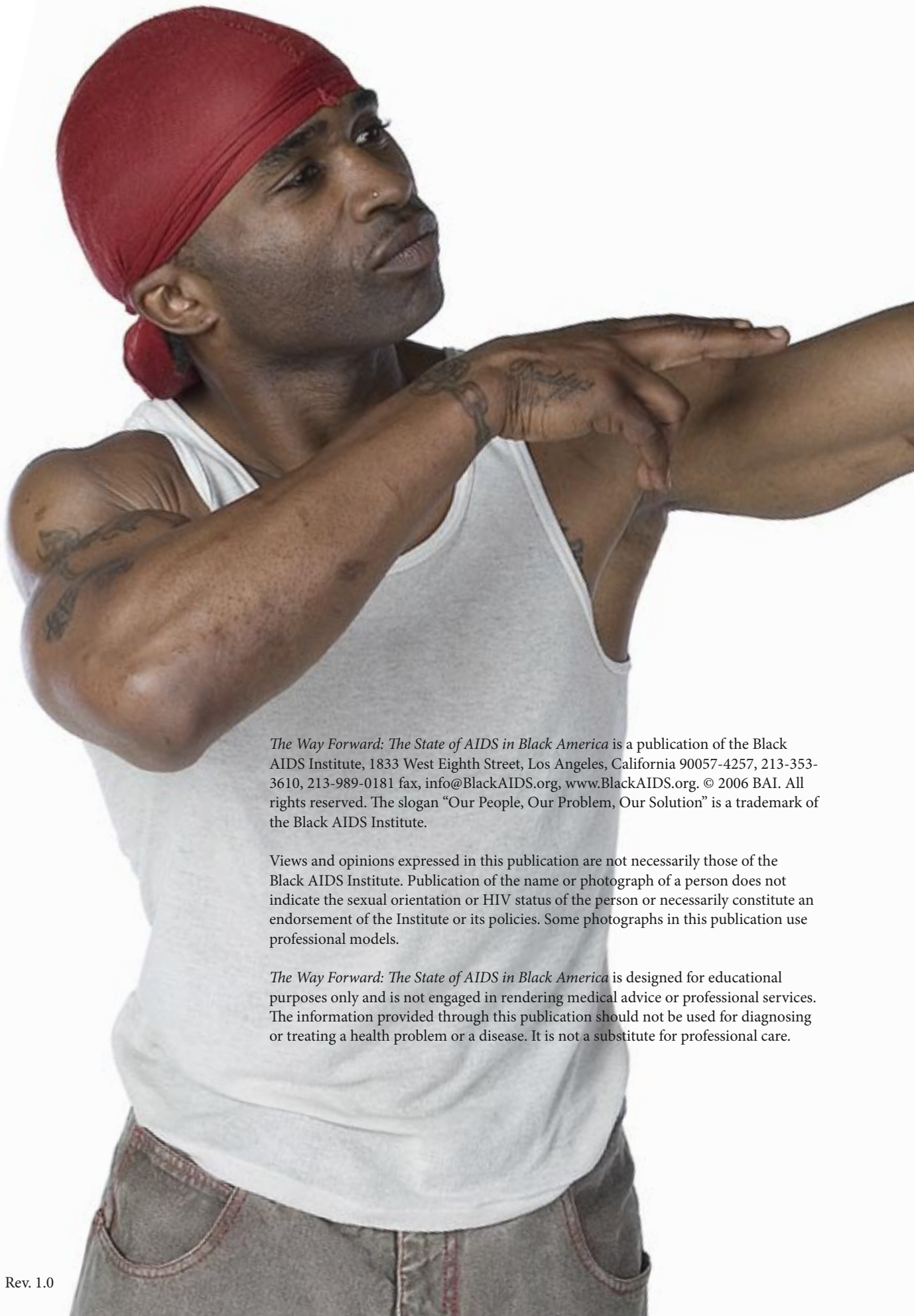


The Way Forward

The State of AIDS in Black America



By Kai Wright
Black AIDS Institute
February 2006



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Table of Contents

5	<i>From the Director</i> Charting Our Course to Health
9	<i>Overview</i> The Way Forward: Brave Successes, Cowardly Failures
21	<i>Chapter One</i> Beltway Blues: Washington's Attack on Treatment Access
33	<i>Chapter Two</i> Left to Die: Black Gay Men Losing Ground
41	<i>Chapter Three</i> Going South: The New Frontier of AIDS in America
49	<i>Chapter Four</i> Prevention that Works: Progress among Women and Drug Users
55	Recommendations
57	About the Author
58	About the Black AIDS Institute

THE FOUR GETS

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

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

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

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

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

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



FROM THE DIRECTOR

Charting Our Course to Health

Welcome to the 2006 report on the State of AIDS in Black America, *The Way Forward*. It is both fitting and ironic that this report is being released on the sixth annual National Black HIV/AIDS Awareness day as we all say our final goodbyes to our beloved Mrs. Coretta Scott King. Of traditional Black civil rights leaders, Mrs. King was the first and most courageous to join the ranks of heroes in the struggle against AIDS.

Black America has suffered tremendous losses in the last year. With the passing of Delores Tucker, Rosa Parks, and now Mrs. King, the ranks of brave leaders who put themselves on the line during the dangerous, heady days of the late fifties and early sixties have become desperately thin.

Coretta and Martin are finally together again. It's been 43 years since Martin had that dream, and 38 years since he stood on that mountaintop and saw our destiny. Now, however, we are faced with a devastating disease running rampant through our communities that threatens not only to prevent us from getting to the mountaintop, but to roll back much of the progress Dr. and Mrs. King fought for.

"AIDS is a human crisis, no matter where you live," Mrs. King said while addressing a gathering of the Southern Christian Leadership Conference. "Anyone who sincerely cares about the future of Black America had better be speaking out about AIDS, calling for preventive measures and increased funding for research and treatment."

Those words have never rung more true. Since we released this report a year ago, much has changed—and too much has remained the same. For the second year in a row, the President raised the specter of AIDS in the African American community and called on America to act. While we don't underestimate the importance of the President keeping the AIDS epidemic in Black America in the public eye, we can't help but note the glaring disparities between his words and deeds. That is a tragedy.

But this report is not about the President or Congress or any kind of "them." This report is about a collective us. As the motto of the Black AIDS Institute says, "Our People, Our Problem, Our Solution." As outlined in this report, when we have the courage to act we make progress; when we don't we lose ground.

The CDC released data in November 2005 showing good news: an annual 6% decrease in AIDS rates among Black women between 2001 and 2004. We've seen a similar annual decrease in the Black community at large driven primarily, the evidence strongly suggests, by successes in reaching injecting drug users. Prevention and targeted interventions work.

In the decade since effective drug treatments for AIDS dramatically cut death rates across the country, Black Americans continue to get infected and die at alarming rates. According to a recent article in *The New York Times*, one in five Black men in New York City between 40 and 49 has HIV or AIDS. Black men die at a rate six times that of white men.

Recently released statistics show an AIDS epidemic among Black gay and bisexual men that outstrips anything we are seeing in the worst-hit parts of sub-Saharan Africa. Nearly 50 percent of Black gay and bisexual men in some of our nation's cities are estimated to be infected with HIV. Nearly 50 percent! That's a pandemic of catastrophic proportions, and each of us must rise to the occasion.

The report also highlights the tsunami-like epidemic growing among southern Blacks, where we see rising case loads, a health delivery system already in tatters, and stifling stigma and silence.

But most importantly, this report points the way forward with a series of recommendations for individuals, leaders, institutions and our government.

We call on leaders to lead. The AIDS story in Black America is mostly one of a failure to lead. Black leaders—from traditional Black ministers and civil rights leaders to hip hop artists and Hollywood celebrities—must join in a national call to action and declaration of commitment to end the AIDS epidemic in our communities immediately.

We call for a lifting of the federal ban on funding for needle exchange programs.

We call for the expansion of comprehensive, age-appropriate, culturally competent AIDS prevention efforts—with messages inclusive of abstinence, delayed sexual activity, sexual responsibility, proper condom use and negotiated safety—that give young people the tools to protect themselves.

We call on a massive effort to address the disproportionate impact this epidemic is having on Black men who have sex with men and a rejection of stigma based on sexual orientation—real or perceived.

Finally, we call on all Black Americans to raise our HIV literacy and find out our HIV status. Knowledge is a powerful weapon in the war against AIDS. There are an estimated 1.3 million Americans living with HIV/AIDS today. Nearly half of them are Black. A quarter of them don't know they are infected—and people who don't know they're infected are less likely to protect their partners and completely unable to receive treatment.

AIDS is not just a health issue. It is a human rights issue. It is an urban renewal issue. It is an economic justice issue.

Mrs. King understood the importance of confronting the AIDS epidemic if we are to have any chance of winning the battle for racial justice. An army ravaged by disease cannot fight. A dead people cannot reap the benefits of a battle won.



Phill Wilson
Executive Director, Black AIDS Institute





OVERVIEW

The Way Forward

Brave Successes, Cowardly Failures

Few things are more banal than an AIDS conference these days. Dozens of them convene every year, hosting thousands of AIDS professionals from all over the world. It's true that the assemblies often offer crucial opportunities to gather and share information. But they are just as often chances to exchange platitudes and empty promises. So it's understandable if the crowd assembled at a June 13 session of the U.S. Centers for Disease Control and Prevention's 2005 National HIV Prevention Conference in Atlanta weren't expecting to hear big news. Nevertheless, we were all about to witness a sadly historic moment in the AIDS epidemic.

CDC AIDS researcher Dr. Alan Greenberg spoke in the subdued monotones of a bureaucrat as he painted a shocking portrait, jarring in its clash with that morning meeting's sleepy calm. As we craned our heads up at the giant slides projected behind Greenberg, he skipped through a disturbing litany of new studies showing just how dramatic the Blackening of America's AIDS epidemic has become.

Greenberg explained that the number of Americans living with HIV and AIDS

had for the first time topped one million, estimating between 1,039,000 and 1,185,000 people were HIV positive as of 2003. African Americans—a mere 13 percent of the total population—represent half of those people. Perhaps most shocking were the early results Greenberg cited from a large study of gay and bisexual men: Nearly half of the Black men tested in the study's early results were positive¹.

Between 24 and 27 percent of those in the overall caseload are unaware they are infected. Greenberg offered no data as to what share of the undiagnosed are African American, but there exists wide concern among AIDS experts that testing rates are lower in Black communities than elsewhere. In one study released at the Atlanta meeting—a 2005 survey of 151 Black college students at Jackson State University in Jackson, Mississippi—researcher Nanetta Payne found that only 44 percent had ever been tested for HIV while 72 percent had been sexually active in the last 90 days, and only a third of those said they used condoms consistently².

CDC researchers also unveiled new data about trends among young people at the June meeting in Atlanta. Looking at HIV infec-



The 2005 Black AIDS Index

In June 2005 the Centers for Disease Control and Prevention announced two key milestones in the American AIDS epidemic: More than one million people are now believed to be living with HIV and half of them are Black. But that's not the only big news from CDC last year. Black America saw good, bad and downright ugly in HIV/AIDS trends in 2005.

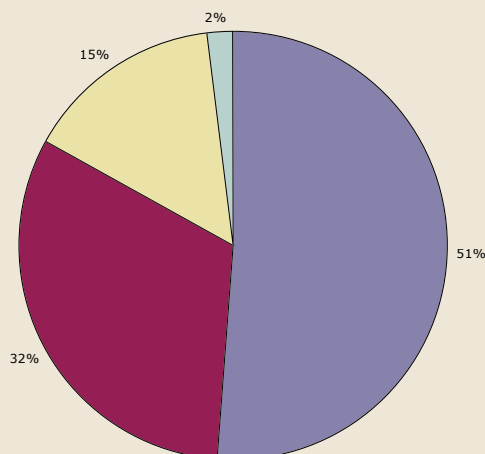
The Good

- 5 percent decline in average annual rate of new infections among African Americans overall between 2000 and 2004;
- 6 percent decline in new infections among Black women between 2000 and 2003;
- 20 percent decline in new infections among 13- to 24-year-old women overall between 1994 and 2003, with significant declines in all racial groups.

The Bad

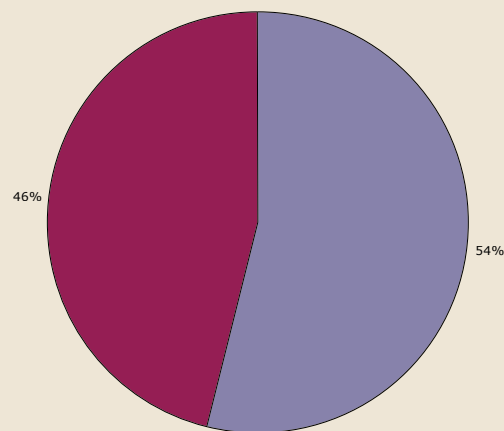
Racial breakdown of new HIV diagnoses, 2000-2003:

- Black – 51 percent
- White – 32 percent
- Latino – 15 percent
- Other – 2 percent

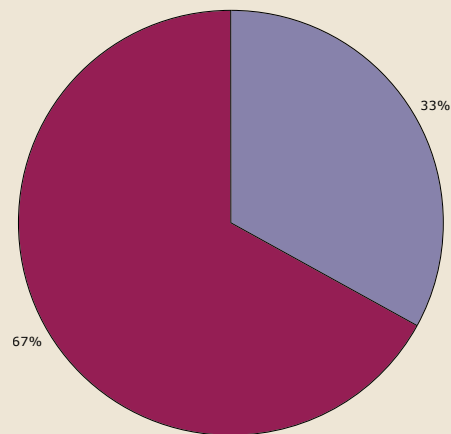


The Ugly

Share of Black gay and bisexual men in five-city* study who tested HIV positive: 46 percent



Share of those men who didn't know they were positive: 67 percent:



*The five cities are Baltimore, Los Angeles, Miami, New York City and San Francisco.

Source: All data from U.S. Centers for Disease Control and Prevention presentations at National HIV Prevention Conference, June 2005.

tion rates among 13- to 24-year-olds between 1994 and 2003, CDC found a disturbing spike in infections among young men. After falling by a dramatic 30 percent between 1994 and 1998, new infections jumped 41 percent between 1999 and 2003. This jump was driven by infections among gay and bisexual men, where new diagnoses climbed 47 percent—60 percent of which were among African Americans³.

It has been clear for many years now that the American epidemic is a uniquely Black concern. What Greenberg told us on June 13, 2005, was that AIDS has irrefutably become a uniquely dire concern for Black America.

Yet, there's plenty reason for hope.

At both the June conference and in studies released later in the year, researchers marked trends that showed real, sustained progress in lowering HIV infections among African Americans, both overall and in specific target populations. That progress, however, is decidedly uneven. Pockets of our community are making strides—women of all ages, injection drug users in some cities—while things are growing increasingly dire elsewhere—among gay and bisexual men and in the South. The difference between these places of success and failure is disturbingly singular: Where we've invested in honest prevention, we're turning the tide; where we continue to refuse to do so, we're drowning in new infections and recalcitrant death rates.

The Unnoticed Good News

While the CDC's 2005 pronouncements included much to be disturbed about, they also included signs of progress in stopping the epidemic's spread. In places where communities and public health leaders have come together to bravely implement proven prevention strategies, they've found success.

In November 2005, CDC released national data that, for the first time, included numbers from New York State. New York began tracking HIV infections by collecting the names of those newly infected in 2000; since CDC's national numbers are drawn only from states that use names-reporting, the November report was the first in which there was enough corresponding name-based data from New York to fold into the national picture. What we learned is that HIV infections among African Americans overall dropped by an average of five percent annually between 2001 and 2004⁴.

CDC could not pinpoint what drove the decline, but the agency's researchers surmised that the drop was the result of New York City's dramatic success in cutting new infections among injection drug users—a success attributed to its long-standing if still controversial needle exchange programs. Despite this sort of proven success, Congress continues to ban federal funding for needle exchange programs; 19 states and three territories had no exchange programs as of 2002⁵. Chapter four will discuss the New York City success story and ongoing federal ban in greater detail.

More good news came when looking at trends among African American women. The CDC's June releases again pointed out an overlooked fact first reported in November 2004: The rate of new infections among Black women dropped by six percent between 2000 and 2003⁶. And among young women overall, aged 13 to 24, new infections dropped a whopping 20 percent between 1994 and 2003, with declines in all racial groups⁷.

During a press conference at the Atlanta meeting, CDC-funded researchers cited a host of prevention programs that are believed to be driving the slow but steady progress among women of color. What the highlighted programs have in common is a focus on helping women to begin talking honestly with one



How HIV Monitoring Works

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

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

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

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

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

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

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

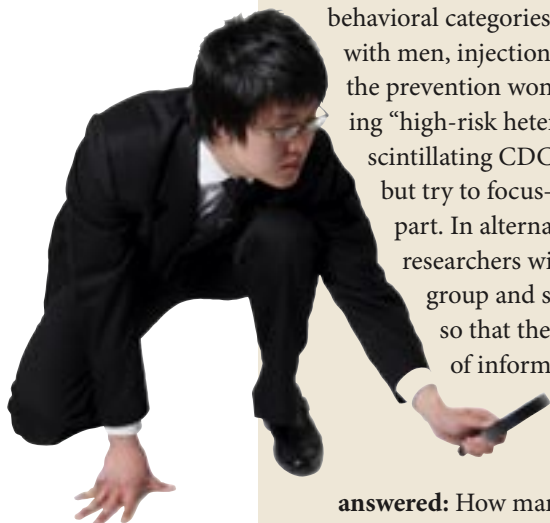
What they want answered: What's the total number of infected?

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

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

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

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



another about their sexual health and thinking about the active and inactive decisions they make in their sexual lives.

Still, in the same time period in which we saw a decrease in infections among Black women, African Americans accounted for a shocking 69 percent of new diagnoses among women overall—with a rate 18 times higher than that among white women⁸. There is clearly much more work to be done. But we are just as clearly learning exactly what that work must look like: open, honest and sustained dialogue among Black women about their sexual and romantic lives, along with ongoing efforts to put protection in their hands through female-controlled prevention methods (i.e., female condoms and microbicides). Chapter four will discuss prevention's success stories among women and injection drug users in more detail.

New Tracking System

The numbers released in Greenberg's presentation were the first in a series of CDC reports in the coming years that promise to flesh out our understanding of the American epidemic. For a decade now the CDC has been saying the same thing about HIV infections: We log 40,000 new ones a year. Everyone accepts the figure and moves on. But the reality is it's an incredibly broad estimate, and we can say with little confidence whether it's wildly inflated or deflated. Greenberg explained how the CDC plans to change that troubling fact.

From the beginning, public health's ability to track the AIDS epidemic has been hamstrung by its broader social and political implications. It was, after all, originally known as "Gay Related Immune Disorder"—and at a time when gay-pride celebrations were still considered radical. As discussed in chapter three of this report, if you spend a few days below the Mason-Dixon Line today, it becomes clear that HIV infection still car-

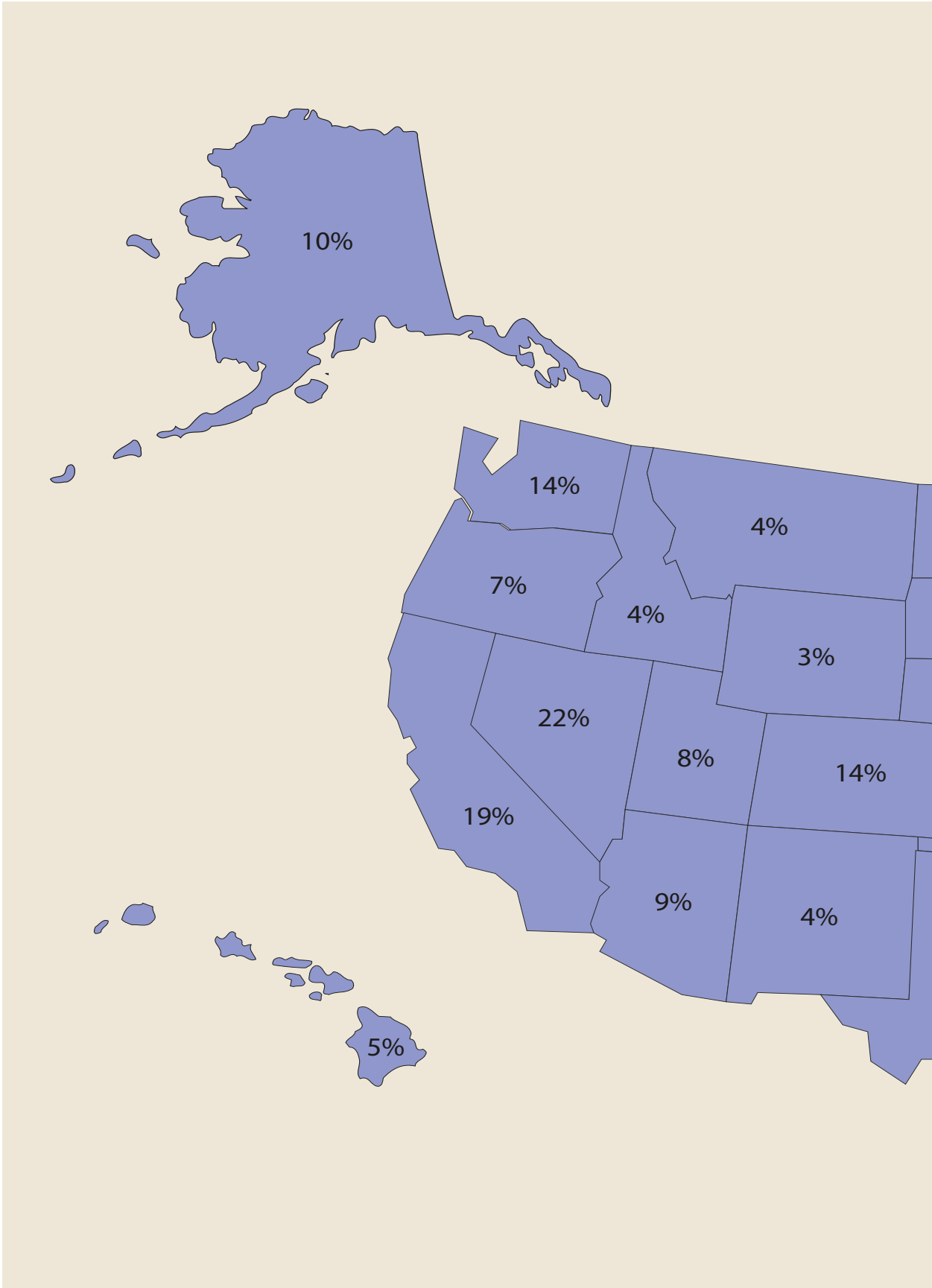
ries massive stigma. So AIDS and gay activists alike have long warned that collecting too much information about those getting tested will encourage the people who most desperately need tests to avoid them.

At the epidemic's outset, then, public health made an untidy compromise with the nation's social realities: Local health departments collected data only on full-blown AIDS cases, rather than on those who were infected with HIV but not actually in immediate danger of illness.

In late 1997, after new drugs drastically prolonged the time between testing positive and developing AIDS, CDC officials first began publicly musing about the need for states to track HIV infections instead—and to do so by using the name-based reporting system employed to keep up with other communicable diseases. The idea ignited hot debates in local communities around the country, between those who feared collecting names would undermine progress in getting people to take HIV tests and those who feared holding the status quo would leave public health operating dangerously blind in its effort to stop the disease's spread.

Slowly, however, most states gave in to the inevitable. While the CDC never made name-based HIV reporting mandatory, the agency made clear its intention to build a national surveillance system anchored on names reporting. It didn't take local officials long to realize Washington would ultimately use that system to divvy up resources, and that states not meeting its standards risked getting short-changed. The most recent national CDC data includes information from 33 states that have been monitoring new infections by collecting names since at least 2000⁹. The remaining states still use some combination of coded identifiers and names.

With that glacial revolution now in irreversible motion, the CDC has launched a multi-pronged plan to more closely examine the much-cited 40,000-new-infections figure.

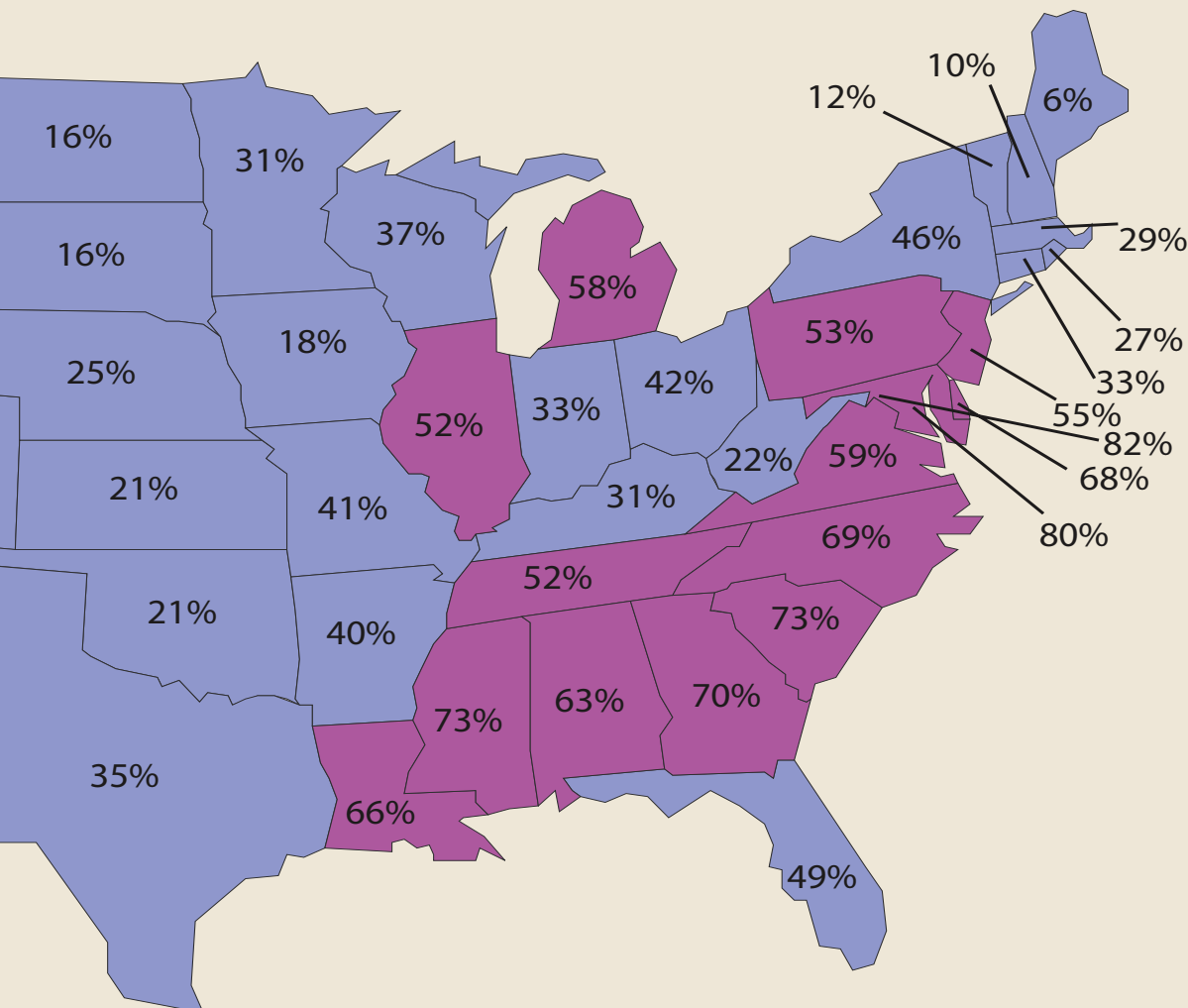




The National Picture: Black AIDS State-by-State

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

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



Devil's Details

Perhaps the most compelling new numbers will come from what the CDC is calling its National Behavioral Surveillance System, or NBSS¹⁰. The idea is to take a closer look at those who are most statistically at-risk for infection, asking what they are doing and how they are interacting with services that public health has set up to help them stay well.

The NBSS will track people who fit three behavioral categories: Men who have sex with men, injection drug users and what prevention wonks have started calling “high-risk heterosexuals”—or, women and men with multiple sex partners and reporting high rates of unprotected vaginal or anal intercourse. In alternating 12-month cycles, researchers will focus targeted surveys on one of the three groups—meaning they’ll get a fresh batch of behavioral information on each group every three years. They will draw their subjects from the same cities each time, in order to create clean data on trends over time.

Men who have sex with men drew the short straw and went first. CDC has already completed research on them for the 2004-2005 cycle, in which researchers interviewed over 14,000 men at 17 sites in 13 states and territories.

In Atlanta, Greenberg released early information from that study, covering just five of the cities. In those locales, researchers found that a stunning 46 percent of Black gay and bisexual men in the study were HIV positive; more than two-thirds of those positive men didn’t know they were infected.¹¹ Chapter two of this report will take a closer look at this new data, as well as the social and political dynamics driving it.

The CDC’s tool for sharpening its annual 40,000-newly-infected estimate is its HIV Incidence Surveillance System. CDC

has chosen 34 sites around the country to focus on each year. In those places, researchers will drill down on newly-diagnosed infections to get, among other things, the person’s demographics and clinical info on that person’s virus. Importantly, they will also run newly-developed tests to determine how recently the person has been infected. This last bit will be key to deciphering where in society the virus is speeding up and slowing down, thereby allowing CDC to target prevention resources in a way that has not been previously possible.

However, CDC will continue to draw its overall estimate of the national HIV case load from the states that track new HIV infections by recording the names of those who test positive.

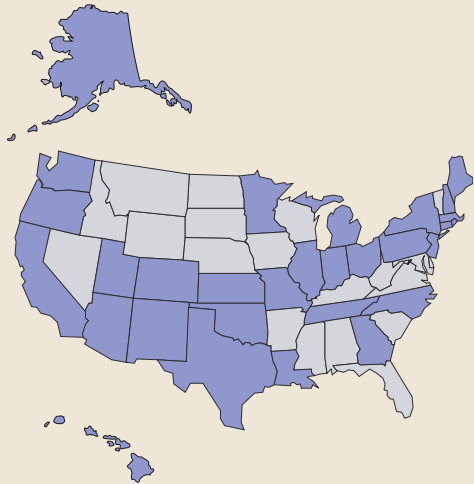
Finally, the agency’s Morbidity Monitoring Project will examine not only how people are faring while in treatment for HIV/AIDS, but also to uncover what’s happening to those who are not in treatment: Why aren’t they getting care? And are they doing something harmful to themselves—or others—while they’re on the outside of the care bubble? Researchers have selected 26 sites in 21 states from which to pull medical records of those in care and ask some questions. They’ll get demographics, lab results and history of antiretroviral use, among other things. They will then do interviews with both people who are in care at those sites and those in the area who are not. In the interviews, they’ll add questions about access to health services and HIV-risk behaviors.

All of this represents the feds’ decision to move past the age-old AIDS debate about balancing public health’s need for information with its equally important need to respect and protect the privacy of those affected. CDC has decided it simply needs more information, and credibly argues that health officials can gather it while still adhering to privacy standards.

The lingering question, however, is how

Keeping Track

Thirty five areas (33 states plus Guam and the U.S. Virgin Islands, shaded below) now monitor new HIV infections by recording the names of those who test positive for the virus. The remaining states use some combination of names and coded-identifiers, prompting CDC to exclude their data when drawing a national estimate of new infections. National estimates of full-blown AIDS diagnoses, however, include all states.



Source: U.S. Centers for Disease Control and Prevention

will the feds' new aggressiveness play out at the local level. Will local officials take the cue and push for even more detailed information about private lives? Will they begin to demand things like mandatory testing for certain populations, compulsory notification of previous sexual partners, or even criminalization of HIV transmission? And, if so, how will these changes impact everyone's willingness to engage the public health system surrounding HIV and STDs more generally?

Treatment Crisis Deepens

While the CDC spent 2005 working to better track and understand the virus' spread, Congress and the White House spent it conspiring to gut the public care systems that have had such stunning success at keeping people alive with HIV for the last two and a half decades. From their inaction on renewing the Ryan White CARE Act—which is the primary vehicle for federal funding of AIDS services—to the drastic cuts they made to Medicaid, Washington lawmakers seemed insistent last year on turning the AIDS-care clock back to the early 1990s.

In November, Congress passed cuts to Medicaid totaling \$11 billion over the next five years and \$42 billion over the next decade¹². (At the time of this report's writing, the bill had not been finalized but was considered a fait accompli.) As the nation's last refuge of health care for poor families, Medicaid is America's leading payer for AIDS treatment, and public insurance pays for two-thirds of African Americans in treatment.¹³ The cuts congressional leaders crammed down the throats of both the nation and their own party members are largely driven by an unprecedented expansion of states' ability to charge subscribers co-pays and premiums—a cynical step that the Congressional Budget Office predicted would not generate actual revenue but, rather, save money by discouraging poor subscribers from actually seeking care.

Meanwhile, Congress allowed last year's session to come and go without reauthorizing the CARE Act. Because the Act is not an entitlement program, legislators must both pass a fixed annual budget for it and reauthorize its existence every five years. Rather than tackle the difficult reform questions the now 15-year-old program faces, Congress punted the issue to next session—leaving the local AIDS service organizations that depend upon it in limbo for both their long-term program-



ming plans and their immediate financial needs.

Chapter one will discuss these programs and the impact cuts to them have on the health of African Americans living with HIV/AIDS in greater detail.

Notes

1. Greenberg, Alan. U.S. Centers for Disease Control and Prevention (CDC). New Approaches to Tracking the HIV/AIDS Epidemic in the United States. Powerpoint presentation at 2005 National HIV Prevention Conference. June 13, 2005. All data and information in this chapter attributed to Greenberg is drawn from this presentation.
2. Payne, Nanetta. HIV Testing Among African American College Students. Poster presentation at 2005 National HIV Prevention Conference. June 2005.
3. CDC. Patterns of new HIV/AIDS among adolescents and young adults in 25 states. Oral presentation at 2005 National HIV Prevention Conference. June 13, 2005.
4. CDC. Trends in HIV/AIDS Diagnoses—33 States, 2001-2004. Morbidity and Mortality Weekly Report (MMWR). November 18, 2005.
5. Kaiser Family Foundation. StateHealthFacts.org. Sterile Syringe Exchange Programs, 2002. Viewed online January 10, 2006.
6. CDC. Diagnoses of HIV/AIDS—32 States, 2000-2003. MMWR. December 3, 2004.
7. CDC. Patterns of new HIV/AIDS among adolescents and young adults in 25 states. Oral presentation at 2005 National HIV Prevention Conference. June 13, 2005.
8. CDC. Diagnoses of HIV/AIDS—32 States, 2000-2003. MMWR. December 3, 2004.
9. For a list of the 33 states, see sidebar in this overview, titled “Keeping Track.”
10. Descriptions of the NBSS and the other CDC tracking programs come from Greenberg, A. presentation at National HIV Prevention Conference.
11. The five cities Greenberg released data from were Baltimore, Los Angeles, Miami, New York City and San Francisco.
12. Parrot, S. et al. Center on Budget and Policy Priorities (CBPP). Assessing the Effects of the Budget Conference Agreement on Low-Income Families and Individuals. Viewed online, last revised January 9, 2006. At the time of writing, the exact figure for the Medicaid cuts was in dispute in press accounts. The Institute accepts the CBPP calculation of the cuts’ total dollar amount.
13. Kates, J. Kaiser Family Foundation. Financing HIV/AIDS Care: A Quilt with Many Holes. May 2004.





CHAPTER ONE

Beltway Blues

Washington's Attack on Treatment Access

America had traveled a long and windy road to the moment when a cadre of House and Senate members emerged from their weekend-long budget-negotiating session in the pre-dawn hours of Dec. 19, 2005. Their policymaking chess match dated at least as far back as Bill Clinton's failed healthcare reform initiative of the early 1990s. But by that morning, such heady efforts at expanding access to care had long since been taken off the table. Today's debate instead turns on whether any form of health insurance should be shielded from the uncertainties of the marketplace. And the Dec. 19 deal for fiscal year 2006's budget may well have finally settled the matter, setting us on a course where a family's health is only as certain as its ability to purchase it.

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

expenditures at all levels of government have exploded in the last 15 years. States now spend, on average, 17 percent of their budgets on Medicaid (making it second only to education as a money grubber). They're groping for ways to reign-in the costs. Between fiscal years 2002 and 2006, 43 states created stricter eligibility standards or lowered the income ceiling to qualify for coverage; 39 states reduced benefits¹.

Since 2001, the Bush administration has worked tirelessly to push its own answer for relieving these budgetary pressures: End America's pledge to keep its most vulnerable citizens healthy. The White House wants Congress to turn Medicaid into a "block grant" that is doled out to states in one lump sum each year. Each state would be left to spend this fixed, predetermined federal contribution as it sees fit—and to fend for itself on whatever expenses go beyond that amount.

Currently, the feds pay an agreed upon percentage of each state's Medicaid bill each year, regardless of how high it gets. In exchange, states follow a host of federal rules dictating how they run their programs—rules



Medicaid Reform by the Numbers

In December, Congress hammered out a budget deal that would cut a number of social service programs in order to save approximately \$40 billion, primarily by reducing Medicaid costs. The cuts are nominally in an effort to reduce budget deficits, but they don't even cover the cost of a round of tax cuts for the wealthy that had been planned for early 2006. Here are the details of the deal:

- \$11 billion over five years and \$42 billion over 10 years cut from Medicaid;
- 10 percent of the cost of each medical service can be charged to subscribers living just above the poverty line; the previous maximum charge was \$3;
- \$10.5 billion over 10 years in savings that the Senate achieved through getting lower prices from drug companies were discarded;
- Four tax cut bills passed the House in the last six weeks of 2005, at a cost of more than twice the savings made through social service cuts in the budget deal;
- All applicants must now provide birth certificates or passports, a barrier for people with unstable lives (i.e., homeless people, displaced Katrina survivors, and countless others).

Source: Parrott, S. and others. Center on Budget and Policy Priorities. Assessing the Effects of the Budget Conference Agreement on Low-Income Families and Individuals. Posted on CBPP website, last updated Jan. 9, 2006.

largely designed to protect the beneficiaries and ensure equal access regardless of where you live or what ails you.

Most governors have long chafed under

those rules. But they've also griped about what they say is an inadequate federal contribution, even when structured in the current open-ended way. So as the Bush offensive has gained steam in the last two congressional sessions, and as the federal purse strings have tightened on a host of programs, governors have seen the writing on the Medicaid wall. They've realized that they're not getting more money out of Washington any time soon, so they better at least get the freedom to maneuver that Bush's block grant offers.

Scrambling to forestall what was building into a fait accompli, moderate governors and senators of both parties worked furiously throughout last summer to hammer out a compromise Medicaid-reform plan, one that both controlled costs in the short term and addressed structural questions about federal/state financing in the long term. The result was a package of ideas that people on all sides of the health-policy debate's ideological divide rallied around, helping it move through the Senate in November.

Backroom Betrayal

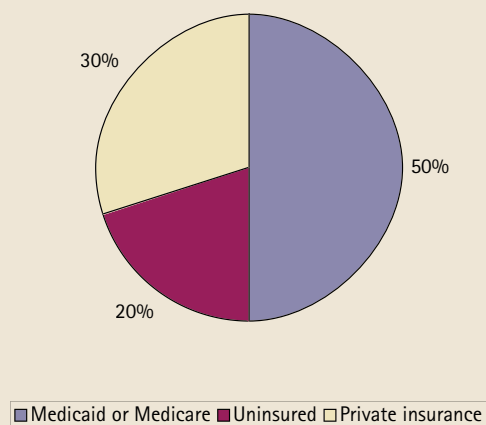
The November Senate bill would have achieved billions in savings by making targeted cuts that spared benefits: It would have gotten a better deal on the massive stock of pharmaceuticals Medicaid buys from drug companies. It would have targeted fraud and waste by hospitals and nursing homes. It would have brought Medicare into the feds' discount drug-purchasing program (a move that was bizarrely left out of the new Medicare drug benefit, at the White House's insistence). And it would have gotten rid of \$10 billion in needless giveaways to managed care companies in the new Medicare program, while cutting further overpayments, saving an estimated \$26 billion over the next 10 years².

All of these carefully crafted ideas were summarily stripped from the budget deal that

Breaking Medicaid's Bank

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

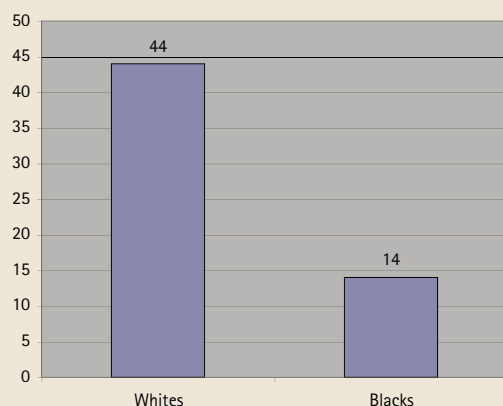
Distribution of payers for AIDS treatment in the U.S. by percentage:



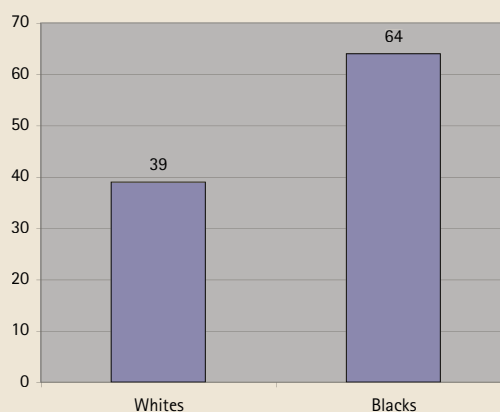
And African Americans with HIV subscribe to public insurance programs in far higher numbers than whites...

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 on 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. On average, states now spend 17 percent of their budgets on Medicaid. Between fiscal years 2002 and 2006, 43 states created stricter eligibility standards or lowered the income ceiling to qualify for coverage; 39 states reduced benefits.

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.

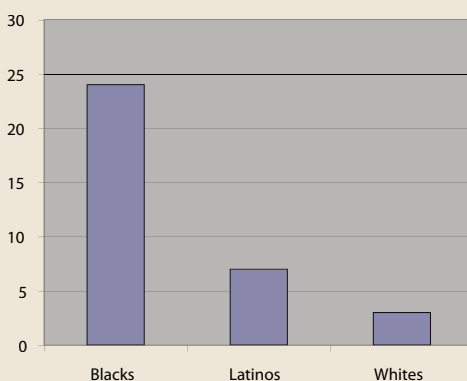


emerged in the wee hours of the morning on Dec. 19. Led by congressional Republicans,

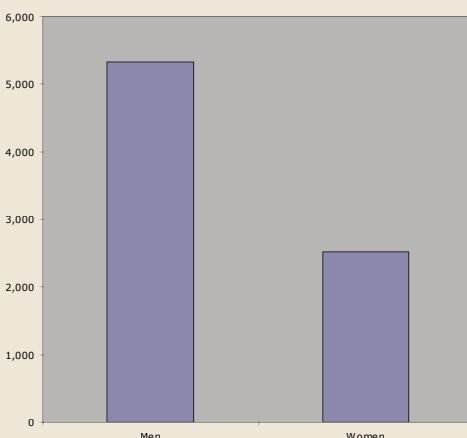
Still Dying

Despite plummeting death rates from AIDS in the United States, Black folks are still dying at much higher rates than whites. 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:



Black AIDS deaths in 2002:



Sources: Agency for Health Care Research and Quality. U.S. Department of Health and Human Services. *National Healthcare Disparities Report: Prepublication Files. Chapter 3.* And Millet, G. CDC. Oral presentation to the Black Media Roundtable on HIV/AIDS, Nov. 17, 2005

the House and Senate negotiators dropped their own version of Medicaid reform onto the House floor at one in the morning. They shoved the bill through by 6 a.m., giving members just five bleary-eyed hours to review the 774-page tome. Days of confusion about what was actually in the bill followed, but when the dust settled what had occurred was clear: Legislators had decided to pay for Medicaid by taking the money from the same poor subscribers the program was designed to help in the first place. (At this report's writing, the bill had not yet been finalized, but was considered a *fait accompli*. It passed the Senate on Dec. 21, but with a minor change that required it to be taken back up in the House before being signed into law by the president.)

The budget deal cuts Medicaid spending by \$11 billion over the next five years and \$42 billion over the next decade³. It achieves these savings in large part by boosting cost sharing from the current \$3 limit to what could be hundreds of dollars in some cases. It allows states to charge co-pays of up to 10 percent on each service for people living between 100 percent and 150 percent of the poverty level (that's around \$16,000 to \$24,000-a-year for a family of three). People above that mark could be charged premiums for the first time ever, and co-pays of up to 20 percent.

The only limitation on all of this is that medical bills may not exceed five percent of a family's annual income. But that's little comfort for those living so close to the poverty line, since nothing stops a catastrophic event—like a recalcitrant opportunistic infection for someone with an AIDS diagnosis—from eating all of a month's income, driving families into homelessness and worse.

All of these bad ideas originated in the Medicaid reform bill that the House originally passed; and the Congressional Budget Office concluded then that the savings they would generate would not come from the actual cost sharing but from discouraging use

of Medicaid at all. Such willful short-sightedness betrays the ideological zeal driving the conservative effort to destroy rather than fix public insurance: A raft of Medicaid reform studies have shown that one of its primary cost drivers is that people wait until they are seriously ill to seek care, then turn up in emergency rooms where the cost is higher and the likelihood of successful treatment is lower.

Moreover, the ostensible force behind congressional determination to cut federal costs in general and Medicaid in particular was to balance the federal budget. As Sen. Judd Gregg (R-N.H.), chair of the Senate Budget Committee, told members, "This is the one vote you'll have this year to reduce the rate of growth of the federal government." Yet, the bill's cuts won't even fully cover the next round of tax breaks for the wealthy, which Congress plans to take up early this year.

All of this has great consequences for the nation's fight against AIDS. Public insurance pays for half of all people getting treatment for AIDS; Medicaid planners predict AIDS spending will reach \$6.3 billion in FY2006, without counting the states' contributions⁴. That money is of particular import to the health of African Americans with AIDS. While 44 percent of whites in treatment for AIDS pay for it with private insurance, only 14 percent of African Americans have that luxury. As a result, two-thirds of Blacks getting AIDS treatment pay for it with Medicaid or Medicare⁵.

Ryan White in Limbo

While African Americans living with HIV rely heavily on Medicaid for access to expensive AIDS treatments, the Ryan White CARE Act is perhaps even more crucial to our community's health. Ryan White is the vehicle for the feds' annual appropriation of money for state and local health depart-

ments' AIDS work. The federal money is paired with local funds to finance a sweeping range of health and support services provided by clinics and other nonprofit AIDS organizations.

Ryan White makes possible things ranging from support groups and counseling to community education and primary care. It also funds the AIDS Drug Assistance Program (ADAP), which provides anti-HIV meds for people who don't qualify for Medicaid but cannot afford private insurance. The Act is divided into four broad categories (see sidebar "How the Safety Net Works" on page 30). In each category, anywhere from 45 percent to 60 percent of clients are Black⁶.

Unlike Medicaid, Ryan White is a discretionary program for which Congress must set a budget each year. Over the past five years, that process has proven a disappointing one for AIDS care providers and local health departments around the country.

Since 2001, as federal resources have been directed towards wars abroad and tax cuts at home, the AIDS care budget has failed to keep pace with the epidemic's growth. In the last five years, the Ryan White budget has inched up by just \$300 million, to \$2.1 billion in FY2006. In that same time period an estimated 200,000 people have been newly infected⁷.

And this year, in which the CDC announced there are more Americans living with HIV and AIDS than any time in the epidemic, the Dec. 19 budget deal again kept Ryan White funding essentially flat. ADAP was the only part of Ryan White to get a funding increase for 2006; the budget deal would boost its budget by \$2 million. It was the smallest budget increase in the program's 15-year history⁸.

ADAP's budget problems have been the most recurring among the Ryan White programs. ADAP was built into Ryan White in 1990, largely with hospice care in mind—funding meds for patients expected to die



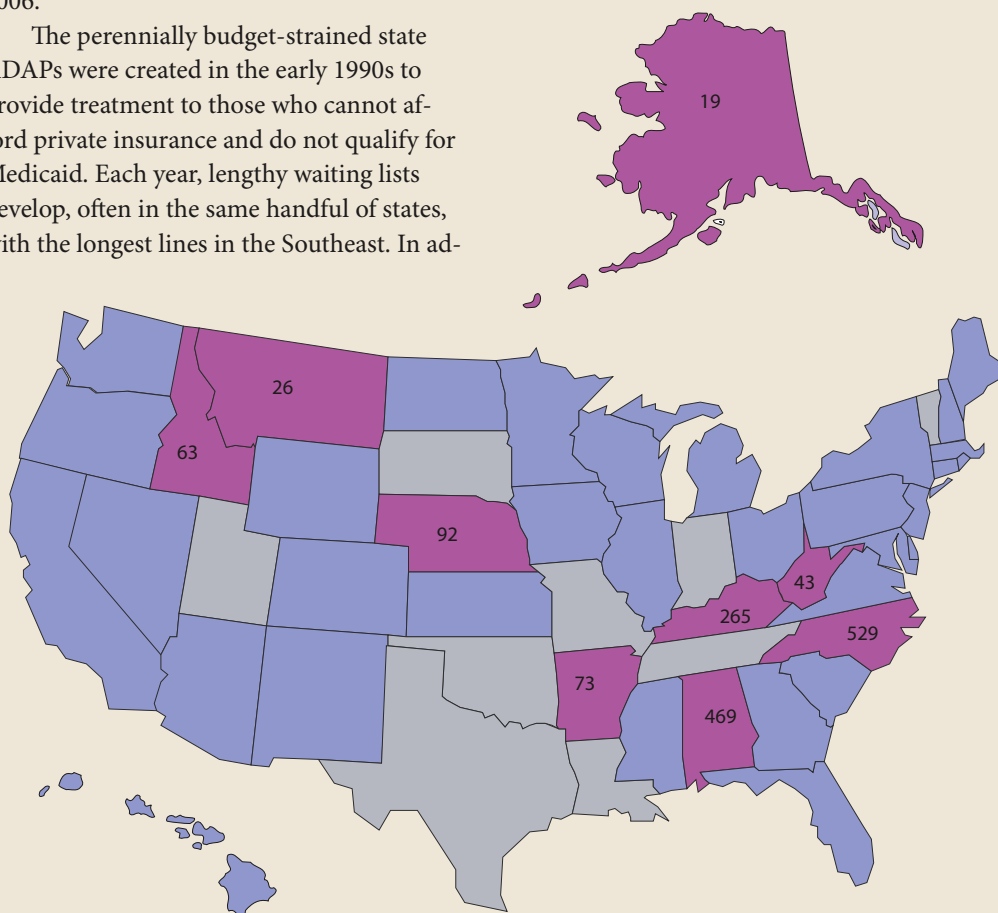
The ADAP Map

As of November 17, 2005, 1,579 uninsured Americans living with HIV or AIDS in nine states were on waiting lists to get access to medications through the AIDS Drug Assistance Program. Of those people, 932 were receiving drugs through an emergency federal appropriation that was set to expire in early 2006.

The perennially budget-strained state ADAPs were created in the early 1990s to provide treatment to those who cannot afford private insurance and do not qualify for Medicaid. Each year, lengthy waiting lists develop, often in the same handful of states, with the longest lines in the Southeast. In ad-

dition to the nine states with waiting lists, 10 states (light blue on map below) have capped enrollment or set up other cost-containment measures since April 2004.

Source: *The ADAP Watch*. National Association of State and Territorial AIDS Directors. December 6, 2005.



*Alabama has both set up a waiting list for existing meds and capped enrollment for a new class of meds that recently became available.

within a few years. Since the advent of protease inhibitors in the mid-1990s, however, the program has been straining under the weight of its own success. The drugs keep people alive, but at great cost and without curing them. That has driven a dramatic expansion

of the ADAP rolls; an estimated 136,000 people get AIDS drugs through ADAP now⁹. Waiting lists and other cost-containment measures recur year after year.

As with Medicaid, Ryan White in general and ADAP in particular are of particular

importance to African Americans living with HIV/AIDS. Sixty percent of ADAP clients are Black¹⁰.

A Community Divided?

In addition to setting an annual Ryan White budget, lawmakers must also reauthorize the Act every five years. Congress has handled that bureaucratic necessity largely without controversy since Ryan White's establishment—until now. The 2005 session came and went without legislators reaching agreement on how to update the program in order to keep it relevant to today's epidemic and deal with recurring funding problems. That impasse was in part due to Congress' busy plate of political controversies, ranging from Katrina rebuilding to Supreme Court nominations and fundraising scandals. But the congressional stalemate also reflected heightened disputes among those working in the AIDS field about what reforms are now most needed.

The divide is a regional one. Since the epidemic's opening days, large cities in the North and West have been the geographic center of AIDS in America—and have thus absorbed a large share of Washington's AIDS resources. But recent years have seen a dramatic shift in the location of new infections: 41 percent of people living with HIV/AIDS are now in the South. So AIDS activists and public health watchers below the Mason Dixon line have begun to demand that the money shift to them as well. (Chapter three will discuss the Southern epidemic in detail.)

The problem, of course, is that the pool of money is finite—indeed, as the epidemic has grown, the federal budget for dealing with it has remained all but the same size. And without additional funding, getting money to manage the South's new epidemic means spending less to control the North's old one. That unforgiving reality has split the AIDS community's usually unified message to Con-

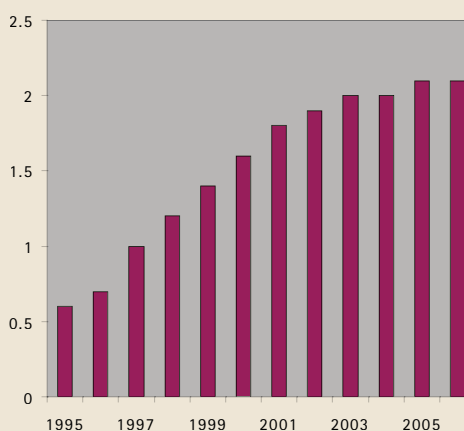
gress on Ryan White reauthorization.

Ryan White money is divvied up based on a complicated formula that puts funding into one of three "titles" and hands it out

Falling Behind

Since 2001, the federal AIDS care budget has failed to keep pace with the epidemic. The Ryan White CARE Act is the primary federal vehicle for funding AIDS care programs, supporting services ranging from support groups and mental health counseling to drug rehab. But while federal health monitors announced this year that there are more Americans living with HIV or AIDS than ever before (over a million), Congress kept the Ryan White budget essentially flat for the fourth straight year. In five years, it has gone up by just under \$300 million.

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



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



based on the size of each state's epidemic. But one pot of money goes to 51 metropolitan areas long-ago identified as AIDS hot spots; states that have one of these metro areas get additional money to deal with the state of "emergency" in those cities. Advocates in the South—who formed a group called the Southern AIDS Coalition to lobby Congress—have complained that this model doesn't work for their epidemic, where people with HIV are spread out in rural areas all over the state rather than just clumped in big cities. Moreover, they argue, the double funding that states with one of the 51 metro areas get is no longer fair.

But both local health officials and AIDS activists in the old urban hot spots have noted that they are hardly in a position to give up resources. Their hold onto the meager successes they have seen in the last 20 years of fighting their epidemics has become increasingly tenuous in the post-9/11 era, in which resources for social services of all sorts have become scarce. The five years of essentially flat funding of Ryan White has led most urban programs into significant service cutbacks.

As the tensions between these two sides grew in the AIDS community throughout the run-up to the deadline for Ryan White's reauthorization last fall, Congress and everyone else waited for a sign of what the Bush administration wanted to see. After all, the President had at least nominally made reforming the AIDS care network a policy priority of 2005.

Bush's AIDS Plan

There it was, wedged into an otherwise unsurprising litany of Bush administration priorities in the 2005 State of the Union: the President's wholly unexpected acknowledgement of the epidemic raging among African Americans. "Because HIV/AIDS brings suffering and fear into so many

lives," President Bush told Congress, "I ask you to reauthorize the Ryan White Act. ... And as we update this important law, we must focus our efforts on fellow citizens with the highest rates of new cases, African American men and women."

But the AIDS world then waited six months on edge to hear exactly what kind of "update" the Bush administration would recommend for Ryan White. On July 27, the administration finally spoke up. The list of reforms it offered was packed with explosive ideas that quickly turned up the heat on an already boiling pot of controversy.

Drugs come first. The recommendation that drew the most universal disdain called for a new rule mandating that 75 percent of Ryan White dollars be spent on "core medical services." What's a core medical service? The Bush recommendations were vague on that point, noting only that "some [services] are clearly life prolonging and essential to maintaining physical and mental health; others are not," and suggesting that a definitive list of each be drawn up—presumably by Washington¹¹. Care providers have uniformly cringed at this idea. They fear services like transportation assistance, food banks and support groups won't make the "essential" list. But doctors treating the sorts of low-income patients who depend upon CARE Act programs note that these things, more than the meds themselves, make the difference between sick and well.

"The irony is, yeah, we've got your \$10,000 worth of drugs for the year, but we can't help you with the \$15 cab fee to help you get here and pick 'em up," scoffs Dr. Laurie Dill, who treats patients at Montgomery AIDS Outreach in southeast Alabama. "And I have patients that literally don't have food in the house and can't take their medicines on an empty stomach. The food bank helps fill in those gaps. ... It's real clear to me that the people who are least adherent [to their treatment plans] are the people who are least





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. At this report’s writing, the FY2006 budget was expected to do the same.

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

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

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

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

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

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

able to be adherent, because of all these other problems.”

Send the money South. The most controversial of Bush’s recommendations undoubtedly were those that pit North and West vs.

South in the scramble for scarce resources. The administration agreed with the Southern advocates’ contention that states with older, urban epidemics are double dipping. While the administration signaled it considered the

current formula unfair, its recommendations did not spell out exactly what a new formula would look like.

Of course, the cities deemed in crisis argue that, well ... they're in crisis. Cutting off their funding may marginally help states with more dispersed epidemics, they point out, but it will come at the cost of retarding decades of progress in urban centers. "Our nation's AIDS budget cannot be balanced on the back of poor people of color—whether in urban or rural America," said Alandra Mitchell, an HIV-positive New Yorker, in a Housing Works statement reacting to the Bush proposals.

Be the last to pay. The CARE Act, like Medicaid and other social safety net programs, was conceived as a "payer of last resort"—meaning it's only supposed to be for people who can't get care through any other route, be it public or private insurance. The administration is convinced Ryan White programs have been too ready to care for people who have other options. So its recommendations called for tougher auditing and reporting requirements to ensure the money's being spent appropriately.

Free government from the community. Currently, law requires that states and cities maintain community boards that work in conjunction with health departments to spend the money feds give them. The administration is convinced this communal input has unnecessarily limited the "flexibility" of all-knowing bureaucrats who, freed from the pesky requirement, could efficiently end AIDS—or something like that. In any case, one volatile recommendation proposed allowing state and local officials to cut the community boards out of the planning process and relegate them to a purely advisory role.

But as much dust as the Bush recommendations kicked up, the Ryan White ball didn't move in Congress. For the remainder of 2005, Congressional Black Caucus members fought to get the program onto the agenda; their

efforts were in vain. From Katrina forward, lawmakers faced a more full plate of political controversies than they could handle. Ultimately, they punted on fixing Ryan White. At this report's writing, Congress expected to pick the matter up again early this year.

Notes

1. Kaiser Commission on Medicaid and the Uninsured. State Fiscal Conditions and Medicaid, Fact Sheet. November 2005.
2. Parrott, S. and others. Center on Budget and Policy Priorities (CBPP). Assessing the Effects of the Budget Conference Agreement on Low-Income Families and Individuals. Posted on CBPP website, viewed Jan. 9, 2006.
3. The exact dollar amounts of the cuts were in dispute in press reports at the time of this report's writing. The numbers here are based on CBPP's analysis. Similarly, details of the budget deal's Medicaid changes are drawn from CBPP analysis of the bill.
4. Kaiser Family Foundation (KFF). HIV/AIDS Policy Fact Sheet: Medicaid and HIV/AIDS. September 2004.
5. KFF. Financing HIV/AIDS Care: A Quilt with Many Holes. May 2004.
6. HIV/AIDS Bureau. Health Resources & Services Administration (HRSA). Program Data Reports and Presentations, 2003. Posted on HRSA website, viewed Jan. 19, 2005.
7. The CDC estimates 40,000 new infections a year.
8. National Association of State and Territorial AIDS Directors. The ADAP Watch. Feb. 1, 2006. In addition to Ryan White's flat funding, Congress agreed to cut all discretionary spending in the federal budget by 1 percent.
9. Kaiser Family Foundation. HIV/AIDS Policy Fact Sheet: AIDS Drug Assistance Programs. April 2005.
10. HIV/AIDS Bureau. HRSA. Program Data Reports and Presentations, 2003. Posted on HRSA website, viewed Jan. 19, 2005.
11. Department of Health and Human Services. Ryan White Care Act Reauthorization Principles. Fact sheet included in press release on White House recommendations. July 27, 2005.



CHAPTER TWO

Left to Die

Black Gay Men Losing Ground

T Lungile's being uncharacteristically quiet. An exuberant 21-year-old, he usually takes a frantic, expansive approach to conversation. He'll talk so fast that his mouth literally can't keep up. His sentences trail off with a rapid, staccato "da-da-da, da-da-da," as he casts aside left-over words that are just delaying his next idea. But now he's just picking at his rice and beans while shrinking into the booth of one of the Dominican delis that fill his Brooklyn neighborhood.

"It's a good question," he grants with a shrug. "It just boggles my mind." The question at hand is why he's having so much unprotected casual sex lately. For the last nine months, he's been pretty frisky, meeting lots of guys on Adam4Adam.com—an internet site where Black men meet each other for sex, love or just to pass the time. Of the scores Lungile's met, he figures he's only used a condom with maybe one in five.

It's not that he's got some sort of secret risk-calculation figured out here. Some guys decide that if they only "top"—or, be the one doing the inserting—they'll be safe when do-

ing it unwrapped; indeed, it's more difficult to contract HIV that way, though certainly still possible. But Lungile's not putting that much thought into it. Nor is he being overly trusting, taking the word of guys he asks about their HIV status. The subject rarely comes up at all. "Bottoming, topping, versatile—all of it," he again shrugs, explaining the positions he's been in. "And most of the time I don't even use protection, maybe 80 percent of the time."

Still, Lungile is also not the picture of depravity that so often gets painted when talking about gay men who eschew protection. He's got no death wish. He's not "bug chasing" or participating in drug-fueled "bareback" sex parties. He's not even "on the down low"—frankly he couldn't be closeted if he tried. None of these clichés of HIV prevention apply to Lungile's sexual decision-making process. He's not, in fact, engaged in anything like a decision-making process. As far as he can see, he's just having sex. It's just that if condoms don't come up, he doesn't bring them up.

Lungile's profile is proving an all-too-familiar one in HIV/AIDS. For years, study

after study has shown increasingly dramatic infection rates among Black gay and bisexual men of all ages. Nearly half of all Black men who contracted HIV between 2000 and 2003 caught it through sex with other men¹. Conversely, nearly a third of all men who contracted HIV through sex with other men in 2003 were African American². But last summer, Centers for Disease Control and Prevention researchers unveiled the most shocking data yet on infection rates among Black gay and bisexual men.

In June 2005, at the National HIV Prevention Conference in Atlanta, CDC laid out its plan for a multi-year survey seeking to identify risk-behavior patterns among “men who have sex with men.” The survey, to be repeated once every three years, includes over 14,000 men in 17 cities (see overview). While announcing the study, CDC released some early findings from it.

The preliminary results broke out data from five cities: Baltimore, Los Angeles, Miami, New York City and San Francisco. Of the 1,746 men tested for HIV in those cities, 25 percent were positive, and 48 percent of those positive men were unaware of their infections. Undiagnosed infections were most pronounced among young men in the study: 79 percent of 18- to 24- year-olds and 70 percent of 25- to 29-year-olds who tested positive didn’t know they had the virus.

But as dramatic as these overall findings were, the numbers are still more troubling when broken out by race. Of the 444 Black men tested in those five cities, nearly half—or 46 percent—tested positive. More than two-thirds of them—67 percent—had been previously undiagnosed³.

A number of gay activists have cautioned that we should not assume this study means that half of Black gay men are positive, and they have argued that the study has too small of a sample size to draw generalized conclusions. While that sobering perspective is important, it is also important to remember that

this is not the first study to find dramatically high infection rates among Black men having sex with other men. Most significant of those was a CDC study released in 2001 that found 32 percent of Black 23- to 29-year-old gay and bisexual men tested in five major cities were HIV positive⁴.

The findings also echo through the CDC’s 10-year tracking of infections among young men. At the June 2005 Atlanta conference, CDC also highlighted a study that showed infection rates among young men aged 13 to 24 first plummeted by 30 percent between 1994 and 1998, but then climbed back up by 41 percent between 1999 and 2003. That jump was driven by a whopping 47 percent rise in new diagnoses among “men who have sex with men” aged 20 to 24—of whom 60 percent were African American⁵.

Finally, it is also important to note the *relative* severity of the 46 percent study’s findings. Regardless of the sample size—though it is a standard one for behavioral science studies—the infection rate among Black men was more than twice that among white men (among whom 21 percent of 616 men tested positive; 18 percent of those were previously undiagnosed).

Groping for Answers

The June 2005 data came on the heels of a frightening announcement about a potential new superstrain of HIV, found in a gay man in New York City in February 2005—a bug resistant to almost every available drug and that rapidly progressed from infection to illness. The local health department eventually backed off of the superstrain claim; after researchers were unable to identify any other cases, it became clear that the strain was just a routine manifestation of the long-documented ways in which the wily HIV behaves oddly in some bodies. But the hysteria the health department’s announcement caused revealed a profound

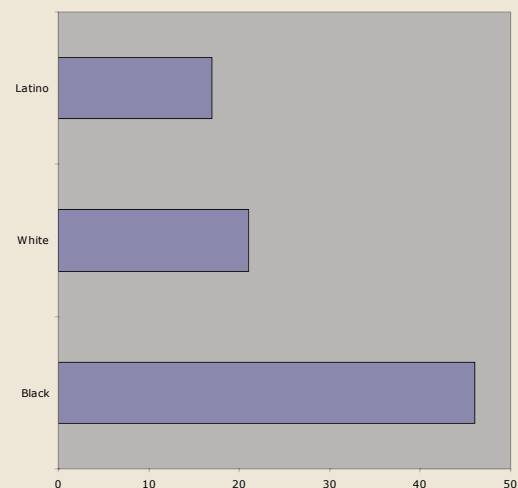
46%

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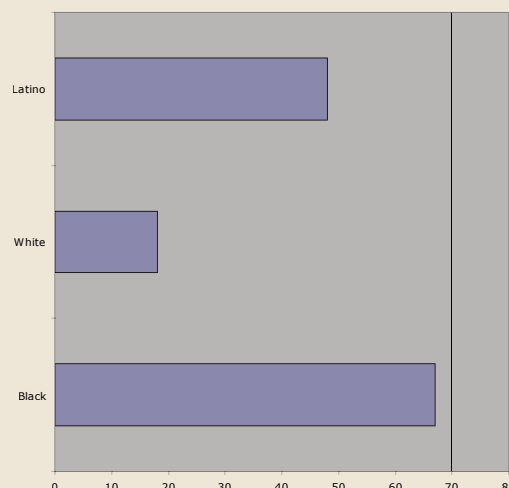
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Percentage of men in study who tested positive, by race:



Percentage of those who tested positive who were also undiagnosed, by race:



Source: Greenberg, Alan. CDC. *New Approaches to Tracking the HIV Epidemic in the United States*. Presentation to National HIV Prevention Conference. June 2005.

anxiety—and real anger—percolating among those charged with stopping AIDS among gay and bisexual men.

At a packed public forum in New York City, convened by local health officials after the superstrain announcement, that anger was palpable in the voices of AIDS veterans. Tokes Osubu, executive director of the group Gay Men of African Descent, articulated why. “My anger stems from seeing that someone in his mid-40s, who had seen the devasta-

tion of the 80s and 90s, [contracted HIV] in 2004. That made me extremely angry,” Osubu somberly admitted, “and angry because I thought that as a provider [of AIDS services] I had failed.”

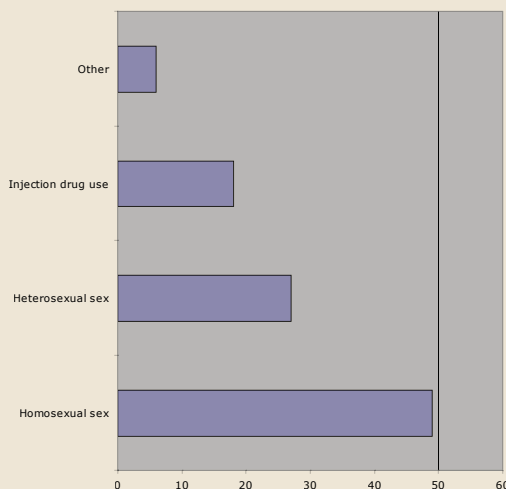
And so, from gay activists to public health experts, everyone’s scratching their heads about what is driving these trends among gay men in general and Black men in particular. After 25 years of messages about safety—and real progress made in



Black is Gay; Gay is Black

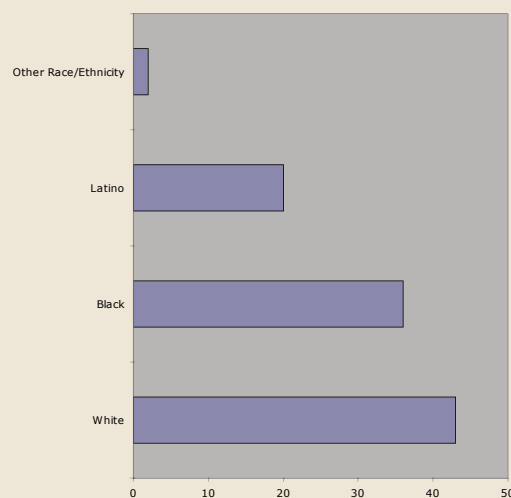
Observers often discuss the epidemic as one most impacting either Black folks or gay folks – pitting one community against the other in the scramble for scarce resources. That divide is a false one, however. No matter which way you look at it, Black gay and bisexual men are disproportionately represented among the ranks of those infected.

Transmission routes for new HIV diagnoses among Black men between 2000 and 2003, by percentage*:



Source: CDC. *The HIV and AIDS Epidemic among African Americans. Press backgrounder for June 2005 National HIV Prevention Conference.*

Racial breakdown of new HIV diagnoses among “men who have sex with men” in 2004, by percentage**:



Source: CDC. *HIV/AIDS Surveillance Report, 2003. Table 20. Vol. 15.*

*Includes data from 32 states that tracked HIV infections by recording the names of those who test positive during the three-year time period.

**Includes data from 35 states and territories that tracked HIV infections by recording the names of those who test positive since at least 2000.

the 1990s—how can it be that men are once again putting themselves at risk in such great numbers?

Unfortunately, too many people have settled on easy answers. An increasingly common one embraces the notion that men who take sexual risks are simply depraved or self-loathing in some way. Words like “murder” and “suicide” come up regularly when talking about gay men’s sexual behavior these days. We cling to caricatures like that of the clandestine man skulking about on the DL, too disconnected with himself to use protection.

And we blame everything from drugs to the internet for spurring impulsive sexual acts.

But for many men like Lungile, the truth is both more complex and more banal. Understanding it requires us to place sexual actions within the larger contexts of people’s lives. “We often treat these issues in decontextualized ways,” offered George Ayala of AIDS Project Los Angeles during the New York City superstrain forum. “And there’s a way in which we objectify gay men as we talk about our responses to HIV that is problematic for me, and that we really need to actively ad-

dress if we're going to get to the root causes."

One root cause, says Bay Area psychotherapist Walt Odets, is an obvious and universal one: The search for intimacy. "Unprotected sex is important in a lot of ways," Odets insists. Sex is, after all, as much about vulnerability as anything else. So the idea of using protection while having it is arguably counterintuitive. "But if gay sex is just this perverse recreation, then it's not worth any risk."

Again, the events of New York City's superstrain scare are instructive. Local health officials repeatedly cited a survey in which researchers found that only 45 percent of gay men said they'd used a condom the last time they'd had sex. The implication was that the city's gay male population was making unusually risky sexual choices. But no one ever mentioned that this was actually a higher rate of condom usage than either straight men or women reported in the same survey. And when isolating men with more than three sexual partners in the last year, condom use rates among "men who have sex with men" were slightly higher than that among heterosexual men⁶.

Indeed, one of the most striking things about the studies showing just how at-risk Black gay and bisexual men are is that the men in the studies are so certain of their safety. In the 2001 study in which a third of twenty-something Black men tested positive, nine out of 10 of them didn't consider themselves at risk⁷. That's likely because they weren't doing anything out of the ordinary when they encountered the virus.

The difficult reality, however, is that HIV transmits more easily via anal than vaginal sex, particularly if you are the receptive partner. And due to the existing infection rates among homosexually and bisexually active men, a negative Black gay man is far more likely to encounter the virus in the course of even a run-of-the-mill sex life than anyone else. That means the stakes are higher for him.

But if public health is going to effectively help gay and bisexual men navigate these treacherous waters, it must first acknowledge that, by and large, they are not behaving any more recklessly than their straight peers. They are in fact already exceptionally cautious. The unfortunate epidemiological and biological realities of the AIDS era are that they must be still more exceptional in order to stay healthy. Given the social context in which gay and bisexual men—particularly African American ones—go about their search for love and lust, intimacy and pleasure, that's a tall order.

A Game Rigged Against You

Alvis Wilson's got a pretty typical family life. The 23-year-old recent college graduate is closest with his grandmother. He and his brother are the babies of the Detroit family, and they've always been grandma's favorites. Wilson even lived with her during his senior year in high school. She always figured that his calm, quiet demeanor, his ambitious mind and his model looks would get him far in life, and make her proud. "I was the second one to go to college," he explains. "She thought I was gonna get married and have a career and all that."

He gave her part of the dream. After graduating, Wilson migrated to New York City to use his skills for good, working for nonprofit groups doing community-building work in the city's Black neighborhoods. But around that time he also told an aunt on his mom's side that, yeah, her suspicions were right; he's gay. He knew the word would spread pretty fast.

"My grandmother called me and was like, 'What's this I hear about you being gay?'" Wilson recalls. He was at dinner at the time, and tried to put her off. But grandma was livid and wanted answers. "She was like, 'Are

you? Yes or no?’ And, ‘I don’t know where you get this faggot s--t from, but you better cut it out! I don’t know what’s wrong with you.’” He hung up on her.

Things were strained between the two for a bit after that, but the relationship was far too important to either of them to let it slip away. Tempers subsided, and they both just dropped the subject. Most of his family never picked it up in the first place, though they conceded some things to Wilson’s new openness. Men in the family used to regularly use words like “faggot;” they stopped that after he came out. And some people even lauded his bravery, including his mom. But by and large everyone just steered clear of the topic, considering it too volatile a subject—Wilson included.

“I think we could talk about it, we just prefer not to—or maybe I prefer not to, and she prefers not to as well,” Wilson says of his grandmother. “But I’ve never mentioned anything else to her about it. I guess I don’t know if it would put her in an awkward position—or me. So I don’t know what she thinks about it. ... In fact, no one ever asks, which I think is something that’s ...” he pauses, squeezing out the last word as more of a question than a statement, “normal? For most people, families don’t really take an interest in that.”

And so Wilson and others like him go through puberty, young adulthood and on into maturity with the foundational knowledge that the particular brand of intimacy they are looking for has the potential to separate them from their families and communities. That’s heavy baggage to carry into the already fraught process of sexual development. Before young men like Wilson and Lungile ever get to the part everyone else struggles with—trying to navigate the tricky waters of sex and love while staying safe—they first have to figure out how to accept their desires to do so, in a world in which those desires are illegitimate at best.

“Ever since I went to work for Gay Men

of African Descent as its first director 10 years ago,” writes Colin Robinson, now director of New York State Black Gay Network, in a December 2005 essay, “my notion of what we need to do to stop HIV has been to promote homosexuality—our own culturally specific experiences and expressions of it—and to battle homophobia. We need to change the conditions under which Black men who have sex with men make decisions about sex and risk.” Robinson penned the essay, entitled “Psst. Homophobia Causes AIDS. Pass it On,” in an effort to focus our attention on the big pink elephant in the middle of the HIV prevention room⁸.

“How can we ask folks to have safer sex when they don’t feel safe in the rest of their lives?” he writes. “When the intimacy and vibrancy that sex provides is often the only place they feel alive?”

Notes

1. U.S. Centers for Disease Control and Prevention (CDC). The HIV and AIDS Epidemic among African Americans. Press backgrounder for June 2005 National HIV Prevention Conference.

2. CDC. HIV/AIDS Surveillance Report, 2003. Table 20, Vol. 15.

3. All details and data from this survey discussed here comes from, Greenberg, Alan. CDC. New Approaches to Tracking the HIV Epidemic in the United States. Presentation to National HIV Prevention Conference. June 2005.

4. CDC. HIV Incidence among Young Men Who Have Sex with Men—Seven U.S. Cities, 1994-2000. Morbidity and Mortality Weekly Report. Vol. 50, no. 21. June 1, 2001.

5. CDC. Patterns of new HIV/AIDS among adolescents and young adults in 25 states. Oral presentation at National HIV Prevention Conference. June 13, 2005.

6. New York City Department of Health and Mental Hygiene. Sex in the City: More HIV Testing and Condom Use Needed. NYC Vital Signs. July 2003.

7. CDC. HIV Incidence among Young Men Who Have Sex with Men—Seven U.S. Cities, 1994-2000. Morbidity and Mortality Weekly Report. Vol. 50, no. 21. June 1, 2001.

8. Robinson, Colin. Psst. Homophobia Causes AIDS. Pass It On. BlackAIDS.org, posted Dec. 19, 2005.





CHAPTER THREE

Going South

The New Frontier of AIDS in America

Alabama's withering summer heat hadn't set in yet, but it was already balmy inside Montgomery's only HIV clinic in April 2005. Somebody had climbed on top of the refitted sewing factory in which the clinic's housed and stole the copper wire out of the air conditioning unit. It's that kind of neighborhood. The clinic sits at the far end of an all-but-abandoned strip mall. The only neighbors are a dollar store and a beauty parlor, neither of which draws much traffic¹.

Much has been made of the “New South” in recent years, of the booming commerce that's brought large numbers of African Americans back below the Mason-Dixon Line. That's not Montgomery. Luxury SUV's may be the rage in places like Atlanta, or even further upstate in Birmingham, Ala., but here the gold standard remains a stout Chevy. It's the state capitol, and downtown's leafy boulevards give the impression of tranquility. But head west into Montgomery AIDS Outreach's neighborhood and it is apparent that the poverty that has always been typical of the South's “Black Belt” persists. Of the 12 states in which at least 20 percent of the population

is enrolled in Medicaid—the public health insurance program for the poor—seven of them are in the South².

Montgomery AIDS Outreach is actually the only AIDS clinic serving the entire southeastern quarter of the state—a geographic area home to the state's highest per capita infection rate. MAO has set up a handful of mobile clinics around the region, along with another permanent center a couple hours away in Dothan. One of its three doctors circulates between those outposts and the Montgomery headquarters. If you've got insurance, there's one private infectious disease specialist in the area; otherwise you come to MAO.

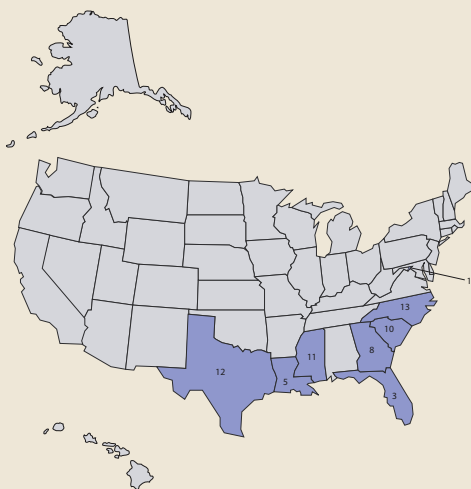
That economic crunch—limited choices for patients, equally limited resources for providers—is a recurring reality throughout the South. But as large a challenge as it represents, there's an ever greater one. Whoever you talk to about HIV in Montgomery and elsewhere around the South, one barrier to getting and keeping people healthy looms largest: Fear.

Nothing outside of MAO identifies it as an HIV clinic. Staffers drop “AIDS” from the name when answering phones. They swap



Bulging Borders

New York and California still play host to the largest populations of people living with HIV/AIDS. But when looking at density—or number of AIDS cases per capita—the South’s crisis becomes clear. In 2004, southern states and territories reported eight of the 13 highest AIDS case rates.



Source: *Statehealthfacts.org*. Online statistical database maintained by Kaiser Family Foundation.

war stories about having to draw blood for HIV tests in fast-food parking lots down the street or discreetly pass meds to cars hidden in the back alley. That’s all necessary because many patients would rather go without care than have someone suspect they’re HIV positive. “We had to move our clinic in Tuskegee,” says long-time staffer Barbara Harper of one of the mobile clinics, “because patients said, ‘Oh, Sister Judy works over there’ or ‘Elder so and so used to work there. I’m not going there.’”

But even as these difficult conditions persist, the AIDS epidemic is exploding in cities

and towns throughout the South. Today, seven of the 10 states with the highest per capita AIDS rates are in the South. Forty-one percent of people living with HIV are in the Southeast. It is a particularly Black epidemic: Eight of the 10 Blackest state epidemics are in the South (See sidebar “The AIDS Black Belt” on page 43)³.

Our Third World Epidemic

You don’t have to go to Africa or the Caribbean to find Black people facing potential death because they can’t access available HIV treatments. You can find them all over the American South. Take Dothan, Ala. That’s where Michelle Lampkin, an outreach worker for the Montgomery clinic, lives with her partner and teenage son.

In April, she had eight days of meds left to keep at bay an HIV infection she’d been fighting since the early 1990s. She was newly uninsured, didn’t qualify for public coverage, and had nothing near the money she needed to pay for the drugs herself. So she and her family were playing the sort of game that has become all too common in places like their rural town—a medical Ponzi scheme where doctors and patients alike juggle whatever meds they have on hand today, hoping they’ll find a source for refills tomorrow. For Lampkin, it was working. Nobody in her family had missed a dose—not of their HIV drugs or, just as important in real life terms, of the sinus medicine she and her 15-year-old son were sharing. As for the future, well, Lampkin was betting on faith. “It’s stressing me out,” she deadpanned, “and I don’t appreciate it.”

Lampkin had been booted out of Medicaid in February because she made too much money on her part-time job at the clinic. The AIDS Drug Assistance Program was designed to fill just this sort of coverage gap—helping people who don’t qualify for Medicaid and can’t afford private insurance. But Alabama’s program has been broke for a while now,

and Lampkin had to take her spot in line on a waiting list that has been hundreds deep for years. At the time, the program hadn't enrolled a new patient in 10 months, and the waiting list was growing by about 30 people a month⁴.

That fact has earned Alabama unwanted attention as one of the worst states in the nation in which to be living with HIV. But the state's woes are part of a larger regional problem. Each year national AIDS lobbyists release an update on the troubles of state ADAPs around the country, and each year Alabama and North Carolina lead the pack. As of November 2005, five of the nation's nine waiting lists were in southern states. The three longest—North Carolina, Alabama and Kentucky—were also in the South⁵.

But observers say ADAP is just the most visible example of the South's broader resource problems when it comes to AIDS care. Things considered necessities in longstanding AIDS hotspots—support groups, transportation assistance, community education—are luxuries in many smaller towns. "We hear about people in places like New York and Los Angeles who have all this stuff, like massage therapists," says Montgomery AIDS Outreach Executive Director James Waid, chuckling through his slow drawl and looking like he thinks it may be an urban legend, "but we're just trying to keep our food bank open."

Blame to Go Around

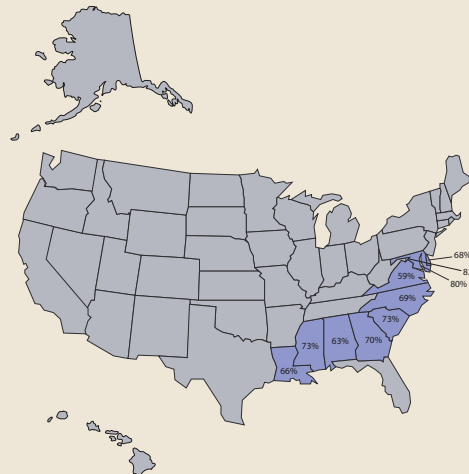
It's easy to blame local government for this resource gap, and indeed there's reason to do so. Statehouses around the South have been dreadfully slow in acknowledging the magnitude of the crisis they face.

Since Rep. Laura Hall (an Institute board member) entered the statehouse 13 years ago, on the heels of her son's HIV-related death, the 62-year-old has moved from being the Alabama AIDS community's fired-up mom to its world-wise grandmother. In her last

The AIDS Black Belt

America's epidemic is growing Blacker by the year, but that trend is in no small part driven by the growth of the South's uniquely Black caseload. At the end of 2004, eight of the 10 states with the Blackest epidemic were in the South.

Percentage of people living with AIDS who are Black:



Source: *Statehealthfacts.org*. Online statistical database maintained by Kaiser Family Foundation.

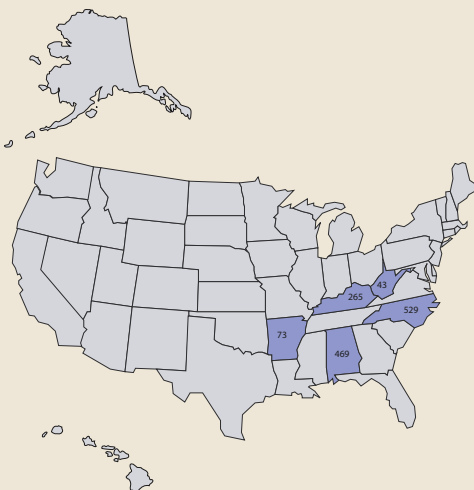
election, Republicans even charged that's all she's good for. "I said I make no apologies for my position," she casually recalls, "and if you choose not to elect me because I've been very outspoken and upfront about this disease, that has impacted my family, then so be it. That means I'll spend 100 percent of my time working on this issue." She flicks at a spot in the air, waving off an annoyance. "Never heard another word."

Last summer, she led a dramatic campaign to get the legislature to appropriate enough emergency money to save still more people from being tossed off of Alabama's



ADAP's Southern Troubles

As of November 2005, five of the nation's nine ADAP waiting lists were in southern states, including the three longest, in North Carolina, Alabama and Kentucky.



Source: *The ADAP Watch*. National Association of State and Territorial AIDS Directors. December 6, 2005.

ADAP rolls. In the eleventh hour of that debate, one state senator made the sort of comment many outside of the South assume is prevalent among its lawmakers. “It’s not fair for the taxpayers of Alabama to have to subsidize the consequence of a behavior that brings this on,” grumbled Senator Hank Erwin, Jr. He suggested that AIDS meds come with warnings about unhealthy lifestyles.

Rep. Hall says she rarely hears that sort of overt hostility from colleagues these days. The problem is more often plain misunderstanding—even among allies. MAO director Waid approached a friendly legislator in a restaurant to thank him for supporting Hall’s

fight for AIDS funding. “He said, ‘Look, I’m totally against these efforts to ban gay marriage,’” Waid recalls, perplexed by the conflation of issues. “I said, ‘Representative, that’s not what we’re talking about.’”

Still, everyone involved stresses that the problem isn’t just AIDS-phobia. “There is no real source of funding,” Hall explains. “We won’t raise property taxes—we won’t raise any kind of taxes. You mention taxes around here and you just sound”—she waves her hands around mimicking a lunatic. “Democrats and Republicans both feel if they talk about taxes they’ve signed their death warrant.”

But access to care for people living with HIV and AIDS in a nation as rich as the United States should not depend on where you live. Lampkin’s originally from New York, where some of her family still resides. But her life is now in Alabama. Must she relocate to get adequate care? Or is it the federal government’s responsibility to level the playing field?

That delicate question is at the heart of the controversy surrounding reforming the Ryan White CARE Act (see chapter one). Ryan White is the primary federal vehicle for dispersing money to support local AIDS services. Clinics like the one in Montgomery depend largely on a combo of Ryan White and state-appropriated funds for their survival. Smaller, minority-run organizations without independent support from private-sector donors often rely wholly on this government funding. And Southern AIDS advocates, both inside and out of government, say the region plainly needs more of it.

The current formula for handing out Ryan White money disadvantages rural states like Alabama, southern activists charge. In addition to the money each state gets based on the overall size of its epidemic, states that have one of 51 metro areas considered to be in a state of emergency get a second pot of money to target in those areas. That formula has been adequate for the epidemic we have known to date, in which infections were clus-



tered in large urban areas. But today, in states around the South, new infections are sprouting and spreading in disparate areas. That's a reality that Ryan White will eventually have to address. As one activist put it, "The status quo is going to kill southerners."

Yet, the fact remains that there is only so much money to go around. As discussed in chapter one of this report, the federal AIDS care budget has remained largely flat since 2001—with portions of it having been cut year after year. And so without additional resources, any new money for the South must come from the northern and western urban areas that have been waging hard-fought battles against the epidemic for decades—places where Ryan White-funded programs have themselves been forced to find ways to cut costs and slow growth, even as the demand for services continues to balloon.

Republic of Fear

Meanwhile, the South's Black communities also face significant challenges from within.

Unlike the epidemics of urban centers in the North, the South's epidemic is a primarily sexual one. The mix of sex and drugs is certainly just as volatile below the Mason-Dixon Line as it is anywhere else, but transmission through injection drug use is not nearly as common. And while a large share of the South's caseload is attributed to sex between men, it is also a far more heterosexual epidemic than that in the rest of the country. Nationally, 13 percent of cumulative AIDS cases reported through the end of 2004 were attributed to heterosexual sex. In New York, it's 11 percent; in California just 5.5 percent. But 10 of the 17 states that the Census classifies as southern have epidemics with more than 15 percent of reported AIDS cases attributed to heterosexual sex. In South Carolina, it's a quarter of the cases; in Florida one in five⁶.

This sexual reality, say southern observers, has heightened the Black community's

unease with talking about the epidemic. The overwhelming silence drives those at-risk away from HIV testing and those who know they are positive into the closet.

Anthony's been positive since 1989. He largely ignored his diagnosis until 1996, when he started getting sick. Fearing people would see his deterioration and figure out the problem, he fled his native Jacksonville, Fla., and migrated to live with a couple of friends in Tuskegee, Ala. "It's just never been a thing for me, as far as disclosure," he haltingly explains. "I came to Alabama to die, man, to get away from my family. ... I came from a very strong, traditional southern Baptist family."

Nevertheless, once he got to Tuskegee, Anthony's fear kept him out of regular care—something his friends encouraged. "When I got there they told me you can't go to the clinic here, because by morning everybody will know you're positive. And you can't tell nobody," he says his friends warned him. "Well, that was right down my alley." So he continued to get care only sporadically, navigating the small Alabama town while trying to conceal both his HIV diagnosis and the fact that he is gay. In the meantime, his long-time struggle with crack cocaine spiraled even further out of control.

It wasn't until he stumbled upon an AIDS outreach seminar that was offering free food that he met an HIV and drug addiction counselor visiting from Montgomery. The two connected and Anthony eventually moved to Montgomery to join her recovery program—called The Lighthouse—and start getting real care. By that point he had a mere 8 T-cells left; doctors consider someone with 250 T-cells to have full-blown AIDS and be in serious danger of becoming ill.

Now Anthony's healthy, and has joined The Lighthouse's local speakers' bureau, going to high schools and recounting how fear of the virus almost killed him. After one recent event, a number of young Black students approached and thanked him for coming. "I

Scattershot Infections

The South's epidemic is dispersed into non-urban, less populated areas. A greater share of the South's cumulative AIDS cases as of 2003 was found in areas with populations below 500,000 than in the North and West.

Reported AIDS Cases and Rates among Adults and Adolescents, by Region and Population of Area of Residence 2003—50 States and D.C.:

Region	MSA of >500,000		MSA of 50,000-500,000		Nonmetropolitan area	
	Number	Rate per 100,000	Number	Rate per 100,000	Number	Rate per 100,000
Northeast	10,556	29.8	761	14.8	387	8.1
Midwest	3,785	12.9	517	5.1	399	2.8
South	13,973	28.7	2,506	15.5	2,241	10.8
West	7,443	19.2	504	6.4	290	4

*Note: Data based on residence at time of AIDS diagnosis.

Source: CDC. *HIV/AIDS Surveillance in Urban-Nonurban Areas, L206 slide series, through 2003. Slide 6.*



was surprised. The little tough guys came up to me and shook my hand. And I said, 'God, we've come a long way,' he recalls, proud of both himself and the young men. "African Americans are more educated now about the epidemic," Anthony concludes. "It's been a positive movement. But it's just moving so slow."

5. The ADAP Watch. National Association of State and Territorial AIDS Directors. December 6, 2005.

6. Statehealthfacts.org, a database of health data maintained by the Kaiser Family Foundation. Data is broken out for HIV/AIDS and tabbed for specific topics and states.

Notes

1. Portions of this chapter have been adapted from a previously published article by the author: "Southern Discomfort." *Poz*. May 2005.

2. Statehealthfacts.org, an online database maintained by the Kaiser Family Foundation. The 12 states, in descending order, are D.C. (36%), Tenn. (29%), Calif. (27%), Maine (27%), Miss. (25%), Vt. (25%), N.M. (23%), Ark. (22%), La. (22%), N.Y. (22%), S.C. (22%), W. Va. (20%).

3. All data in this graph is drawn from Statehealthfacts.org. HIV/AIDS data is broken out and tabbed to produce a range of up-to-date state rankings.

4. Data on the Alabama ADAP program is drawn from author interviews with the state HIV program director Jane Cheeks, April 2005.



CHAPTER FOUR

Prevention that Works

Progress among Women and Drug Users

Here's one of the least-discussed but more startling facts about HIV among women in America: Some studies have shown as many as half of women living with the virus report a history of sexual abuse in their childhood, according to the U.S. Centers for Disease Control and Prevention¹. It's just one of the forms of trauma that researchers focusing on the epidemic's disproportionate impact on women of color have begun to zero in on. And their efforts to counter that trauma, the CDC says, are helping drive one of the few pieces of good news about the Black epidemic: slow, but steady declines in new infections among African American women².

"This is an issue that our society hasn't totally embraced as one of concern," says Dr. Gail Wyatt, who is leading a CDC-funded research project with colleagues at the UCLA AIDS Institute in Los Angeles, Calif. that is testing new prevention programs for Black and Latina women. "The events themselves have to do with someone else making decisions about your body, many times insisting on silence." The result, Wyatt and others believe, is a learned pattern of passivity

surrounding your body's sexual well-being. "It's almost like a curse," says 57-year-old Fatima Johnson, whose father molested her as a child. "You draw people into your life with the same kind of emotional attachment and low self-esteem."

Wyatt's research has found that women who report early and chronic sexual abuse show a seven-fold increase in HIV-related risk behavior. She's designed an intervention for those women that the CDC is holding up as part of a suite of model programs for dealing with the female epidemic. Above all, hers and the others have one thing in common: Creating space for women to have open, honest dialogue about their sexual and romantic lives. "[They have to] talk about it, not be ashamed of it, and to also meet other women who have had similar experiences," Wyatt explains. "And making the connection between past experiences, when someone takes advantage of you, and current experiences, where they may be willfully selecting partners who take advantage of them."

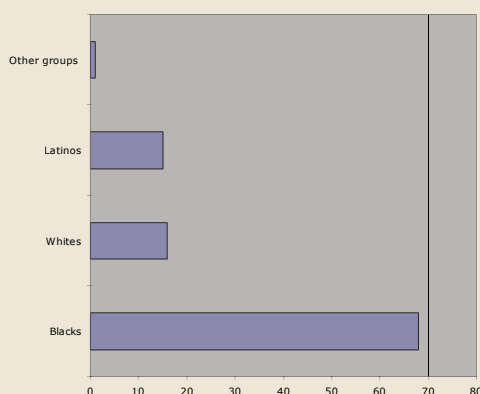
In December 2004, CDC announced that infection rates among African American



Leader of the Pack

Here's the underreported good news: The U.S. Centers for Disease Control and Prevention announced in June 2005 that **HIV infection rates among Black women had dropped by six percent between 2000 and 2003**. But here's the bad news: In November the CDC announced that Black women still account for 68 percent of new HIV diagnoses.

Racial breakdown of new HIV diagnoses among women between 2001 and 2004:



Source: CDC. *Trends in HIV Diagnoses—33 States, 2001-2004*. MMWR 2005; 53 (45).

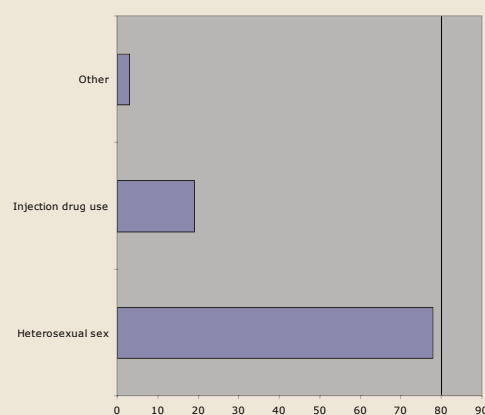
women dropped by 6 percent between the years 2000 and 2003³. Just months later, in June 2005, there was still more good news, this time focusing on young women of all races. During the 10-year period from 1994 to 2003, new infections among girls aged 13 to 24 dropped by a whopping 20 percent⁴. The gains were seen across all race groups. This is particularly good news when considering that half of all new infections every year come among people under 25 years old.

During the June 2005 National HIV Prevention Conference, CDC highlighted Wyatt's

Getting it Straight

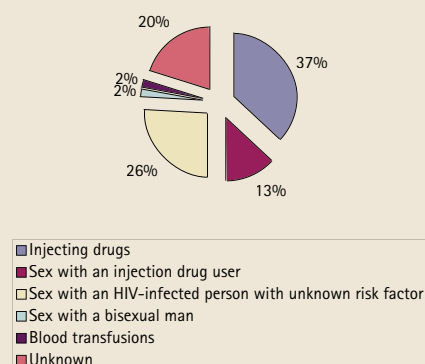
Heterosexual sex is by far the most common route of HIV transmission for Black women. However, included in the share of women who contracted the virus through unprotected sex is a large share whose sex partners contracted it through injection drug use.

Infection routes for new HIV diagnoses among Black women, 2001 to 2004:



Source: CDC. *Trends in HIV Diagnoses—33 States, 2001-2004*. MMWR 2005; 53 (45).

Infection routes for all diagnosed AIDS cases among Black women, cumulative through 2003:



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

and a handful of other prevention initiatives as models driving this progress. Wyatt's program was the first designed specifically to target HIV-positive women with a history of childhood sexual abuse, and it focused on women of color in particular. The program organized participants into small groups of six to eight women and had them gather for weekly two-and-a-half-hour discussions for 11 weeks. The women engaged in frank dialogue about how and why they choose their sexual and romantic partners, use condoms, mix sex with drug and alcohol use and their decision-making process for a host of other actions that impact their overall well-being. In sum, they had open, sustained conversation about things that they had previously simply done passively.

The result? Participants increased condom use by 100 percent and were 1.5 times more likely to report reductions in sexual risk-taking than women who simply received information brochures and attended a single group session. Follow-up studies found that 83 percent of participants continued to reduce risk-taking three months after the program's end and 78 percent continued to do so six months later⁵.

CDC also highlighted a program that used preexisting social and sexual networks to effectively bring African Americans and Latinos into testing and counseling. Outreach workers began by recruiting people from local communities who had behaviors that put them at high risk for HIV transmission. Those recruits received testing and counseling and then were trained to do outreach themselves. They were tasked with identifying other individuals in their personal sexual, drug using or general social networks who also may be at high risk for HIV and encouraging them to come in for services. The program then repeated the process with that new crop of recruits.

All told, 133 recruiters in seven cities brought 814 individuals in for testing and counseling during the program's first 12

months. Of those, 46 percent received new HIV diagnoses—a rate almost six times that found at publicly funded testing sites overall⁶.

Both of these programs allow prevention to grow organically out of the community for which it is intended—thereby allowing it to be relevant to folks' actual lives—and then build *sustained* dialogue around the issues that emerge.

Much More to Do

Despite the progress these initiatives have driven in slowing the pace of new infec-

STDs: HIV's Little Helpers

The presence of certain STDs increases the chances of someone contracting HIV once encountering it by three- to five-fold. And African Americans have the highest rate of STD infection. Old progress is reversing: In 2004, syphilis rates went up among Blacks for the first time in a decade, driven primarily by increases among men.

In 2004, African Americans were STD overachievers once again. We were ...

- 19 times more likely to be infected with gonorrhea than whites, and nine times more likely than Latinos.

- Eight times more likely to have chlamydia than whites, and almost three times as likely as Latinos.

- Five and a half times more likely to have primary or secondary syphilis than whites, and almost three times as likely as Latinos.

Source: U.S. Centers for Disease Control and Prevention, STD Surveillance, 2004.



tions, Black women remain at dramatically disproportionate risk. They still accounted for 68 percent of all new infections between 2001 and 2004⁷. Among young women, the disparity remains equally pronounced. Nearly three-quarters of all girls 13 to 19 years old infected as of 2001 were Black. And 66 percent of 20- to 24-year-old young women infected as of 2001 were Black⁸.

Researchers focusing on Black women are zeroing in on other forms of trauma beyond sexual abuse as causal factors for this racial disparity. And one that a building pile of research points to is poverty, along with the host of traumas that are associated with it. Wyatt's research in fact found that despite the racial disparities, race itself isn't the best indicator of risk for HIV infection. Examining the histories of 490 women of diverse racial backgrounds, her team found poverty and exposure to violence to be the best indicators of HIV risk.

University of North Carolina researcher Dr. Adaora Adimora is finding similar results in her work. She presented a study at the June 2005 meeting in which her team interviewed just over 200 North Carolinian African Americans who said they were neither men who have sex with men nor injection drug users. Seventy-eight percent were women. The study revealed the importance of what Adimora calls "sexual networks patterns"—or, the dynamics within the small, often overlapping social circles from which African Americans typically chose sexual partners.

These networks are relevant in a number of ways. One is that STDs spread more easily because of the networks' overlapping nature. But the other is that poverty and structural inequality shape relations within these networks, informing the decisions women make about who they are having sex with, and when and how they are having it⁹. "Decreased social capital over time can place people in situations that increase their susceptibility

for a variety of things," Adimora says. "So poverty is a risk factor for disease."

Not Fearing Needles

Another piece of good news about the Black AIDS epidemic came at the end of 2005. In a November article in its weekly update on disease control, the CDC quietly noted an average annual decline of five percent in Black infections between 2001 and 2004¹⁰.

The trend emerged when CDC folded data from New York State into its national HIV estimate. While the overall national AIDS caseload is drawn from reports made by all 50 state health departments to the CDC, the agency only uses HIV data from states that track new infections by recording names of those who test positive (see overview for full explanation). New York began using a name-based HIV tracking system in 2000, and the November report was the first to crunch the national data with New York's numbers in mind. Doing so revealed a slow but statistically significant downturn in new Black infections.

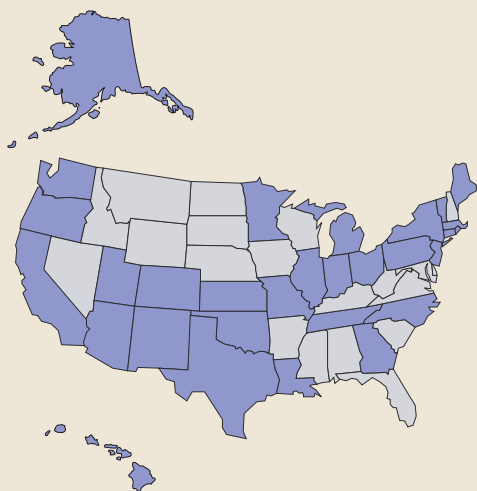
CDC speculated about what may have sparked this trend, including the fact that New York's epidemic is among the oldest, meaning its rate of growth may have already peaked. But CDC noted that the state's remarkable success in bringing down infection rates among injection drug users was clearly a significant cause for the improving national picture.

New York City has the nation's largest injection drug using population—an estimated 150,000 to 175,000 people—and somewhere between 10 and 20 percent of those people is believed to be HIV positive, making it also the nation's largest population of infected users¹¹.

In 1992, the city began setting up formal needle exchanges—nine in total—to try and get infected needles out of circulation and link users with a range of harm reduction services, including addiction treatment. In just the first three years of operation,

Reducing Harm

As of 2002, 32 states (dark shading below) had some form of syringe exchange program. But most states had just one program. According to a July 2005 Centers for Disease Control and Prevention survey, in 2002 just 126 programs were in operation in 102 cities*.



*Researchers identified 148 programs, but only 126 responded to the survey confirming the existence and scope of their operations.

Source: CDC. Update: Syringe Exchange Programs—United States, 2002. *Morbidity and Mortality Weekly Report*. July 15, 2005.

the programs cut the rate of new infections among users in half. Over the 10-year period that marked the programs' first decade of existence, the prevalence of HIV infection among the city's drug users plummeted from 51 percent to 12.5 percent¹².

Despite this stunning success, needle exchange programs continue to operate—if at all—under severe restrictions around the country. In a July 2005 report, CDC noted disturbing

trends among needle exchange programs nationally. The agency conducts biannual surveys of the programs to determine their scope. The survey for the years 2000 to 2002 found that both the total number of programs in operation and public funding for them declined for the first time in nearly a decade.

The survey identified 148 syringe exchange programs, down from 154 in 2000—a nearly 4 percent decrease. In every previous survey, dating back to 1994, the number of operating exchange programs had steadily increased. The number of states and territories with needle exchanges also fell, down to 32 in 2002 from 35 in 2000.

Meanwhile, CDC found that public funding for needle exchanges dropped by a whopping 18 percent between 2000 and 2002, down to \$7.3 million from \$8.9 million. Overall budgets for the programs nevertheless increased, because private-sector funding stepped in to fill the space left by public retreat. As a result, the vast majority of exchanges still in operation reported larger budgets.

Still, needle exchanges have always operated on shoe-string budgets, and the survey showed that a handful of large programs are fairing well while the majority struggle. The median budget for the programs surveyed in 2002 was just over \$53,000. More than a quarter of them ran on less than \$25,000¹³.

Congress continues to ban federal funding for the programs, despite their proven success and the fact that no less than eight government-funded studies have concluded that they both effectively stop new HIV infections and help drive users into addiction treatment. "There is conclusive scientific evidence," wrote Surgeon General David Satcher in 2000, "that syringe exchange programs, as part of a comprehensive HIV prevention strategy, are an effective public health intervention."¹⁴ But very little about drug policy in America has anything to do with public health, and so it is with needle exchange. The wildly successful program—which we now





Needles by the Numbers

In 2002, researchers surveyed 126 needle exchange programs to determine the scope of their work. In July 2005, the CDC released the results, which showed the network of these proven-effective programs is shrinking rather than growing. Here's some of what the survey found:

■ **Progress Lost.** For the first time in eight years, the network shrunk by several measures: number of programs, number of localities with programs, and public funding for them.

■ **A Private Affair.** Public funding dropped 18 percent between 2000 and 2002, down to \$7.3 million from \$8.9 million. (All public funds come from states, as Congress continues to ban federal funding for syringe exchange.) Overall budgets, however, increased as a result of private funding. The vast majority of exchanges still in operation reported larger budgets, and their total funding went up to \$13 million, from \$12.1 million in 2000.

■ **The Money Divide.** Most funding, however, goes to a few big players. Almost two-thirds of the programs ran on less than \$100,000 a year, and more than a quarter had less than \$25,000 a year. Annual budgets ranged from \$0 (nine programs) to just over \$1 million.

■ **In a Year's Work.** The programs exchanged nearly 25 million needles in 2002, a 10 percent hike from 2000. And they offered more than just clean needles. Seventy-seven percent made referrals to addiction treatment programs, 72 percent did HIV testing and counseling and 23 percent provided on-site medical care.

Source: CDC. Update: Syringe Exchange Programs—United States, 2002. *Morbidity and Mortality Weekly Report*. July 15, 2005.

know has contributed to a measurable, significant decline in Black infection rates—remains captive to needless political and moral debates.

Notes

1. Centers for Disease Control and Prevention. The women's health project: The efficacy of an integrated intervention for HIV-positive women with histories of child sexual abuse. Poster presentation at National HIV Prevention Conference, June 14, 2005.

2. For an expanded discussion of the epidemic among Black women, see previous Institute report: Beard, Hilary. *Getting Real: Black Women Taking Charge in the Fight Against AIDS*. Dec. 2005.

3. CDC. Diagnosis of HIV/AIDS—32 States, 2000–2003. *Morbidity and Mortality Weekly Report*. Vol. 53, n. 41. Dec. 3, 2004.

4. CDC. Patterns of new HIV/AIDS among adolescents and young adults in 25 states. Oral presentation at National HIV Prevention Conference. June 13, 2005.

5. CDC. The women's health project: The efficacy of an integrated intervention for HIV-positive women with histories of child sexual abuse. Poster presentation at National HIV Prevention Conference, June 14, 2005.

6. CDC. Using social networks to reach high-risk individuals for HIV infection in communities of color. Oral presentation at National HIV Prevention Conference. June 13, 2005.

7. CDC. Trends in HIV Diagnoses—33 States, 2001–2004. *Morbidity and Mortality Weekly Report*. Vol. 54, no. 45. November 2005.

8. CDC. HIV/AIDS Surveillance Report. Vol. 13, n. 2. Table 8.

9. Adimora, Adaora. HIV Prevention among Rural Women and Their Partners. Oral presentation at National HIV Prevention Conference. June 14, 2005 press conference.

10. CDC. Trends in HIV/AIDS Diagnoses—33 States, 2001–2004. *Morbidity and Mortality Weekly Report*. November 18, 2005.

11. New York City Department of Health and Mental Hygiene. Presentation by Commissioner Thomas Frieden to Queens Community Board 2. March 4, 2004.

12. Ibid.

13. All of the preceding needle exchange data comes from: CDC. Update: Syringe Exchange Programs—United States, 2002. *Morbidity and Mortality Weekly Report*. July 15, 2005.

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

Recommendations

Making a Commitment

The good news of 2005—that we’re making slow but steady progress in slowing infections among women and injection drug users—is not mere coincidence. These are two areas where, in recent years and select locations at least, we’ve begun to target our energy and resources in a meaningful and sustained fashion. That sort of progress is possible in every dimension of HIV/AIDS, from prevention to care to treatment.

In the final analysis, this epidemic isn’t terribly complicated: When we allow politics, subjective notions of morality and profit-driven health economics to reign over public health, the most vulnerable in our society are left for HIV to prey upon. When we make a genuine commitment to meet people where they are at with the resources they need to chart a healthy path and stay on it, we find success.

With that mandate in mind, the Institute calls on all individuals and institutions in Black America to commit to taking action against HIV/AIDS.

What We Must Do

■ **Leaders must lead.** Those who have come into leadership roles in Black America, whether it be as opinion shapers or industry titans, must use their positions to help build a mass community movement to end HIV/AIDS. From local heroes to Hollywood stars to trailblazers in business and politics, our leaders must lead. And those who are already educated about the epidemic must reach out to those leaders to give them the knowledge they need to carry the message forward.

■ **Demand expansion of proven prevention work.** We must no longer allow politics and subjective notions of morality to stand in the way of stopping the virus’ spread. We know beyond a doubt that needle exchange stops HIV’s spread among injection drug users, and thus their sexual partners as well; the ban on federal funding for these programs must end. We also know that comprehensive AIDS and sex education works. Schools must uncompromisingly teach young people about both delaying sexual activity and protecting themselves if they do have sex.

■ **Protect access to treatment.** We must demand Congress and the White House maintain and strengthen the network of programs designed to make healthcare affordable. The effort to shift Medicaid costs onto poor families must end, and Washington must partner with state governments to develop a fair and sustainable solution to financing the program. Congress must also reauthorize Ryan White and fund it adequately, so that people with HIV/AIDS have access to life-saving services no matter what region of the country they live in.

■ **End the debilitating stigma that helps HIV spread.** Perhaps more than anything else, Black America must finally put an end to the stigma surrounding this virus. It cripples efforts to both prevent the virus' spread and treat those who are infected, particularly in the South and among gay and bisexual men. It fuels distracting and debilitating conspiracy theories. And it renders us incapable of

defending ourselves in crucial policymaking battles. Worst of all, it rips at the souls of individuals and families struggling to build a healthy future in the face of HIV's attack. It must end. And that begins with each person in Black America, whether positive or negative, being willing to stand up and declare that the era of shame and silence about HIV is over.

It is time that Black America understand that it is one community, inclusive of a wide and beautiful range of African American people. That community includes gay, lesbian, bisexual, transgender people, and people living with HIV/AIDS, and they must be not only accepted but supported. Black GLBT people must come home and share in the responsibility for building this unity by refusing to live in shame and secret, by standing up within the community and demanding to be counted.

About the Author

Kai Wright is a writer and editor in Brooklyn, N.Y., and publications editor for the Black AIDS Institute. Kai's work explores the politics of sex and race, both in the U.S. and abroad, and particularly as it plays out in urban life. He contributes regularly to leading independent and community press such as *The Progressive*, *Out* and *Mother Jones* magazines, and has written for publications ranging from the *Village Voice* to the *San Francisco Chronicle*.

Kai has worked with the Institute for five years, helping to build its publications department and partnerships with Black media outlets. He was the author of the Institute's 2005 report, *The Time is Now!: The State of AIDS in Black America*, and editor of two subsequent State of AIDS reports—one focusing on Black youth and the other on Black women.

Kai is currently working on a book for Beacon Press that chronicles the adolescence of a group of Black gay men growing in New York City. To read more of his work, visit KaiWright.com.



About the Black AIDS Institute

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

What We Do

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

viders, opinion shapers and “gatekeepers.”

■ **The African American HIV University (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 news-

letter, **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, barbershops, beauty parlors, bookstores and doctors' offices. The Institute's newest publication is **Ledge**, a magazine produced by and for Black college students and distributed on the campuses of historically Black colleges and universities around the country.

■ **Heroes in the Struggle**, 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 that 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.

