal responsibility for sexual communication and behavioral choices of both sexual partners.

We distort the truth about HIV in the Black community to divert our attention from the real "down low" issues of oppression, racism, low self-esteem, sexual abuse, substance abuse, joblessness, hopelessness and despair. The time for irrational, fear-based HIV prevention tactics is over.

*This essay first appeared in BAI's special coverage of the XV International Conference on HIV/AIDS in Bangkok, Thailand. David Malebranche is an assistant professor at Emory University's Division of General Medicine.*





## CHAPTER FIVE

# Prevention's Untouchables: Prisoners and Youth

**The visiting room of the medium-security prison at Auburn Correctional Facility in New York State looks a lot like high school detention. Young couples squeeze into plastic chairs around Formica tables, munching junk food and whispering conspiratorially about nothing. But they're following carefully scripted rules.**

Inmates must sit on the north side, so the desk guard can look them in the face. Visitors have been put on notice: there can be no drop-neck tops, no short skirts, nothing that shows more than half of your back. Corrections officials, it seems, consider every detail of their charges' interaction with the outside world. That is, all except the ones that involve their health and that of the communities they call home.

Rahiem, a 53-year-old lifer at Auburn, has experienced the full range of the system's public health failures during his nearly 30 years as a ward of the state. He tested positive for both HIV and hepatitis C in 1996. He thinks he got infected during a stretch in Attica, where he had conjugal visits with a woman he later heard was shooting up back home. Condoms are banned in New York's

prisons, as they are in all but two prison systems nationwide (Mississippi and Vermont supply condoms in their prison system, along with jails in New York City, Philadelphia, San Francisco and Washington, D.C.). But he could have gotten some for these officially approved trysts; no one ever told him that. "It's up to the officer" to decide whether to offer condoms, Rahiem explains. He certainly never bothered to ask for them. "I was too busy celebrating."

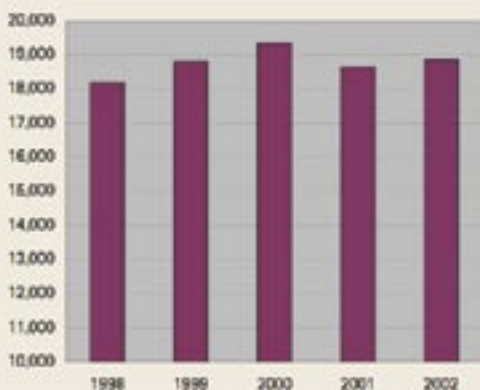
So now Rahiem is part of an estimated 14 percent of state inmates who have hep C and 8.5 percent who have HIV.<sup>1</sup> In fact, the residents of New York's prison system stand out as among the nation's most thoroughly infected populations: More than a fifth of all U.S. inmates known to be HIV positive in 2002 were housed in New York's prisons.<sup>2</sup>

Nationwide, at the end of 2002, nearly 24,000 prison inmates were known to be living with HIV, accounting for around two percent of those incarcerated in state and federal prisons. Meanwhile, the prevalence of diagnosed AIDS cases was three and a half times that of the general population.<sup>3</sup> These positive prisoners are largely concentrated in

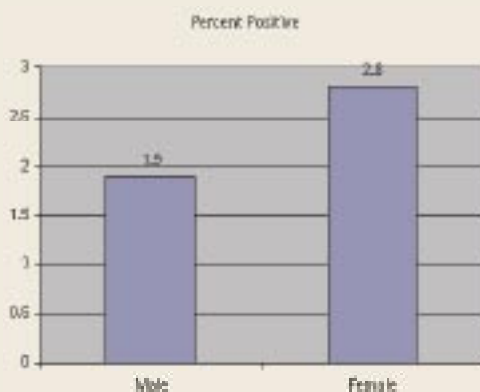
**Figure 1**

At the end of 2002, the nation's correctional facilities reported 23,864 inmates living with HIV, or 1.9 percent of the national prison population. Of those people, 5,643 had been diagnosed with AIDS.

Corrections officials boast that the number of positive inmates has steadily declined since the late 1990s. That is accurate, unless you discount New York State, which uses a formula for estimating infection rates that throws off the national numbers. Discounting New York, the number of HIV infected prisoners has remained steady.



While the known infections among men far outnumber those among women, a higher percentage of the female inmate population is known to be positive.



Source: Maruschak L. *HIV in Prisons and Jails*, 2002. Bureau of Justice Statistics. U.S. Department of Justice. December 2004.

just three states: Florida, New York and Texas house about half of all inmates living with HIV.<sup>4</sup> Meanwhile, estimates for hep C infection rates among prisoners range from 20 percent to 60 percent. (See Figures 1 and 2.)

National prisoner HIV infection rates are not broken out by race, but we can turn to two sets of data to see that this slice of the epidemic is a uniquely African American concern. First, there is the astoundingly disproportionate number of African Americans incarcerated today: African Americans account for 44 percent of all state and federal inmates, while five percent of all Black men are in prison.<sup>5</sup> It is reasonable to assume Black inmates account for a similarly disproportionate share of the HIV infections. But further, more than three times as many African American inmates died of AIDS-related causes in 2002 than did whites.<sup>6</sup> Politically and culturally, the African American community desperately needs to demand more of the public health systems governing state and federal prisons.

Rarely do we see as gaping of a disconnect between public policy and the reality it is intended to govern as that between the rules organizing our nation's prisons and the rapid spread of HIV and hepatitis C within them. The party line among prison officials around the country is that HIV infection rates are high in their facilities because they are high among the populations from which prisoners are disproportionately drawn—young Black and Latino men and women. But what if it's the other way around? What if HIV's disproportionate impact on urban Black and Latino communities can be traced at least in part to the high incarceration rates in those same neighborhoods—and the unsafe sex, drug use and tattooing that takes place inside prisons?

In the absence of structured epidemiological studies, these are questions that, for now, must remain unanswered. But even if we simply accept the fact that a large number of those entering prison do so with an HIV



infection, the potential epidemic inside—and, eventually, outside—is awesome, for few environments would better facilitate the virus' spread.

## Sex, Drugs and Tattoos Behind Bars

All of the tools public health has developed to slow HIV's spread on the outside—condoms, clean needles, fresh tattoo ink—are not only scarce in prison, but possession of them will get time added to your sentence. Around the country, prison officials embrace the strange belief that if they simply bar the paraphernalia associated with sex, drugs and tattooing, the problem will go away. "It's against their rules," scoffs prison health advocate and ex-offender Romeo Sanchez, director of the Latino Prison Project, "so they don't want to talk about it."

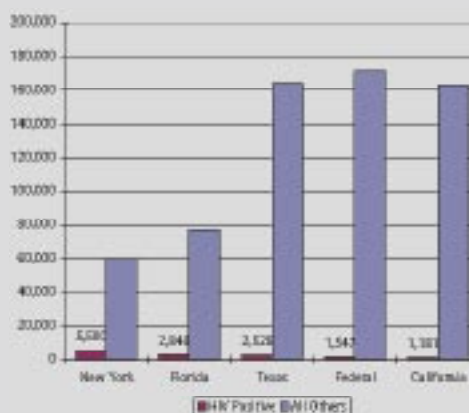
Meanwhile, communicable diseases spread unchecked. Prison officials are infamously reluctant to allow researchers to study the frequency of risk behavior in their facilities, and they do few epidemiological studies of their own on how often communicable diseases are passed on inside. But given the testimony of current and ex-offenders about the realities of inmate behavior, and given the high prevalence of both HIV and hep C, we can only assume the worst. "There's drugs in jail; there's HIV in jail," shrugs Hector, a Bronx Puerto Rican who logged most of the 80s and 90s in New York's prisons for drug crimes. "Everything that's out here is in there—except your freedom."

While more locked-up users sniff or smoke heroin than shoot it, ex-offenders widely acknowledge that plenty inject as well. And for those shooting, the needles are far more scarce than the drugs—which creates an ideal opening for HIV's spread. Even those that sniff drugs aren't really safe from com-

**Figure 2**

The nation's prison epidemic is largely concentrated in a handful of states, which also boast the nation's largest prison systems. **New York, Florida and Texas account for almost half of all HIV positive inmates.**

Prison jurisdictions with largest HIV epidemics at the end of 2002:



Sources: Maruschak L. *HIV in Prisons and Jails*, 2002. Bureau of Justice Statistics. U.S. Department of Justice. December 2004. And Harrison P, Beck A. *Prisoners in 2003*. Bureau of Justice Statistics. U.S. Department of Justice. November 2004.

\*New York's estimates are higher than that provided by the Justice Department's report. They are from Goord S. Commissioner of New York State Department of Correctional Services. Testimony to Combined Assembly Correction and Health Committees Hearing on Health Care in New York State Prisons. November 14, 2003.

municable disease: hep C can pass from person to person through the straws and rolled up pieces of paper that people share when snorting heroin and cocaine.

"It's rampant," says Greg, who spent 17 years in New Jersey prisons. "If you get one set of works, the whole wing's using it. And that's how HIV and hepatitis C is spread. That's where I believe I got it." Greg says he took risks inside that he never would have while free. "On the street I was careful," he





says. "When I was home, I had access to stuff [like fresh needles or materials to clean used ones]."

Despite clear anecdotal evidence of widespread drug use, no U.S. correctional facility offers a program to reduce the spread of blood-borne diseases by giving prisoners some form of access to clean needles or products to sterilize used ones. There is an important distinction to be made here: prisons effectively ban access to *clean* needles, but not to dirty ones.

The methods inmate addicts employ to inject drugs are myriad. The simplest way to get "works" is to buy syringes that have been stolen from the infirmary, particularly in minimum and medium security facilities. Anything banned inside a prison can be found on its black market, sold by someone whose job allows access to either the item itself or a supplier on the outside. "If I know a guy who works in the kitchen, and he has access to raw meat, I'll buy me a steak with a pack of cigarettes and I'll cook me a steak tonight," explains Hector. "Same thing with the needles. The guy that does the cleaning in the infirmary, somewhere along the line he'll come across a drawer of syringes and he'll bring them out and sell them. A lot of people have caught AIDS like that, 'cause you only got one syringe now." Hector—who has hep C but not HIV—says you could get black market syringes in exchange for three packs of cigarettes when he was locked up; the heroin itself is usually more expensive than street prices, \$40 for a bag that would run just \$10 outside.

When syringes can't be stolen, inmates just make them. "You ought to see how they do things," says Greg. "One guy came back from the hospital who got an IV needle, and we made a syringe out of it." Once you have some sort of needle, all you need is a rubber band and something resembling an eye dropper. Fasten them together, and you've got a syringe. "You press the bulb in a little bit, and

when you let it go it sucks in," explains Hector. "If it sucks blood in, you know you got a shot, and you squeeze [the heroin] in." If a previous user was HIV or hep C positive, you squeeze in that virus as well.

Widespread tattooing inside prison offers a similarly efficient way to contract HIV or hep C. Tattooing is banned in most prisons, but as with drugs, inmates still find a way to do it. Tattoo machines are as easy to make as syringes—just pull a motor out of an old Walkman and hook it up to anything sharpened into a point.

The problem is the ink, which prisons ban and thus make scarce like needles. Jailhouse artists have unlimited ingenuity for milking ink out of ordinary substances. They shave down lead pencils. They burn plastic and turn the ash into ink. When carbon paper was still used widely, they would shave it down into ink. Because they must go to such extremes to get this valuable commodity—which gives them a source of income and influence inside—the artists protect it dearly and do not dream of wasting it by making a new pool each time they have a new customer, as tattoo artists do in the free world. Instead, they must use the same batch of ink for customer after customer. HIV lives only a few hours outside of the body, but hep C can live for days inside an ink pool. "A lot of people get sick," Hector sighs. "I think I caught my hep C from tattooing."

And then, of course, there's sex. In an informal survey of just over 100 New York State prisoners and ex-offenders in 1999, 63 percent of respondents reported having witnessed other inmates having sex. Nearly a fifth acknowledged having had sex themselves. And over 30 percent said they knew someone who had contracted HIV while in prison due to unprotected sex.<sup>7</sup>

It is important to note that sexual behavior in prisons has little to do with sexual identity: three quarters of the participants in the same survey identified themselves as het-

erosexual. Nor can we assume all of the sex is rape, as the survey participants reported seeing only five cases of forced sex.<sup>8</sup> But much research remains to be done on the full extent and nature of sex inside prisons. How much of it is forced? How much of it takes place between prisoners and guards, particularly in women's facilities? What do the people who participate in it consider themselves to be doing? How does it impact their sexual behavior upon release? And how much of it leads to HIV transmission?

One of the few thorough studies on prison sex, a 2001 Human Rights Watch investigation, hinted at the complexities that obscure the answers to each of these questions. While overtly forced sex is less common, sex is in fact widely used to buy and sell protection from violence. Individuals may submit freely to a sexual relationship, but do so because they feel they have no other choice—their acceptance into a social group that will provide protection may be dependent upon sex, for instance. Agreeing to be the receptive partner in a sexual relationship, therefore, may be the lesser of a series of unwanted choices. As the Human Rights Watch report explained, “In the context of imprisonment, much more so than in the outside world, the concepts of consent and coercion are extremely slippery. Prisons and jails are inherently coercive environments. Inmates enjoy little autonomy and little possibility of free choice, making it difficult to ascertain whether an inmate's consent to anything is freely given.”<sup>9</sup>

Often, once an individual submits to sex with one person, his is also submitting to prostitution. Most prison societies are staunchly segregated by gang affiliation. And when a person agrees to a sexual relationship—as the receptive partner in anal or oral sex—he becomes not just the solicitor's “property,” but is often the “property” of that inmate's entire gang as well. The gang may freely share its property among one another,

or an inmate may earn money through selling his property to others. As one Michigan inmate explained to Human Rights Watch, “I became obedient, telling myself that at least I was surviving. ... He publicly humiliated and degraded me, making sure all the inmates and guards knew that I was a queen and his property. Within a week he was pimping me out to other inmates at \$3.00 a man. This state of existence continued for two months until he sold me for \$25.00.”<sup>10</sup>

Making condoms available is unlikely to impact HIV transmission during violently forced sex. But in the grey area of coerced consent that Human Rights Watch details in its report, the sexual encounters are more scripted and planned. While the myriad emotional and physical problems that will grow out of such encounters cannot be prevented or healed by a mere condom, HIV transmission can be prevented.

But prison officials uniformly agree that making condoms available to inmates both offers a route by which drugs can be smuggled (packed inside a condom and ingested) and implicitly condones sex. Prison health advocates counter with the obvious: high volumes of both sex and drug use already take place, they don't need to also facilitate disease transmission. In the absence of substantive research on risk behavior and disease transmission inside prisons, the debate becomes one of he said/she said. And in the absence of public demand for a real examination of the dynamics surrounding sex and drug use in prisons, corrections officials have no impetus to break the circular argument.

## **False Security**

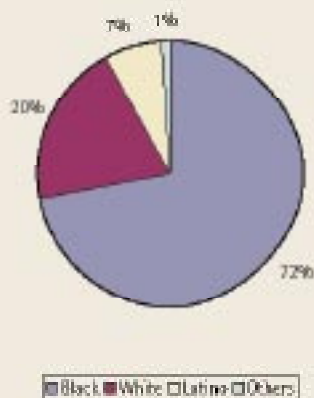
**The stalemate between corrections officials and prison health advocates endures in large part because, as a society, we embrace the myth that those who are incarcerated truly stand apart from the community at**

**Figure 3**

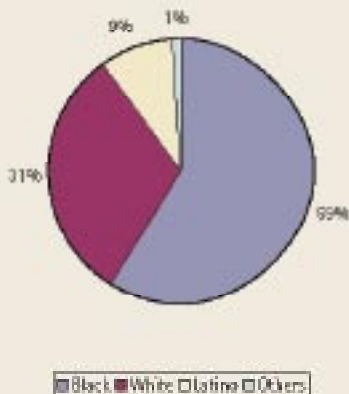
A quarter of all new HIV infections every year are among people under the age of 25, and African Americans account for 56 percent of those infections. The racial disparity is particularly dramatic among teenage females.

Breakdown of HIV infections among 13-19 year olds by race and gender, through 2001:

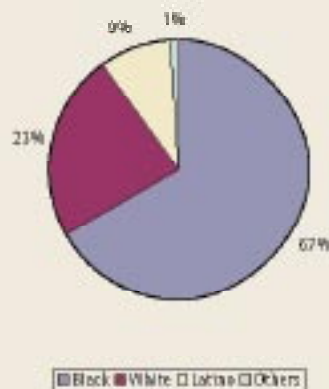
Females



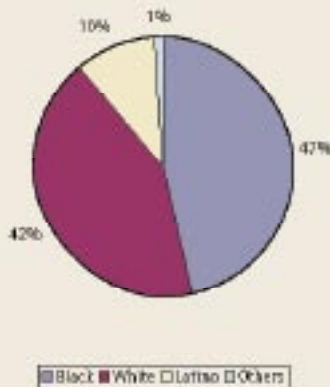
Males



Breakdown of HIV infections among 20-24 year olds by race and gender, through 2001:



Females



Males

Source: CDC. *HIV/AIDS Surveillance Report*, v. 13, n. 2. Table 8.

large. As Michel Foucault articulated in his famous consideration of discipline and punishment in modern Western societies, our penal system no longer seeks to punish the body through torture, but to reform, or at least contain the faltered soul. Rather than chop off a hand for stealing, we confine a person because of his or her desire

to steal. And rather than understanding crimes as acts that threaten order, we define individuals as criminals—deviants who threaten the community and must be set aside and permanently marked as such.<sup>11</sup> (Meanwhile, of course, the practice of reform has rarely lived up to the ideal.)

The problem, particularly in Black neigh-

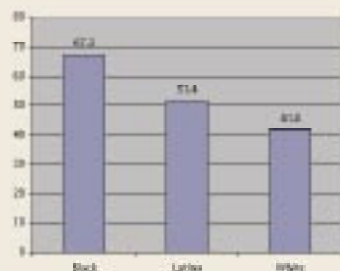
## Young Folks and Sex

Every year, the U.S. CDC surveys the “risk behavior” of high school and college-aged youth on things ranging from diet to violence. On sexual activity, the survey found that since the early 1990s teens increasingly have had less sex and done it safer. There have been distinct racial differences in the trends, however.

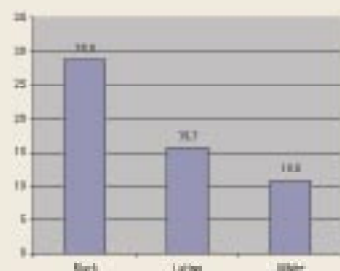
African Americans report having more sex, at an earlier age than any other group...

And within the racial categories, there are distinct gender differences. Black males report far more sexual activity than Black females...

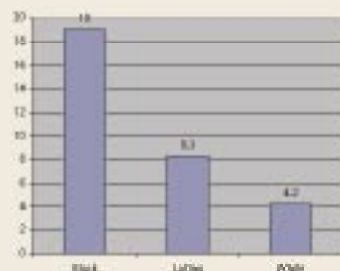
Youth who reported ever having sexual encounters, 2003:



Youth who reported more than four lifetime partners, 2003:

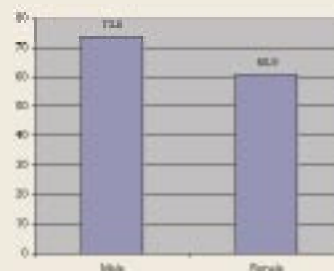


Youth who reported having sex by the age of 13, 2003:

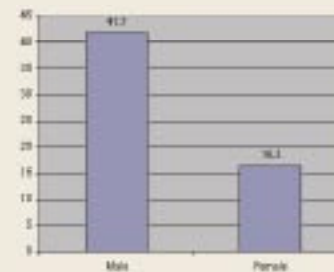


And within the racial categories, there are distinct gender differences. Black males report far more sexual activity than Black females...

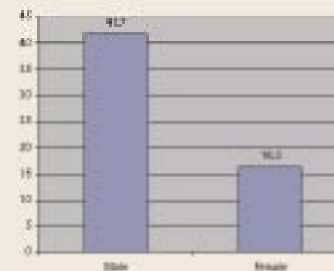
Black youth who reported ever having sexual encounters, 2003:



Black youth who reported having more than four lifetime partners, 2003:



Black youth who reported having sex by the age of 13, 2003:



We will require far more *qualitative* research on teen sexual behavior to understand both the racial and gender disparities—and what they mean for controlling STDs.

Source: CDC. Youth Risk Behavior Surveillance—United States, 2003. *Morbidity and Mortality Weekly Report*. May 21, 2004.

borhoods suffering from high rates of incarceration for nonviolent crimes, is that those we've defined as criminals and removed from society aren't quite as segregated as public policy would like to believe. The connections to community are fluid and lasting. People transition back and forth between incarceration and their neighborhoods, and as they travel they carry communicable diseases such as HIV and hep C with them.

In New York State, around 27,000 prisoners return home every year.<sup>12</sup> In 2002, the corrections department provided transitional services to less than 700 of those leaving prison who were HIV positive.<sup>13</sup> So, if the infection rate among people getting out is the same as that of the larger inmate population, that means less than a third of the people who left with HIV got the support they needed to live with the virus and prevent its further spread. And New York boasts one of the nation's most aggressive transitional services programs for people with HIV.

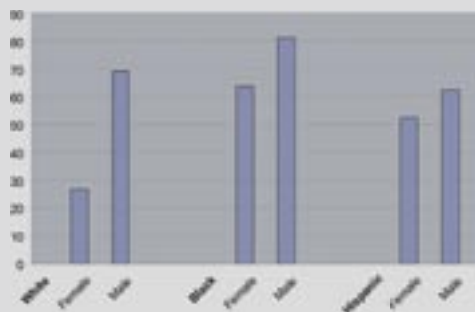
"What's happening," says hep C-positive ex-offender Hector, "is they're not educating the people in the streets or the person who's going to be released into society. Because they come out looking good. You're working out every day in prison. Now you're infected, but you don't look it. You look real healthy. And you meet a woman out here, and she gets infected like that."

## Sex and America's Youth

**The incredible danger of America's faltering interest in addressing HIV/AIDS is perhaps most starkly displayed among high school and college-aged young people. An estimated half of all new HIV infections each year are among people under the age of 25. And once again, African Americans are driving the trend: Black youth account for 56 percent of annual new infections among 13 to 24 year olds.<sup>14</sup> Rising infec-**

**Figure 4**

Racial breakdown of condom usage among sexually-active 14-17 year olds.



Source: CDC. Youth Risk Behavior Surveillance—United States, 2003. Morbidity and Mortality Weekly Report. May 21, 2004.

tions among young Black women are of particular concern. Through 2001, African Americans accounted for nearly three quarters of diagnosed HIV infections among 13 to 19 year old girls and two thirds of 20 to 24 year old women.<sup>15</sup> (See Figure 3.) These transmissions among young people happen largely through unprotected sex.<sup>16</sup>

Despite the high infection rates, however, there is reason for hope. Throughout the 1990s public health saw a marked decrease in the sexual behavior that puts youth at risk for HIV infection. The U.S. Centers for Disease Control and Prevention tracks youth "risk behavior" in a series of annual surveys. The latest results of that survey shows condom use among 14 to 17 year olds *increased* 17 percent between 1991 and 2003.<sup>17</sup>

The outlook among Black youth is more mixed. African American youth in the latest CDC study reported the highest rates of having ever had sexual intercourse: 67 percent compared to 42 percent of whites. They also reported having more sexual partners: almost 30 percent of African American youth reported more than four lifetime partners, compared to just under 11 percent of whites. Most startlingly, almost a fifth of Black youth



reported having had sex by the age of 13, compared to four percent of white youth.<sup>18</sup> (See “Young Folks and Sex” on page 66.)

On the other hand, African American youth report condom usage in far higher numbers than any other group. Eighty percent of Black male teens and more than 60 percent of Black female teens told the CDC they used condoms during their last sexual encounter.<sup>19</sup> (See Figure 4.) African American youth also report less alcohol or drug use associated with sex than other groups. Around a fifth of Black youth said they used drugs or alcohol before their last sexual encounter, compared to almost 27 percent of white youth.<sup>20</sup>

So, if African American youth are having safer sex—though in higher numbers—why are they accounting for such a disproportionate share of new infections? That question remains unanswered, and we will need serious and sustained research into Black youth risk behavior to answer it. One theory is the same as that offered by North Carolina’s HIV program director when asked about the recent outbreak of infections among Black gay and bisexual college students (See Chapter 4): African American youth have sexual encounters within a small pool of partners in which HIV has already been introduced, thus expediting its spread. On the other hand, the gap between the sexual behavior youth report and the behavior in which they actually engage—both in terms of condom use and volume of activity—may simply be greater among African Americans than other groups.

The gender breakdown among sexually active Black youth also begs questions. Far more young Black men report having had sex than women—74 percent versus 61 percent, respectively. Among white youth, the gender balance is nearly equal. And more than twice as many Black male youth (42 percent) report multiple sexual partners as Black female youth (16 percent), while again the balance is roughly equal among white youth.<sup>21</sup> Again,

we need to do more research to understand if and how these dynamics impact HIV infection rates among our youth.

## The Assault on Comprehensive Sex Education

**Current research is making at least one thing clear: the success that we have seen in reducing sexual risk behavior among youth is being jeopardized by Washington’s increasing embrace of “abstinence-only” sex education.**

Throughout the last decade, sexual health experts both inside and out of government agreed that what is known as “comprehensive” sex education made the most sense for our schools. Comprehensive sex ed stresses the value of delaying sexual activity until adulthood, but also gives youth all of the information they need to prevent diseases and pregnancies should they decide to have sex. As the CDC states on its website, “Research has clearly shown that the most effective programs are comprehensive ones that include a focus on delaying sexual behavior *and* provide information on how sexually active young people can protect themselves. Evidence of prevention success can be seen in trends from the Youth Risk Behavior Survey conducted over an 8-year period, which show both a decline in sexual risk behaviors and an increase in condom use among sexually active youth.” (*Italics in original.*)<sup>22</sup>

More-targeted studies have also shown that comprehensive sex education programs in schools reduce risk-taking in sexually active youth without increasing the likelihood that those who are not having sex will begin to do so. Indeed, one study in Massachusetts found that students attending schools where condoms are made available are both less likely to be sexually active and twice as

# What Our Kids Are Learning

Since 2001, when the Bush Administration took office, the federal budget for abstinence-only programming has doubled, reaching nearly \$170 million in 2005 (of the \$270 million originally requested). Because a portion of the federal money is distributed to states, which are required to provide matching funds, the actual amount of spending driven by federal policies is significantly higher.

The federal spending increase during the last four years has been driven almost entirely by a U.S. Department of Health and Human Services (HHS) program that gives grants directly to community-based organizations to develop and administer abstinence-only projects. The HHS initiative, named Special Programs of Regional and National Significance, or SPRANS, has grown from \$20 million for 33 programs in 2001 to \$104 million for more than 100 grantees in 2005.

These hundreds of programs all utilize a handful of abstinence-only curricula. In 2003, 13 curricula were used by more than two-thirds of the SPRANS programs. In 2004, California Democratic Congressman Henry Waxman ordered a Congressional review of those 13 curricula. **The review found that 11 of the 13 abstinence-only curricula contained "false, misleading or distorted information."** Here are some examples of the sorts of things Rep. Waxman's review found that the SPRANS programs teach America's school children.

■ **You can get HIV from tears and sweat.**

One curriculum fantastically listed tears and sweat in a column titled "At Risk" for transmitting HIV. Both fluids have been dismissed as transmission routes for HIV since the early days of the epidemic. HHS funded 19 programs that used this curriculum in 2003.

■ **Condoms don't work.** Several curricula cited a long-discredited 1993 study that claimed condoms prevent HIV transmission only 69 percent of the time. In 1997, HHS publicly distanced itself from the study, echo-

ing countless other researchers in explaining that the study was based on "serious errors" in methodology. Another curriculum attacked one of the leading studies proving condom effectiveness, citing "university groups" that challenged its findings. The study in question looked at 15,000 acts of intercourse between an HIV-positive and negative person in which a condom was used; it did not find a single incidence of viral transmission. The challenging "university groups" that the abstinence-only curriculum cites turn out to be six letters to the editor of the *New England Journal of Medicine*, where the original study was published.

■ **Women need money from men.** The curricula regularly presented gender stereotypes as scientific facts. One curriculum, used by 19 HHS grantees, listed "Financial Support" as among the "5 Major Needs of Women" and "Domestic Support" under the same list for men. It goes on to explain, "Just as a woman needs to feel a man's devotion to her, a man has a primary need to feel a woman's admiration. To admire a man is to regard him with wonder, delight, and approval." Another curriculum, used by 32 HHS grantees, taught that "guys are able to focus better on one activity at a time" because women "experience feelings and emotions as part of every situation."

■ **Men need sex from women.** The same curriculum that listed financial support as a top female need and domestic support as a top male need also taught, "A male is usually less discriminating about those to whom he is sexually attracted. ... Women usually have a greater intuitive awareness about how to develop a loving relationship."

In 2003, 69 programs in 25 states used the curricula in Rep. Waxman's study. Those 69 programs have received over \$90 million in federal funding since 2001.

*Source: Committee on Government Reform, Minority Staff. U.S. House of Representatives. The Content of Federally-Funded Abstinence-Only Education Programs. December 2004.*



likely to use condoms when they eventually do have sex.<sup>23</sup> This is the sort of research that prompted then-Surgeon General David Satcher to state in his 2001 "Call to Action" on sexual health, "Few would disagree that parents should be the primary sexuality educators of their children or that sexual abstinence until engaged in a committed and mutually monogamous relationship is an important component in any sexuality education program. It does seem clear, however, that providing sexuality education in the schools is a useful mechanism to ensure that this nation's youth have a basic understanding of sexuality. Traditionally, schools have had a role in ensuring equity of access to information that is perhaps greater than most other institutions. In addition, given that one-half of adolescents in the United States are already sexually active—and at risk of unintended pregnancy and STD/HIV infection—it also seems clear that adolescents need accurate information about contraceptive methods so that they can reduce those risks."<sup>24</sup>

African American parents agree with Dr. Satcher. A recent CDC survey of 680 Black parents found that 97 percent believe they should be teaching their pre-teen kids about sex-related topics and 88 percent don't think that doing so will encourage their kids to have sex.<sup>25</sup>

But in recent years, Congress and the Bush administration have broken away from the consensus on comprehensive sex education. In 1996, conservative lawmakers slipped a program to fund abstinence-only sex education programs into a massive bill reshaping the welfare system. The measure set aside \$250 million over the following five years for state-run abstinence programs, and required states to put up matching funds if they took the federal money. The law stipulates that abstinence-only programs meet a strict set of guidelines, which include teaching that "sexual activity outside of marriage is likely to have harmful psychological and physical effects."<sup>26</sup>

Abstinence-only programs believe talking about safer sex techniques such as condom use and masturbation encourages sexual behavior, and they thus discuss condoms only to point out their potential deficiencies. To date, there exists no federal funding set-aside for comprehensive sex education.

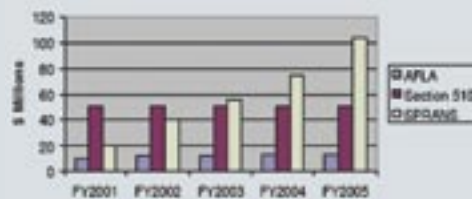
The funding for abstinence-only education in the welfare bill was not the first time conservative legislators delineated money for these programs. Nevertheless, this latest round was nominally to fund a pilot program, meant to test the efficacy of abstinence-only education. But the only measure by which the programs were to be graded was whether they increased the number of kids who said they want to be abstinent. The programs were not held accountable for actual sexual behavior, and the funding has since been renewed.

It's a good thing for those programs that they haven't had to stand up to scrutiny. To date, there exists no research showing abstinence-only programs delay the onset of sexual activity. There is, however, a mounting pile of research suggesting that they not only fail to slow sexual activity, but may also put kids at greater risk for disease. A popular aspect of abstinence programs is the "virginity pledge" that students take, in which they vow to either remain a virgin or to re-embrace abstinence if they have already had sex. One large-scale, national study found virginity pledges can in fact delay the onset of sexual activity, but only when they are built around a relatively small group of youth reinforcing one another as part of a counter-cultural identity. The participating youth must build what the authors call a "moral community" and define themselves against the larger social environment they are navigating; for the pledge to have effect, they must be virgins in a sea of whores. But the pledges still delayed sexual intercourse for an average of just 18 months. And when the youth who had taken the pledge eventually had sex, they were less likely to use contraception than those who had not.<sup>27</sup>



**Figure 5**

Abstinence-only education is funded through three federal programs: money budgeted annually under the 1996 welfare reform law, which was most recently renewed in 2004; the Adolescent Family Life Act (AFLA), which was first passed in 1981; and direct grants from the Department of Health and Human Services (HHS). Under the Bush Administration, the annual abstinence budget has more than doubled, driven almost entirely by grants from HHS.



But more troubling data comes from state-level evaluations of the abstinence programs that were launched with the funding provided under the welfare reform law. In the first five years of the initiative, every state but California accepted the federal money and launched an abstinence program. (California balked at the money because it had just completed its own pilot on abstinence-only education and had found that the programs did not work.) All told, around \$500 million in federal and state money was funneled into these programs between 1998 and 2003. In 2004, Advocates for Youth, a progressive organization that promotes youth sexual health, culled information from 10 of the state evaluations that were publicly available, along with California's evaluation of its earlier pilot. Despite stipulations in the law that all the states review their programs' efficacy, Congress renewed the funding without having seen many state evaluations.

The Advocates for Youth review found that, of the 10 program evaluations available, three showed the programs having no impact

on sexual behavior at all and two actually showed an *increase* in sexual activity among participating youth. Even looking just at the participants' intentions, only four state programs saw a favorable impact in their students' intentions to abstain from sex.<sup>28</sup>

Meanwhile, California Congressman Henry Waxman ordered a study of the abstinence-only programs funded through new Bush Administration initiatives, which will total \$104 million for fiscal year 2005. Waxman's study found that 80 percent of the curricula used by the programs that the U.S. Department of Health and Human Services (HHS) funds contain information that is "false, misleading or distorted." Those curricula were used by more than two-thirds of the programs that HHS funded in 2003. Much of the information provided by these federally-funded programs was not only false, but spectacularly so. One curriculum taught that as much as 10 percent of abortions cause sterility. Another teaches that HIV can be transmitted through sweat and tears. Another asserted that condoms failed to prevent HIV almost a third of the time they are used. Moreover, they not only blurred the lines between religion and science, they promoted negative gender stereotypes. One curriculum taught that, as a rule, women are seeking "financial support" in their relationships while men seek "admiration." Another asserted, "Women gauge their happiness and judge their success on their relationships. Men's happiness and success hinge on their accomplishments."<sup>29</sup> (See "What Our Kids Are Learning" on page 69.)

All told, the federal government will spend \$167 million on these sorts of sex education programs in fiscal year 2005. The White House had proposed spending \$270 million. Since the Bush Administration has taken office, funding for abstinence-only education has more than doubled, largely driven by funding for the HHS programs described in Rep. Waxman's report.<sup>30</sup> (See Figure 5.)





What Rep. Waxman's report implies is that, ultimately, these programs are less interested in helping young people remain sexually healthy than they are in fighting the culture wars. For African Americans, far too much is at stake to allow our children to be caught in the crossfire of the national fight over sexual morality. Our children need information on how to protect themselves when they are sexually active, as well as support in delaying that sexual activity until they are capable of handling it. Science shows that, when they are given useful and valid information, youth are making increasingly healthy choices. Research shows that African American parents overwhelmingly agree. And, yet, our federal government has launched an effort to silence these vital conversations in our schools by tying federal support to abstinence-only messages. African Americans must stand up and fight this backdoor censorship.

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# Hiding in Plain Sight

*Kai Wright explains how lurid reports obscure the bigger story.*

**B**ob's story was certainly compelling. *The New York Times* found him "prowling" for sex in a Manhattan bathhouse, high on "a wildly addictive stimulant" even as he spoke with the reporter. The sentiment of most of the men in the bathhouse was that, as one of them said, "rubbers are a killjoy." None cared about the threat of AIDS, and all were hopped up on crystal meth—a drug the story's headline described as THE BEAST IN THE BATHHOUSE.

The article was but one in a recent spate of shocking tales about how the nexus of drugs and sex has led too many gay men to ignore the danger of HIV. It's gripping stuff, and it's this year's hot AIDS story in the U.S.

Too bad it's such a distortion of reality. Crystal meth use is indeed spreading among well-heeled, largely white, urban gay men. And HIV is certainly on the rise among gay men as well—new infections shot up 17 percent between 1999 and 2002. The problem is that that increase is driven by infections among low- and middle-income African Americans. And those infections have little to do with "sex marathons." To the contrary, they're most likely the result of serial monogamy within small social circles where HIV is already present.

That's a far less eye-popping tale, and one we have seen woefully little coverage of. Nor have we seen much coverage of the fact that the epidemic is aging—44 percent of new HIV diagnoses in New York City each year are among people over forty—because of growing infections among middle-aged Blacks who aren't using condoms with their partners. No beasts, no bathhouses, just the small but crucial miscalculations that add up to today's still growing AIDS epidemic.

All reporters love a good lead. From drugs to crime to poverty, we cover America's social concerns with a dose of perception-skewing hype. An ambitious study recently released by the Kaiser Family Foundation makes this clear. The study illustrates how, from the beginning, the AIDS story has been driven by a series of big, attention-grabbing events. In the early years, it was the effect on the blood supply and debate over San Francisco bathhouses being shut down. Next came the public infections of Rock Hudson and Magic Johnson, followed by a pair of very large events, the discovery



of the drugs that have staved off death for so many people, and, finally, by the AIDS devastation in Africa.

The Kaiser study didn't analyze how much the hot story of the time colored how life with HIV was depicted. But it offered a disturbing hint at what this approach misses: overall, only three percent of stories focused on U.S. minorities. African Americans account for half of all new infections every year, but they have rarely been involved in the epidemic's high drama.

Even when Blacks have entered the frame, the picture has remained out of focus. A recent hot story was about Black men "on the down low"—guys who consider themselves straight, and live as such, but maintain homosexual relationships on the side. For most publications, those pieces offered a rare focus on Black gay men. Yet, just before the down-low infatuation emerged, a high-profile study estimated that a third of twentysomething Black gay and bisexual men are infected with HIV. Beyond the initial news reports, journalists have shown little interest in these largely out-of-the-closet (and thus boring?) people whose primary risk is unprotected sex inside a relationship with someone they've trusted too quickly.



To be fair, the quest for a dramatic story angle goes beyond journalism. Many of those leading in the fight against HIV insist on framing it as an emergency rather than a lasting concern. That means creating a sense of urgency—something best done by focusing on hyperbolic scenarios.

In its laudable effort to get the epidemic onto the front page, the U.S. Centers for Disease Control and Prevention focuses journalists on attention-getting theories. The down-low hysteria began when the CDC started pushing studies that speculated that such men form an "HIV bridge" to straight Black women. The crystal meth hype is now being driven by the CDC's effort to understand what it's calling "HIV-prevention fatigue" among young gay men.

The result is a myopic understanding of this epidemic. We see white where there's actually black. We see drug-induced orgies where there are really complex sexual choices complicated by the search for intimacy. And we see something that demands our attention for just a few fleeting, hysterical moments when we're actually facing a systemic, decades-long problem.

*This essay originally appeared in the March/April 2004 Columbia Journalism Review. Kai Wright is a journalist in New York City. More of his work on HIV can be found at [www.kaiwright.com](http://www.kaiwright.com).*

# About the Black AIDS Institute

The Black AIDS Institute, founded in 1999, is a training and mobilization center focused exclusively on Black people. The Institute's mission is to stop the AIDS pandemic in Black communities by engaging and mobilizing Black institutions and individuals in efforts to confront HIV. The Institute interprets public and private sector HIV policies, conducts trainings, offers technical assistance, disseminates information and provides advocacy 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 Univer-

sity (AAHU), the Institute's flagship training program, is a two-year fellowship program designed to increase the quantity and quality of HIV education in Black communities by training and supporting peer educators of African descent.

- **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 800 Black media members.

- The Institute publishes original editorial materials on the Black AIDS epidemic. Our flagship publication is a monthly newsletter, **Kujisource**, which has a distribution of 25,000. Our web site, **www.BlackAIDS**.

**org** attracts nearly 100,000 hits a month. The **Drum Beat** newspaper is a semi-annual tabloid with a distribution of 300,000. It is distributed to Black conventions, barber-shops, beauty parlors, bookstores and doctor's 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**, an annual photographic tribute to the work of Black warriors in the fight against AIDS, is currently traveling to Black universities, museums and community-based organizations throughout the United States, providing information on HIV/AIDS.

■ 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. The 2004 Rap-It-Up winner, first-time filmmaker Tracy Taylor has been nominated for an NAACP Image Award. Taylor's film, *Walking on Sunshine*, aired on BET and will

be screened at film festivals throughout the year.

Rap-It-Up is designed to provide a voice and visual outlet for the thousands of African Americans living with or caring for those with HIV and AIDS, and/or fighting AIDS in Black communities. 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 who would like to work more effectively with traditional African American institutions.

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

