

# **LIGHT AT THE END OF THE TUNNEL**

**ENDING AIDS  
IN BLACK  
AMERICA**

**BLACK AIDS INSTITUTE, 2013**

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

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# LIGHT AT THE END OF THE TUNNEL

## A FIVE-YEAR ACTION STRATEGY TO DEFEAT AIDS IN BLACK AMERICA

By Phill Wilson  
President and CEO, Black AIDS Institute

Welcome to *Light at the End of the Tunnel*, the 10th report on the State of AIDS In Black America. This is the Black AIDS Institute's 19th report looking at the many challenges and opportunities confronting the Black response to the HIV/AIDS epidemic in America.

When we published the *Nia Plan* in 1999, our first report on the epidemic in Black America, the AIDS response in Black communities was behind the curve. Awareness of the AIDS crisis in Black America was low, and commitment to address the problem was even lower. Even as HIV cases spiraled upward in Black America, the country as a whole looked the other way.

While much work remains to be done to increase awareness and commitment, we've seen nothing short of a sea change in the response to AIDS in Black America since the founding of the Black AIDS Institute in 1999. Today, Black Americans report a higher level of personal awareness of AIDS and a greater commitment to fight it than any other racial or ethnic group in the country. Many Black political, faith, and civic leaders are working to turn the tide against AIDS in our communities, and grassroots AIDS leaders have emerged in Black neighborhoods nationwide.

Unfortunately, one thing hasn't changed. America's AIDS epidemic continues to affect Black people far more than any other group. And with all of the recent scientific advances made over the last few years, we

have not turned the tide on the disproportionate impact HIV has had on Black communities.

Accounting for less than 14% of the U.S. population, Black America represents 44% of all new infections. Black women are 15 times more likely to be living with HIV than white women. And new infections among young Black gay and bisexual men rose 48% from 2006 to 2009.

The epidemic has made inroads in Black America as it has in no other quarter of the U.S. Reversing the epidemic in Black America will require a level of commitment, evidence-based action, and follow-through unlike that required for any other group of people in our country.

But AIDS can be ended in Black America. Today, we have the tools to do what was unthinkable only a few short years ago. We can actually end AIDS for all time.

*Exit Strategy*, our 2012 State of AIDS report, outlined why such optimism about the epidemic's eventual end is justified, describing recent breakthroughs in both policy and research that together have the potential to dramatically lower new HIV infections and prevent AIDS-related deaths. Strategic use of these many new tools, last year's report advised, would represent an "exit

strategy" from a health crisis that has devastated Black communities from one coast to the other.

But words alone won't help us bring AIDS to an end. Against a foe as determined as HIV, we must translate these words into strategic action. And we must be willing to see this fight through to its end. Ending the epidemic will undoubtedly require new and better tools than we currently have—especially a preventive vaccine and a cure for HIV infection itself—but the tools that currently exist, if used in conjunction with a strategic vision, can build a life-preserving bridge to a future when the means exist to eradicate the virus altogether. Our programs, though, will need to be far more effective, far more comprehensive, if we are to build this bridge by ensuring that all of the 500,000 Black Americans estimated to be living with HIV are virally suppressed.

This report outlines a five-year action strategy to defeat AIDS in Black America. It describes what needs to happen each year, who needs to take charge of specific areas of work, and how we must all hold one another accountable for results.

Here at the Black AIDS Institute, we are retooling and repositioning ourselves to contribute to this

collective effort to lay a foundation for the end of AIDS. In these pages, you'll read about the Institute's new five-point strategy. You'll read about AIDS organizations that are busy retooling to play a leadership role in an evolving response, as well as about individuals who are changing lives by living openly with HIV. This report describes the incredible potential offered by the Affordable Care Act to close life-threatening gaps in our health care system, and what each of us needs to do to ensure its full and effective implementation.

As someone who's been in the trenches fighting AIDS for over 30 years, I must admit that I'm tired a lot. Acquaintances ask me how and why I keep going.

The answer is easy. I simply won't quit until this fight is won. After living through the most horrible days of the epidemic, when only the sturdiest among us could hold onto hope, I can't quit now, when ultimate victory over the epidemic is in our grasp. Not only would quitting now dishonor the memory of the countless friends and loved ones we've lost to this epidemic, but it would also betray the hopes of today's young people and of future generations.

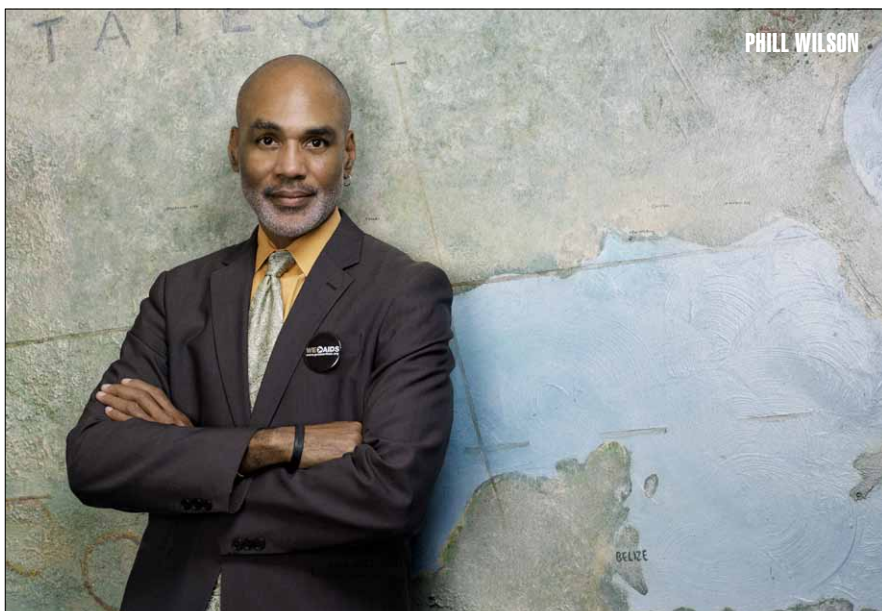
From climate change to the December shootings at a small school in Newtown, Connecticut, we know we live in an often-dangerous world. But there is one danger we have some control over. There is one battle we can win. There is a light at the end of the tunnel. We can end AIDS in our community.

I, for one, am committed to moving toward the light. I hope and trust you are too.

Now let's get busy!

Yours in the Struggle

*Phillip Wilson*  
Phill Wilson



# CONVERTING REALITY INTO RHETORIC

## A STRATEGIC ACTION PLAN TO MOVE TOWARD THE END OF AIDS

A clear consensus now exists that the tools exist to lay the foundation for the eventual end of AIDS.

The quest to end AIDS occupied center stage at the 2012 International AIDS Conference in Washington D.C. Leading scientists have advised that it is now feasible to begin planning for the end of AIDS.<sup>1</sup> And leading AIDS organizations have offered guidance about what needs to happen to speed the end of the epidemic.<sup>2</sup>

Actually making AIDS a thing of the past will ultimately require new tools, including a cure for the disease and a vaccine capable of preventing infection. But there is little doubt from a scientific standpoint that we have the means to dramatically lower rates of new HIV infections and AIDS deaths, extending lives until these ultimate AIDS-fighting tools are available for widespread use.

Will we seize the historic opportunity to move toward the epidemic's end game? After more than three decades when AIDS devastated countless communities worldwide, will we display the wisdom, commitment, and fortitude required?

In this country, the job of ending AIDS will be hardest in Black America. Black people in the U.S. are nearly eight times more likely to become infected with HIV than whites.<sup>3</sup> While new infections are stabilizing or declining in most groups, HIV incidence has sharply increased among Black gay and bisexual men.<sup>4</sup>

Key to laying the foundation for the epidemic's end is ensuring



that all people living with HIV are diagnosed early and that they receive the services and support they need to achieve viral suppression. Timely and effective antiretroviral therapy saves lives by preventing the progression of the disease and by dramatically lowering the odds that an HIV-positive individual will transmit the virus to another person.<sup>5</sup>

In recent years, the steps needed to achieve viral suppression have been outlined in what has become known as the “treatment cascade.”<sup>6</sup> According to the Centers for Disease Control and Prevention, only one in four people living with HIV in the U.S. has achieved viral suppression.<sup>7</sup>

The reasons why the U.S., the most powerful country in the world, has assembled such a poor record of HIV treatment success are straightforward. Too many people learn they have HIV late in the course of infection, too many who test HIV-positive are not quickly linked to care, too few people who need HIV treatment actually receive it, and those who enter care often drop out.

Closing gaps in the HIV treatment continuum is a central challenge of the entire AIDS field, but it is especially critical for Black Americans. Due to gaps in health care access and utilization, Black people living with HIV are least likely to have viral

suppression—43% less likely than HIV-positive whites.<sup>8</sup>

While scaled-up antiretroviral treatment is pivotal to future progress against AIDS, treatment alone is unlikely to lay the foundation for the epidemic’s end. An intensified commitment to delivering necessary treatment services and support to all who require it will need to be coupled with a commensurate commitment to achieving saturation coverage of Black communities of “high-impact HIV prevention.”

Some elements of high-impact prevention are especially critical for Black Americans. For example, the higher background prevalence of sexually transmitted infections in Black America is an important reason why Black communities have been so disproportionately affected by AIDS.<sup>9</sup> A meaningful plan to move toward ending AIDS in Black America will require a concerted national push over several years to sharply lower STI rates in Black communities.

Just as research has been critical to getting us to the point where it is possible to envision an end to AIDS, robust research efforts will continue to be needed to enable us to move from aspiration to reality in the quest to achieve a world without AIDS. New tools (such as simpler treatments, a cure for HIV, and a preventive vaccine)

will be needed, and implementation trials are critical to improving the effectiveness and comprehensiveness of HIV programs.

In the current fiscal climate, many will argue that additional HIV funding is a non-starter. But any meaningful action plan to end AIDS will require new resources, although the additional amounts needed are relatively modest in the context of the broader federal budget.

Especially in the context of the country’s long-term structural deficit, spending that reduces the government’s long-term economic burden should be prioritized. In 2012, the federal government spent \$14.8 billion to provide care and treatment for people living with HIV.<sup>10</sup> With every new case of HIV infection representing lifetime treatment costs that exceed \$600,000<sup>11</sup>, it is a no-brainer that programs that prevent new infections before they occur represent a sound investment for American taxpayers.

**W**hat follows is a five-year strategic action plan to lay the foundation to end AIDS in Black America. Consisting of five pillars, the plan includes year-by-year targets for key actions and key results.

The plan focuses considerable attention on public policy actions that will be needed to end AIDS, but government alone can’t get the job done. Black America itself will need to renew its own commitment, working to ensure full implementation of the Affordable Care Act, building demand for services, and retooling its own infrastructure to accomplish what will be needed in the coming years.

No plan succeeds unless it is implemented, and unless those with a stake in the outcome hold each other accountable. The Black AIDS Institute plans to monitor results achieved under this plan, and we encourage our many partners nationwide to join us in this undertaking.

## OVERARCHING GOAL

**ENSURE THAT AT LEAST 80% OF THE OVER 500,000 BLACK AMERICANS ESTIMATED TO BE LIVING WITH HIV ACHIEVE VIRAL SUPPRESSION BY 2017.**

## STRATEGIC PILLARS

**Ensure that at least 95% of Black Americans living with HIV know their HIV status.**

Invest in community-based treatment literacy programs to help Black communities understand the benefits of HIV testing, use state-of-the-art marketing and outreach strategies to promote HIV testing, and scale up multiple modes of testing delivery, including comprehensive implementation of provider-initiated HIV testing in health care settings.

**Eliminate gaps in the HIV treatment cascade for Black Americans living with HIV.**

Capitalize on implementation of the Affordable Care Act to move as close as possible to universal health coverage, reauthorize a revised Ryan White to focus on effective linkage and retention strategies, integrate evidence-based treatment-adherence supports into clinical and community-based practice, improve the monitoring of HIV clinical outcomes, and implement financial incentives for policy-makers, strategic planners and clinicians to reduce patient loss at each stage of the treatment continuum.

**Deliver high-impact HIV prevention services to all Black Americans at risk of HIV.**

Refocus prevention services at the federal, state, and local level to achieve saturation coverage in Black communities; undertake a targeted national campaign to dramatically reduce STIs in Black communities; capitalize on implementation of the Affordable Care Act to establish reliable new funding streams for evidence-based HIV prevention; and implement financial incentives for state and local health departments to demonstrate progress in reducing new HIV infections among Black Americans.

**Invest in strategic HIV-related research to accelerate the end of AIDS in Black America.**

Strengthen and sustain targeted research to accelerate progress toward development of a preventive vaccine and a cure for HIV; prioritize research to develop new HIV prevention tools for Black Americans, including affordable vaginal and rectal microbicides; and implement focused research to enhance the efficiency and effectiveness of HIV prevention and treatment programs in Black communities, taking priority steps to rapidly translate research results into actual programs and practice.

**Build the capacity needed in Black communities to accelerate the end of AIDS in Black America.**

Increase and sustain federal support for capacity-building in Black and Black-serving community-based organizations, with a particular focus on equipping Black communities with the means to increase HIV science and treatment literacy and to retool to contribute to the scaling-up of integrated biomedical and behavioral approaches to HIV prevention and treatment.

# ENSURE THAT AT LEAST 95% OF ALL BLACK AMERICANS LIVING WITH HIV KNOW THEIR HIV STATUS.

<div>2013</div> <div>CDC convenes national summit with professional medical, nursing, and hospital associations on implementation of routine HIV screening in health care settings</div> <div>Congress allocates \$30 million for social marketing to promote HIV testing in Black communities</div>	<div>2014</div> <div>Locally targeted social marketing campaigns begin to promote testing in high-burden communities</div> <div>CDC-supported survey finds that at least 50% of Black patients are offered HIV testing during encounters with health care providers</div>	<div>2015</div> <div>CDC documents promising practices in social marketing for HIV testing, drawing from experiences under national social marketing initiative</div> <div>Number of Black Americans tested for HIV in the prior 12 months increases by 20% over 2012 baseline</div>	<div>2016</div> <div>CDC-supported survey finds that at least 80% of Black patients are offered HIV testing during encounters with health care providers</div>	<div>2017</div> <div>At least 90% of Black Americans living with HIV know their HIV status</div>
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# ELIMINATE GAPS IN THE HIV TREATMENT CASCADE FOR BLACK AMERICANS LIVING WITH HIV.

## 2013

Medicaid drug coverage gap eliminated

States establish essential benefits packages that include comprehensive HIV treatment and prevention services

National initiative launched to educate Black communities about new health care options under ACA

HHS oversees collaborative process to develop comprehensive national initiative to build HIV science and treatment literacy in Black communities

HHS collaborates with community stakeholders to develop national strategy to increase treatment demand in Black communities

Ryan White reauthorized, with program reoriented to prioritize funding for targeted initiatives to address patient loss at each step of HIV treatment cascade (e.g., linkage to care, retention in care, patient education, provider training in provider-patient communications, adherence support)

## 2014

States accept Medicaid expansion under ACA

Roll-out of ACA's individual mandate to have health insurance

Elimination of annual insurance coverage limits under ACA

Health insurance premium and cost-sharing subsidies begin for families with incomes from 133-400% of the federal poverty line

First competitive funding round for revised and newly reauthorized Ryan White program

Congress approves at least \$30 million in funding for targeted national initiative to build HIV science and treatment literacy in Black communities

Congress approves at least \$30 million in funding for targeted national initiative to increase treatment demand in Black communities

Continuation and intensification of community education programs on health care options under ACA

## 2015

HHS undertakes comprehensive national review of HIV policies and practices under expanded Medicaid program, with aim of ensuring that all states provide essential HIV-related services

Implementation of new Ryan White programs focusing on linkage to care, retention in care, patient education, and adherence support)

HRSA provides financial incentives to HRSA grantees for demonstrated progress in reducing unmet need for HIV primary care

## 2016

With ACA now fully implemented, the percentage of Black Americans without health coverage has fallen below 10% (from 20.8% in 2010)

## 2017

At least 90% of Black Americans who test HIV-positive are linked to care

At least 90% of HIV-positive Black Americans are retained in care

At least 95% of treatment-eligible Black Americans receive antiretroviral therapy

# DELIVER HIGH-IMPACT HIV PREVENTION SERVICES TO ALL BLACK AMERICANS AT RISK OF HIV.

## 2013

Undertake geographic and population mapping of STIs to inform development of national plan to reduce STI prevalence in Black communities by 80%

Congress removes restrictions on federal funding for harm reduction programs

CDC issues comprehensive guidance for state and local health departments on implementation of high-impact HIV prevention

To accelerate progress toward ending the epidemic, Congress approves 10% increase in federal funding for high-impact HIV prevention

## 2014

Launch strategic, multi-year national initiative to strengthen STI-related case-finding, prevention, and treatment services in Black communities (with services concentrated in communities with high STI prevalence)

\$30 million allocated for harm reduction programs in minority communities

With economy experiencing an increasingly robust recovery, Congress increases HIV prevention spending by \$100 million

Congress approves additional 10% increase in federal funding for high-impact HIV prevention

## 2015

Building on results from PrEP pilot studies, federal agencies collaborate with state and local health departments to launch major initiative to deliver PrEP to Black MSM and high-risk heterosexual women

The Obama administration issues report on results achieved under the National HIV/AIDS Strategy, including recommendations to accelerate progress and address documented shortcomings

Number of sterile needles/syringes distributed by harm reduction programs in the U.S. increases by 25% over 2012 baseline

CDC evaluation finds that at least 80% of its partner state/local health departments have taken steps to reallocate their HIV prevention portfolio in line with the principles of high-impact prevention

## 2016

Federally convened national meeting examines experiences to date with PrEP roll-out, offers opportunity for program implementers to share experiences and learn about promising practices

CDC issues interim results from national STI initiative (particularly focusing on results in high-prevalence minority communities)

## 2017

The number of new HIV infections in Black America is 50% lower than in 2010

# INVEST IN STRATEGIC HIV-RELATED RESEARCH TO ACCELERATE THE END OF AIDS IN BLACK AMERICA.

## 2013

HIV incidence assay validated as a tool for monitoring the effectiveness of HIV prevention programs

Federal government launches major implementation science initiative to improve the effectiveness of HIV prevention and treatment programs

Robust PrEP pilot studies rolled out for Black MSM and high-risk Black heterosexual women

Launch of multi-country Phase II trial of microbicide reformulated for rectal application

Federal government sponsors baseline survey on HIV science and treatment literacy in Black America (using standardized indicators)

## 2014

Results from separate efficacy trials for two vaginal microbicide candidates (i.e., 1% tenofovir gel, dapivirine ring)

Grants awarded for implementation science research projects to improve the effectiveness of HIV prevention and treatment programs

## 2015

Final results on HPTN 052 to assess durability of protection provided by antiretroviral treatment as prevention

Results from Phase II rectal microbicide trial

Implementation research agenda developed and launched for roll-out of microbicides

## 2016

Launch of major efficacy trial of product that builds on early positive results of Thai RV144 vaccine

Results of implementation science studies enable local programs to dramatically reduce patient loss at each stage of the HIV treatment continuum

## 2017

# BUILD THE CAPACITY NEEDED IN BLACK COMMUNITIES TO ACCELERATE THE END OF AIDS IN BLACK AMERICA.

<div>2013</div> <div><p>HHS launches \$50 million multi-year initiative to build capacity in Black and Black-serving organizations to retool to integrate biomedical and behavioral interventions</p><p>CDC and HRSA collaborate to issue guidance to community-based organizations on retooling</p></div>	<div>2014</div> <div><p>At least 200 Black or Black-serving HIV/AIDS organizations receive intensive capacity-building support for retooling</p><p>Federal government sponsors major national meeting on organizational retooling for an evolving epidemic, with particular focus on engaging minority community organizations</p></div>	<div>2015</div> <div><p>At least 200 Black or Black-serving HIV/AIDS organizations receive intensive capacity-building support for retooling</p></div>	<div>2016</div> <div><p>Federally sponsored survey finds that scores on standardized indicators for HIV science and treatment literacy have risen by at least 20% among Black Americans since 2013</p><p>At least 200 Black or Black-serving HIV/AIDS organizations receive intensive capacity-building support for retooling</p></div>	<div>2017</div> <div><p>Robust community-based infrastructure exists to strengthen and sustain an effective AIDS response in Black America that integrates biomedical and behavioral approaches</p></div>
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# HELPING ESTABLISH THE FOUNDATION TO END AIDS

## A NEW STRATEGIC DIRECTION FOR THE BLACK AIDS INSTITUTE

With the aim of galvanizing needed action to ensure that at least 95% of all Black Americans living with HIV achieve viral suppression, the Black AIDS Institute is implementing a new five-pronged strategy. In keeping with the Institute's motto, "Our people, our problem, our solution," the new strategic approach specifically focuses on what Black America itself can do to lay the foundation for an end to AIDS in our communities. The Institute's aim is nothing less than to roll back the epidemic in Black communities across the country and narrow the torrent of new infections to a mere trickle.

Since its founding in 1999, the Institute has primarily focused on sounding the alarm on AIDS in Black America. By nearly any measure, these efforts have succeeded. Polling by the Henry J. Kaiser Family Foundation consistently reveals that Black Americans are more aware of HIV than any other racial or ethnic group and more concerned about the epidemic's impact on their own lives and in their communities.<sup>12</sup> Black leaders—in government, religion, business, the media, arts, and entertainment—are visibly engaged in the AIDS fight. The National HIV/AIDS Strategy both acknowledged the epidemic's disproportionate impact in Black America and set forth clear, concrete strategic actions to reduce the rates of new infections and AIDS deaths.<sup>13</sup>

With research breakthroughs now offering a genuine chance to lay the foundation for the ultimate end of the

epidemic, a new focus is required that translates awareness into action. All stakeholders in Black America need to join together in a shared endeavor to ensure that all Black Americans living with HIV have the services and support they need to achieve viral suppression.

Toward this end, the Institute seeks to leverage its influence and organizational strengths to close gaps at each stage of a patient's contact with the health care system. Particular emphasis will be placed on the key stages of the "treatment cascade": promoting early diagnosis, promptly linking those who test HIV-positive to care, and retaining patients in care for the rest of their lives.

The Institute's new strategic approach has five pillars:

### **Fully implement the Affordable Care Act.**

To ensure full implementation of ACA and seize its potential to close gaps in the HIV treatment continuum, the Institute will prepare community-based organizations and grassroots advocates to understand the potential benefits of expanded health coverage, to educate their constituents about these new opportunities, and to strategically link with advocacy efforts in their states to promote full implementation of expanded health coverage. Service organizations will need to integrate community education and client assistance into their work to help their constituents take advantage of the new law. As a first step in this new work priority for the Institute, a two-day national ACA "boot camp" will be convened throughout the country in 2013, with the aim of preparing community leaders to support expedited, comprehensive implementation of health care reform in their states.

### **Support people living with HIV to come out.**

The act of coming out about one's HIV status is perhaps the single most effective means of combating stigma, and it also helps build demand for treatment services within local communities and social networks. Through outreach, training, and ongoing capacity-building support, the Institute will jump-start local mobilization efforts on coming out in 10 high-burden cities, using a corps of trained advocacy leaders and liaisons to plan and convene major community events about the benefits of living openly with HIV. In 2013, the Institute aims—through its programs Positively Out and Beyond the Quot (the latter focusing specifically on Black gay men)—to put in place a national coming-out advocacy network of at least 1,000 people nationwide who work together to encourage all people living with HIV to come out of the closet.

### **Increase the demand for treatment.**

Moving forward, the Institute will use its national Black Treatment Advocates Network (BTAN) to plan and implement initiatives to educate local communities about the benefits of treatment. BTAN advocates will work to correct misconceptions about existing therapies, helping communities understand that people living with HIV can live a virtually normal lifespan without experiencing severe side effects. The Institute will also train grassroots leaders to advocate for policies and programs to alleviate factors that may interfere with effective use of existing therapies, such as cost, housing instability, competing survival priorities, or administrative barriers to accessing Medicaid or other essential services.

The Institute also seeks to expand its flagship capacity-building initiative, the African-American HIV University (AAHU), to include a new college devoted to HIV science and treatment literacy. This new AAHU Science

& Treatment College will build the capacity of strategically placed organizations around the country to integrate biomedical interventions in their service spectrum and to plan and implement patient navigation programs for people living with HIV.

### **Integrate biomedical and behavioral approaches.**

Although behavioral and biomedical interventions have often been considered distinct from each other, they are actually complementary. Treatment as prevention doesn't work as well without condoms; new biomedical HIV prevention tools are substantially less effective when consumers don't use them as directed; and patients enrolled in antiretroviral therapy often need behavioral or practical support in order to adhere to prescribed regimens. While working to optimize access to biomedical tools, the Institute will work to ensure that research and funding continue for behavioral strategies to reduce HIV risk behaviors and to improve the effectiveness of biomedical interventions. Black community-based organizations and advocates need to help lead efforts to generate a truly integrated approach that combines biomedical and behavioral approaches.

### **Black community-based organization and AIDS service organizations must retool to respond to an evolving landscape.**

As new biomedical tools come to occupy center stage in the AIDS response, the Institute will help link Black-serving organizations with clinical providers in their communities. The Institute is working to obtain funding to host a national summit of AIDS organizations to explore options for retooling for a changing environment.

# A BRAVE NEW WORLD IMPLEMENTING THE AFFORDABLE CARE ACT

**T**he Affordable Care Act (ACA) is one of the most important pieces of legislation ever enacted for people living with HIV. Extending health coverage to millions of Americans who currently lack it, the ACA has the potential to substantially strengthen efforts to close gaps in the HIV treatment continuum and ensure that all of the 515,000 Black Americans living with HIV achieve viral suppression.

## **A Fragmented Health System**

The ACA aims to correct many of the weaknesses in the health care system that presently undermine efforts to provide life-saving services to people living with HIV. As Robert Greenwald, Director of the Center for Health Law and Policy Innovation at Harvard Law School, advises: “The status quo equals lack of access to care. Employment-based coverage, the primary way that people in the U.S. obtain health insurance, doesn’t work for a lot of people living with HIV.”

This is especially true for Black Americans. Blacks are more than twice as likely as whites to be unemployed<sup>14</sup>, with people living with HIV considerably more likely to lack employment than the non-HIV-infected. More than one in five Black Americans have no health coverage, a rate that is almost twice as high as for whites.<sup>15</sup>

While Medicaid, Medicare, and other safety-net programs provide critical health services for many

who are otherwise uninsured, these programs aren't designed to provide early access to preventive and comprehensive health care for people with HIV or other chronic diseases.

"Medicaid and Medicare as they currently exist are great programs, but they are disability-based programs, not health care programs for the chronically ill," Greenwald said.

Medicaid largely excludes coverage for non-disabled adults, effectively foreclosing assistance to a huge share of people living with HIV. And, according to Greenwald, the Ryan White program, with funding that represents a small fraction of spending on Medicaid and Medicare, can't address the enormous holes in the health care safety net for the 1.2 million Americans living with HIV.

The fact that Black Americans have inequitable access to meaningful health coverage greatly contributes to disparities in HIV-related health outcomes. According to the Centers for Disease Control and Prevention, Black people living with HIV are 43% less likely to have viral suppression than whites living with HIV.<sup>16</sup> Having

Americans mean that HIV-positive Black people are more likely to become ill or die, and sub-optimal utilization of health services also contributes to the spread of HIV in Black communities.

### **The ACA's Potential to Transform the AIDS Response**

Not a moment too soon, the ACA has stepped into the breach to offer needed help in strengthening the health care safety net for people living with HIV. After vociferous opposition to the ACA emerged, key events in 2012 ensured that the law would survive. First, in a dramatic 5-4 vote, the Supreme Court largely rejected a challenge by several states to the constitutionality of the ACA. Second, in November, voters re-elected President Obama to a second term, rejecting a challenger who had vowed to take steps to repeal the ACA on his first day in office.

The ACA has the potential to sharply increase health care access for people living with HIV. In 2012,

people living with HIV.<sup>18</sup> According to Crowley and Kates, "The passage of the ACA provided significant, new opportunities for expanding access and coverage to millions of people in the United States, including people with HIV."<sup>5</sup>

Some of the key ACA provisions highlighted by Crowley and Kates include the following:

#### **Medicaid**

Beginning in 2014, the exclusion of coverage for single childless adults will be eliminated, with a new minimum income eligibility threshold of 138% of the federal poverty line to take effect. The ACA increases Medicaid payment rates for primary care and also allows states to permit chronically ill patients to designate a Medicaid provider as their health home.

#### **Medicare**

The ACA phases out the Medicare drug coverage gap, which currently places chronically ill patients on the hook for thousands of dollars in drug costs. A \$250 discount for Medicare recipients who enter the so-called "drug donut hole" is now available, with the discounts to increase over time until the coverage gap is completely eliminated. Until the drug coverage gap is completely eliminated, the ACA allows AIDS Drug Assistance Programs around the country to cover HIV-positive Medicare recipients' out-of-pocket costs for HIV-related medicines.

#### **Health Insurance**

Beginning in 2014, all U.S. citizens and legal residents are required to have health coverage, with insurance premium subsidies made available to families with incomes from 100-400% of the poverty line and cost-sharing subsidies offered to families above 250% of poverty. Beginning in 2014, both annual coverage limits and exclusions of coverage for pre-existing conditions are eliminated. Private health insurance exchanges will be available in all states (either operated



health coverage is associated with greater use of essential HIV-related health services and with improved health outcomes.<sup>17</sup> Lower rates of treatment success among Black

Jeffrey Crowley, former director of the White House Office of National AIDS Policy, and Jen Kates of the Henry J. Kaiser Family Foundation, surveyed the ACA's key provisions for

by the state or the federal government) to enable individuals to purchase affordable health insurance.

### Health Care Quality

All health plans, including Medicaid, will be required beginning in 2014 to provide a package of essential health benefits. The ACA mandates that these essential benefit packages include comprehensive services across 10 different service categories. The ACA mandates collection and reporting of data on health disparities.

### Prevention

The ACA aims to increase the health care system's focus on prevention. Priority prevention services are to be covered as part of the essential benefits package, and the Act also created a new prevention and public health fund, which has already provided additional funding for HIV prevention activities by the CDC.

### Ensuring Full Implementation of the ACA

Although passage of the ACA represented a potentially transformative moment in the nation's three-decade-long struggle with AIDS, its promise has yet to be realized. To help lay a foundation for ending AIDS in the U.S., the ACA will need to be fully implemented.

Several potentially critical obstacles to full implementation will need to be overcome. First and foremost, each state now has to decide whether to expand Medicaid under the terms of the ACA or leave it as it is, with broad exclusions of coverage for non-disabled adults. While the ACA, as originally adopted, made continued federal support for state Medicaid programs contingent on the state's agreement to expand the program, the Supreme Court held that the federal government could not withhold all Medicaid funding from states that refuse to expand the program. As a

result, the Medicaid expansion that is so critical to people living with HIV is now an *option* for the states, not a requirement.

Several Republican state governors have announced their opposition to expanding Medicaid in their states.

Opposition is most intense in the South, which is now the epicenter of the U.S. AIDS epidemic. Accounting for a third of the nation's population, the South is home to half of all people newly infected with HIV, with cases heavily concentrated in Black communities.<sup>19</sup>

The opposition to the Medicaid expansion is curious in some respects, as the ACA makes Medicaid expansion an exceedingly good bargain for the states. Under the ACA, the federal government pays for 100% of the costs of expanding Medicaid in 2014-2016, with the federal cost share falling to 90% in 2020 and beyond. This contrasts with other Medicaid costs, for which the federal share varies from 50% to nearly 75%.<sup>20</sup>

As Greenwald notes, the reasons state governors have given for opposing the Medicaid expansion vary. Notwithstanding the generous terms offered to states under the ACA, some governors have argued that the expansion would increase future spending obligations for states that are currently experiencing extreme financial distress due to economic conditions.

As Greenwald observes, the economic arguments against Medicaid expansion are weak. "For every dollar the states put in, the federal government will put in \$9," he notes. "This is federally funded business activity in states. The flip side is that the ACA cuts federal payments for uncompensated care in half, regardless of whether a state expands Medicaid or not. If you don't embrace Medicaid expansion, you will have less money for uncompensated care."

"We need to acknowledge to the states that Medicaid expansion is an



investment. But it will generally save money over time and will bring in huge amounts of revenue to the states."

Some governors have questioned whether expanding Medicaid will improve health outcomes, arguing that so-called "social determinants" have more to do with health results than health care access. This argument ignores not only substantial evidence that Medicaid coverage improves health outcomes for low-income individuals and families, but also the reality that inadequate health care access is itself a social determinant.

Other opponents of expansion argue that Medicaid is a "broken system" that should be scrapped rather than expanded. While the traditional Medicaid has long had problems, Greenwald notes that under the ACA Medicaid is "actually an entirely new program." The ACA transitions Medicaid from a disability-based program to a health care program that prioritizes prevention.

Were many states to opt not to expand Medicaid, much of the promise of the ACA would be undermined for people living with HIV. In particular, access to preventive and early intervention health care would remain largely outside the mainstream public health care system.

In addition to deciding whether to expand Medicaid, states will also have considerable say over which services are included in their essential benefits package. Although the federal government issued guidance to states in 2012 on the development of an essential benefits package, states will have substantial flexibility in designating the scope and level of services that Medicaid and private health plans will be required to cover.

“A lot of discretion is being left to the states on the essential benefits package,” Greenwald said. “In some states there will be robust benefit packages, and in other states there won’t.” This raises particular concerns with respect to people with HIV and other chronic conditions, which require costly coverage and innovative delivery strategies not needed by the typical patient. Were state-determined essential benefits packages not to mandate coverage of key services needed by people living with HIV, the quality of HIV care would suffer and health disparities would persist.

The ultimate impact of the ACA will depend in large measure on whether individuals make use of the new health care options available under the law. For any number of reasons—lack of information, misperceptions, or life conditions that make accessing services difficult—many people from all walks of life fail to use the health services that are available. Community education will play a vital role in helping individuals understand the health care options available to them, and community service organizations will need to revise their approaches in order to assist their constituents in taking advantage of expanded health coverage. As service systems and essential benefit packages will vary considerably, community education and support strategies will need to be tailored to individual settings.

Congressional decisions on the future of the Ryan White program could also have an important effect

on the ACA’s success for people living with HIV. The program is due for reauthorization in 2013, and there is little doubt that the program will need to adapt to the changes brought about by the ADA. Especially given the possibility that some states will adopt restrictive benefit packages, a revised Ryan White provides an ideal vehicle for supporting essential services that may not be covered in all states. In particular, an adapted Ryan White program could provide vital funding for innovative service models for linkage to care, retention in care, adherence support, and treatment education.

### **Advocacy to Ensure Full Implementation of the ACA**

With so many critical decisions now in the hands of the states, state-level advocacy is vital to maximize the ACA’s benefits for people living with HIV. And with Black people living with HIV currently most likely to fall through the cracks of our health care system, Black advocates need to play a pivotal role in state-level advocacy.

Greenwald and his team at Harvard Law School are already working with advocates in key states. “I spend most of my time at the state level working in the South to highlight the importance of expanding Medicaid to low-income individuals and families,” he said.

The Institute is working to link Black community leaders in key states to ongoing advocacy efforts on ACA implementation. In 2013, the Institute will collaborate with the Center for Health Law and Policy Innovation at Harvard Law School, AIDS United, Latino Commission on AIDS, and state and local health departments to convene a two-day “ACA Boot Camp” for AIDS advocates. The boot camp will particularly focus on preparing local Black Treatment Advocates Networks to link with other health reform advocates and support efforts to persuade decision-makers in their states to fully implement the ACA.

By the end of the two-day boot camp, participants will be able to explain the effect of the ACA on their local health care landscape, develop locally tailored advocacy and education tools, and implement an action plan to improve the responsiveness and effectiveness of local AIDS programming.

The resistance in some states to certain ACA provisions is hardly unprecedented. After the Medicaid program was first established in the 1960s, it took 18 years before all states had agreed to implement it. As when Medicaid was created, experts anticipate that all states, including those where resistance is currently greatest, will eventually embrace Medicaid expansion, as both the economic benefits for states and the public rationale for expansion are simply too compelling to ignore.

However, neither the many thousands of HIV-positive, low-income individuals who urgently need life-saving care, nor the broader AIDS response, can afford to wait 18 years to fully implement the ACA. With research breakthroughs offering the real chance to lay a foundation for the eventual end of the epidemic, states need to take action now to seize the potential of the ACA.

# COMING OUT THE POWER OF LIVING OPENLY WITH HIV

To lay the foundation for an end to AIDS, all people living with HIV need to come out of the closet and determine to live openly and proudly with HIV.

There are many reasons why coming out is so vital. First and foremost, the individual who lives openly with HIV is able to live a fuller, more complete life. It allows people in our lives to share our journey, offer us love and support, and know us in our fullness.

People who live openly with HIV are also able to seek the services they need to thrive. Without fear that their HIV status will be discovered, people who live openly with HIV are able to visit the doctor or clinic of their choice, seek health-related information, network with and learn from other people living with HIV, and obtain care and support when they need it.

Having an army of openly HIV-positive people in place also helps build demand for treatment. By bringing HIV into the light of day, people living with the disease are able to join together to advocate for their needs. And seeing HIV-positive people living long, happy and healthy lives encourages at-risk individuals to seek HIV testing.

When it comes to the fight against AIDS, you can't scratch too far below the surface to discover the ugly, hurtful role of stigma. Stigma prevents people from getting tested, discourages people from seeking the care they need, and reinforces the hesitation that many HIV-positive people have about coming out.

But coming out about your HIV



status is the best weapon we have against stigma. Coming out defeats the myths and stereotypes about AIDS and contributes to social norms of compassion, inclusion, and community solidarity.

Not everyone has the means at the moment to come out. In some states, laws that criminalize HIV exposure, transmission, or non-disclosure understandably give some people pause about disclosing their HIV status. And some people are in relationships that cause them legitimate concerns that

they might be the victims of violence if they disclose their HIV infection to their partner.

While as many people with HIV as possible determine to live openly with HIV, we need to work to create an environment where all HIV-positive people are able to live openly, without fear of ostracism, discrimination, or physical injury.

Too often, though, people living with HIV allow their own unfounded fears to keep them in the closet. The push to encourage as many HIV-

positive people as possible to come out aims to ensure that all individuals have the support they need to take this important step in their lives.

What follows are profiles of three people living with HIV who made the decision to come out about their HIV status. Each of them experiences challenges, but each found a way to overcome them. And what they learned is that coming out has expanded their personal and professional horizons and given them the freedom to help others as well as themselves.

# MARVENE EDWARDS

## FROM HOPELESSNESS TO SELF-ACCEPTANCE AND PERSONAL HONESTY

Ten years ago, Marvene Edwards had what can only be described as a spiritual revelation. After hitting bottom from a life of drugs and hopelessness, she embarked on a path toward healthy living, self-acceptance, and personal honesty. A decade after reaching the lowest point in her life, Marvene now works full-time to help people living with HIV obtain the health care services they need.

Marvene tested HIV-positive in 1987. After a group of men assaulted her as she was walking home from a bar, one pulled a gun and shot her after discovering she had no money to steal. A woman who was walking her dog the next morning found Marvene and called an ambulance.

Barely alive when emergency workers reached her, Marvene survived, losing her right eye as a result of her gunshot wound. Her father took in her children to care for them while she recovered. Upon discharge from the hospital, she was sent to rehabilitation center, where she tested HIV-positive.

"I was in complete denial when I heard I was positive," she recalled. "I couldn't hear what these people were telling me. I didn't want to live, because people at the time didn't accept people who were HIV-positive."

Marvene eventually walked away from the facility, turning to alcohol and drugs to find some kind of peace. She graduated over time from marijuana to harder drugs, such as crack cocaine.

Marvene was living in Miami when



her oldest son was approaching his high school graduation in Gainesville, Florida. Her family brought her to Gainesville and insisted she stay. However, her life continued on a downward spiral, and she ended up in a homeless shelter.

Eventually, Marvene began living with her son's family, which included Marvene's two grandsons. It was on the porch of their house where Marvene's life took a turn.

"One day, my son and my grandsons left the house," she recalled. "As soon as they left the house I went to get my drugs. I had promised myself I'd never do drugs around my family. I sat on the porch, and that was my bottom. I cried out to the Lord for help, and I haven't picked up a drink or drug since. That was almost 10 years ago."

"I had stopped loving myself and stopped respecting myself," she said. "Then one day on my son's front porch, I saw my future, and I got a second chance."

Marvene began attending church, and her life slowly turned around.

After years of on-and-off treatment for her HIV infection, she began treatment again and has consistently taken her HIV meds for the last nine years.

But her HIV status remained a challenge for her, as no one in her family knew she had tested HIV-positive. She began visiting an AIDS counselor and participating in support groups for people living with HIV. On one of her counseling visits to the health department, she met Teresa Wright, the HIV/AIDS coordinator in Gainesville, who asked if Marvene would be willing to volunteer to help with the local Positives Empowering Positives initiative. Marvene agreed and became responsible for reminding members of upcoming support group meetings.

"After participating in the support group, I knew it was time to disclose my status. I had gotten comfortable with the idea of being positive and was motivated to do more. But in order for me to do more, I needed to let my family know I was positive."

She asked her family to sit down

for a talk and told them she was living with HIV. Her entire family was supportive, which helped give her the freedom to become more active on AIDS issues. Marvene began speaking about her HIV status at local Job Corps settings, in churches, at the University of Florida, and in other public settings. She has also appeared on TV talking about her life with HIV.

Today, Marvene works as a peer navigator in Gainesville, helping ensure that people living with HIV receive needed services. "I let them know I am HIV-positive, that they can live life productively, how important it is for them to take their medicine," she said. "I remind them that they are beautiful in their own skin. People need to know they aren't alone in this fight, that there is someone else who understands where they are and what they are living through."

"No one has to be another statistic. You need to learn to love yourself and not allow people to make you feel a particular way. This is your power; don't give it away!"

# **LOLISA GIBSON-HUNTE**

## **LIVING OPENLY HAS ALLOWED LOLISA TO BECOME THE PERSON SHE ASPIRED TO BE**

**L**olisa Gibson-Hunte was a teenager living in Wilmington, Delaware, when she had a series of health problems, including esophagitis and shingles. Her doctor recommended she get tested for HIV.

“I didn’t know what HIV stood for,” she said, “but I knew I wasn’t positive!”

When she came home from school one afternoon, her mother told her the doctor’s office had called several times that day. Thinking little of it, Lolisa had just sat down to watch TV when the phone rang. It was her doctor again, asking her to come into the office immediately. She told him she couldn’t drive and asked him to tell her over the phone why he was calling. It was then she found out that her HIV test had come back positive.

“My mother was on the other phone downstairs,” Lolisa recalled. “After he told me I was positive, I blacked out and went into my own world. I didn’t mind my mother hearing the results, because my main concern at the time was I was going to die.”

After her doctor made an appointment for her with an HIV specialist, she was sure the specialist would tell her the test result was a mistake. Instead, the specialist spent their visit explaining about concepts such as viral load and T-cell counts. Tests revealed she had 115 T-cells and a viral load above 100,000 copies. She left the office with three prescriptions and immediately began taking anti-HIV medicines.

“I was confused by some of the things the specialist told me,” Lolisa



said. “I started doing research about what HIV was, and I found out I wasn’t the only one living with it. It took me about six months to really begin to understand what I was dealing with.” Eventually, Lolisa would determine that she was likely born with HIV.

Lolisa began talking to other young women at the clinic who were also HIV-positive. She began to feel less alone, and she volunteered at an AIDS service organization. “I wanted to get involved because, in my research, I learned that one of the age groups most affected by HIV are young people, 13-24 years old. That included me, my brother, all my friends. But none of us knew anything about HIV.”

Determined to ensure that young people had the information they needed, Lolisa began working full-time for an AIDS service organization in Wilmington. She helped establish Delaware’s first needle exchange program.

Like many others living with HIV, Lolisa’s path toward living openly with HIV took time. A young woman she met at the HIV clinic asked Lolisa to speak at a World AIDS Day event. “I was 21 at the time,” Lolisa said, “and I told her I couldn’t do that. No one in my family knew my HIV status at the time except my mom. But I changed my mind, and I went ahead and did it. That was the first time I was able to speak to strangers and tell my story. It felt good, like a breath of fresh air or like something had been lifted from my shoulder. I decided I wanted to do more, and I started telling my family members about my HIV status.”

**M**oving to New York in 2008, Lolisa began working for the New York City AIDS Housing Network, helping with counseling and testing and needle exchange services. “I started to get involved in doing interviews for

magazines like *POZ*. I felt like I wanted to get out and touch more people who were positive.” In 2008, Lolisa participated in a speaking tour across the United Kingdom sponsored by the Student Stop AIDS Campaign and Dance for Life.

An important milestone in her journey toward openness and self-acceptance came at a World AIDS Day panel in her home state of Delaware. The event was held at the high school where she graduated, and young people attended from all over the state. “It was going to be attended by a lot of people I know, people who didn’t know I was positive,” she said. “At first, I said I can’t do that. But I decided it was important to reach people I know and tell them what this virus really is.”

Today, she is married to an HIV-negative man and has a son, born in September 2009, who is also HIV-negative. “By the time my son was born, I was educated about what I needed to do to prevent him from becoming infected.”

Living openly with HIV has allowed Lolisa to become the person she aspired to be. “When I learned my status, I didn’t even know what HIV stood for. I couldn’t find anyone to talk to, and everyone I talked to was secretive just like I was. I wanted to be the person I needed when I found out I was HIV-positive. I want everyone who tested HIV-positive to see you can be HIV-positive and still be healthy and what you want to be. And also for people who are HIV-negative, I want to help wake them up because HIV can happen to anyone.”

# VENTON JONES

## COMPLICATED AND CHALLENGING BUT BETTER THAN TRYING TO KEEP IT A SECRET

Venton Jones' discovery in 2007 that he was HIV-positive was a bit more circuitous than most, but it placed him on a path toward personal honesty, self-respect, and empowerment through community advocacy.

Venton was volunteering for an AIDS organization in Dallas and knew the importance of testing. "I was aware of the need to test frequently," he said, "so I did so." At that time, Jones was in the process of acknowledging his own sexual attraction to men, having trouble getting his career started, and living on his own for the first time after graduating from college.

"All this led to a lot of clubbing and partying," he said. "It was nothing unique or about being a Black gay man. It was really just about being a young person."

In the summer of 2007, Venton was admitted to the hospital for an ailment the physicians had trouble diagnosing. Symptoms included an extremely high fever and night sweats. "I actually had to ask the hospital to test me for HIV," recalled Venton, who had previously informed the doctors he was gay.

When the hospital's test results came back, Venton was told he had tested HIV-negative.

His symptoms disappeared, and he was released from the hospital. Two weeks later, in an effort to get his life on track, he enlisted in the U.S. Army. Venton received his job assignments and leave dates and was busy preparing for a life in the military.

Prior to his scheduled departure for military service, Venton received a



certified letter from military medical personnel. They needed to see him for an urgent medical matter.

Surmising that he was, in fact, HIV-positive, notwithstanding the negative test result he had just received, Venton sought testing services at a local community organization. His results came back positive, a finding that was shortly confirmed by the Army itself. “In hindsight, it was clear to me I was seroconverting when I entered the hospital,” Venton said. “When I got the news from the Army, it was kind of surreal. I had just had a negative test result from the hospital.”

On the drive home after testing HIV-positive, Venton made a pledge to himself. “I had to be able to look myself in the mirror and love myself, even if everyone turned their backs on me,” he recalled. “As soon as I got home, I picked up the phone and called my sister to let her know. And then I called one of my best friends to let them know.” Early responses from friends and family members were supportive, assuring Venton that people with HIV could live long and productive lives.

“I never wanted to be a victim,” Venton said. “I kept talking to myself because I wanted to make sure I was stronger than the virus.”

Although he pledged not to let his infection overcome him, opening up about his HIV status was a process. “I had only come out to my family as gay a few months before I tested HIV-posi-

tive,” Venton said. “I had a bit of shame about immediately telling my family I had tested positive because HIV was what they expected. But I knew it was important that I shared this news.”

After testing HIV-positive, he experienced an upsetting break-up with someone he had begun dating before he received his test results. “He suggested I knew I was HIV-positive when I got into the relationship, which wasn’t true,” Venton said. To this day, disclosure in the context of dating remains a challenge. “It reawakens the conversation every time you go through it. Disclosing it every time I began dating someone and waiting to see how they would respond was a real challenge. In time, I became comfortable dating people who already knew I was positive.”

Venton estimates it took about four years for him to become comfortable with speaking publicly about his HIV status. AIDS activism was his road to personal peace and tranquility about living openly with HIV. In 2011, Venton moved to Washington, D.C., where he now works as communications and education manager for the National Black Gay Men’s Advocacy Coalition. “When I moved to D.C., I decided that the shame of disclosure would be something I would leave in Dallas,” he said. “I decided I was going to be

my authentic self, and HIV is a part of me.”

As the 30th anniversary of the first official AIDS report approached, Jet magazine asked Jones whether he would be willing to be profiled. “I thought this was the opportunity to finally leave my shame of disclosure behind. Jet is something you see in most Black houses. My dad actually found out about my HIV status through the Jet article. After it came out, I went home for the Fourth of July holiday, and the article was the topic of conversation for my family. But they saw that I was okay, and that gave them the permission to be okay.”

Although his coming out was a complicated and sometimes challenging process, Venton is certain that living openly with HIV is better than trying to keep it a secret. “One of the main reasons I decided to come out was as a tool to help other people,” he said. “And I wanted to be open and honest with my family because that’s how I was raised.

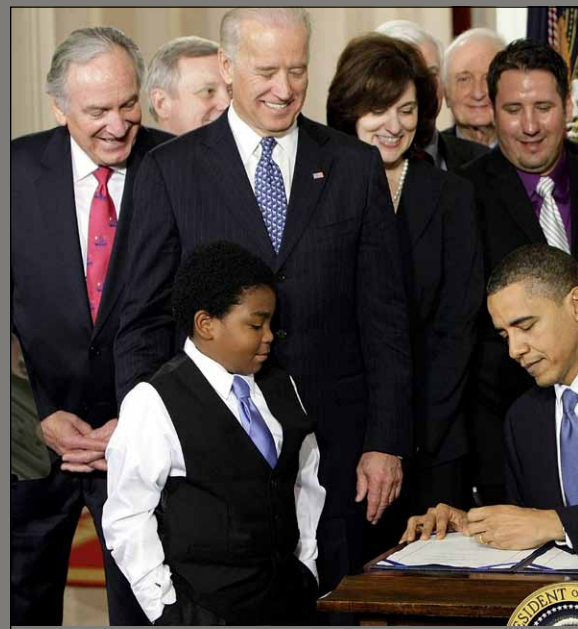
“Coming out shows you aren’t alone. So many people who test HIV-positive feel like they are alone, that they are the only person who has to shoulder this responsibility. When you come out and live openly with HIV, you help others break through their own isolation.”

Venton feels a special obligation to young people. “Not a lot of young people are comfortable enough to disclose their status. Helping young people get the support they need to live with HIV is something that has become really important to me.”

# ORGANIZATION RETOOLING IN THE FACE OF CHANGE ENSURING THAT BLACK AMERICA HAS THE CAPACITY IT NEEDS TO END AIDS

The AIDS landscape is rapidly changing. Over the last several years, new biomedical tools have emerged that have quickly transformed the AIDS response. Today, we are no longer talking about managing AIDS but instead about how to end it.

The world around the AIDS response is also being transformed. In 2013 and 2014, the country will take a major step toward the ultimate goal of universal health care access, offering a historic new opportunity to close



gaps in the HIV treatment continuum. As the Affordable Care Act is fully implemented, however, traditional funding streams for HIV programs are likely to dramatically change or, in some cases, go away entirely.

These changes have momentous

consequences for community-based organizations that provide HIV-related services to Black communities. Unless community organizations adapt to the many changes that are taking place, many will not survive. The closure of Black-serving community organizations will weaken the capacity of Black America to respond to AIDS at the very time that genuine success against the epidemic is achievable.

Although some AIDS service organizations in Black communities have grown to become prominent pillars of their neighborhoods, the AIDS response in Black America primarily relies on organizations that are much smaller than the large service organizations created in white gay communities in the epidemic's early years. Smaller organizations, with a limited funding base, are most vulnerable in the current environment.

Many Black AIDS organizations have primarily focused on HIV prevention outreach and education. In large part, these organizations



have looked to the Centers for Disease Control and Prevention for funding to implement the CDC's DEBI (Diffusion of Evidence-Based Interventions) programs. Yet in launching its approach to High Impact Prevention, CDC has signaled that funding



for DEBIs will inevitably decline, potentially imperiling agencies that have focused almost exclusively on DEBI-related funding in the past.

With biomedical prevention tools now taking center stage in the AIDS response, CDC and other federal agencies will need community-based partners with the skills and expertise to integrate behavioral and biomedical approaches. Yet many AIDS organizations, especially smaller ones that have traditionally focused on delivery of DEBIs, lack in-house medical expertise. At a moment when closing the HIV treatment continuum has arguably become the central challenge for the AIDS response, many AIDS organizations lack the ability to influence the health care services their clients receive. Often, smaller organizations have few, if any, strong programmatic linkages with local HIV clinics.

At the same time that biomedical advances are transforming the AIDS response, the Affordable Care Act is poised to dramatically alter the way health care is financed and delivered. Whereas prevention services have long been financed through discretionary federal programs, the Affordable Care Act aims to fold many prevention services into mainstream health care delivery. And the future of the Ryan White CARE Act, on which many AIDS organizations have long depended for funding, is uncertain, with Congress due to take up reauthorization in 2013 in the face of a sense of crisis over the federal budget.

These and other changes are not

theoretical, nor are they coming down the road. They are real and imminent. To survive, AIDS organizations will need to change as the environment itself changes.

Some AIDS organizations are already moving to adapt to an evolving environment. Empower “U”, a Black community-based organization in Miami, serves as an example. Founded in 1999 by two women living with HIV, Empower “U” has provided a range of services, including outreach, prevention services, housing support, HIV testing and counseling, and case management. Today, the organization has determined to couple its social service programs with health care delivery, seeking to obtain certification to become a Federally Qualified Health Center.

For other organizations, beginning to deliver health services may not necessarily be the answer. Rather, linking with a clinical program and entering into a multi-agency alliance may be the best way to integrate behavioral and biomedical approaches.

This section highlights two organizations that are working to adapt to the many changes affecting the world of AIDS service delivery—the Community Education Group in Washington, D.C., and Harlem United in New York City. Each of these organizations has proven nimble in the face of change, although they have chosen different paths based on their respective organizational missions and the needs of their constituents.

# COMMUNITY EDUCATION GROUP REMAINING RELEVANT IN THE CITY MOST HEAVILY AFFECTED BY HIV

In Washington, D.C., the Community Education Group has worked to stay ahead of the curve of changes in the AIDS epidemic and the broader health care environment. Nationally known for its extraordinary success in linking people who test HIV-positive to ongoing primary care, CEG is increasingly leveraging its HIV expertise to address the broad range of health and social service needs presented by CEG clients and their families.

CEG's home is in Washington's Ward 7, where 95% of residents are Black.<sup>21</sup> CEG serves residents of four of the city's wards—all of which are located in the southern part of the District of Columbia.

Washington has been more heavily affected by AIDS than any other city in the U.S. HIV prevalence citywide is 2.7%, with 4.3% of Black Washingtonians living with HIV. Washington also has the nation's highest rate of new AIDS diagnoses. Although Black people account for less than half of Washington residents, they represent 75% of all people living with HIV.<sup>22</sup>

When the National Women and HIV/AIDS Project (NWAP), CEG's predecessor organization, was founded in 1993, infections were rapidly growing in Washington's Black community, especially among Black women. To alter the misperception that AIDS was solely a disease of white gay men, NWAP primarily focused on outreach and culturally appropriate education in its early years. In 1999, when NWAP became



CEG, the organization expanded its outreach to heterosexual males and the recently incarcerated, created a broader spectrum of programs, and launched an initiative to train other not-for-profits.

A foundation for many of CEG's programs is the organization's work to promote and deliver HIV testing services. CEG operates eight mobile testing units that conduct outreach, HIV testing and counseling, and referral services in diverse neighborhoods on Washington's south side. CEG uses a "saturation approach" that positions the agency as a familiar, trusted resource in each community it serves. With CEG aligning its testing work with the District of Columbia's citywide initiative to increase knowledge of HIV status, the number of individuals tested through CEG rose from 200 in 2006 to more than 10,000 in 2012.

While proud of its contribution toward the city's goal of increasing knowledge of HIV status, CEG soon began grappling with the limited utility of testing on its own. "The real issue," says CEG Executive Director A. Toni Young, "is whether you can find people in six months and whether they are accessing care and remaining in care."

In assessing its service approach, CEG was especially persuaded by the HIV treatment cascade documented

by Edward Gardner and colleagues.<sup>23</sup> This analysis found that the majority of people with diagnosed HIV infection had yet to achieve viral suppression—because they were not linked to care, failed to receive antiretroviral therapy where medically indicated, or had dropped out of care at some point.

In 2010, CEG opted to implement a new service approach for people who test HIV-positive. Instead of providing individuals who test HIV-positive with a paper referral, CEG immediately schedules a doctor's appointment and pledges to provide transportation for the patient's first five primary care visits. During these client encounters, CEG staff also engage clients to learn whether other factors—such as housing instability, child care responsibilities, or other needs—might be interfering with the ability to remain engaged in care. For individuals who have such needs, CEG works to link the client with the non-clinical support they need to remain in care.

**C**EG's approach has achieved extraordinary results. In 2012, 98% of individuals who tested HIV-positive through CEG were actually linked to HIV primary care. CEG's linkage rate far exceeds the national average of 77%.

With the Affordable Care Act set

to be implemented in stages through 2014, CEG is examining its future directions. A particular focus is to position CEG to help address the broad range of its community's health needs, including hypertension, diabetes, and other health problems in addition to HIV. "The first rule of thumb [in the evolving landscape] is that it is not a good idea to be focused on a single disease," said Young.

According to Young, the seven core indicators (HIV positivity, late HIV diagnosis, linkage to care, retention in HIV medical care, receipt of antiretroviral therapy, viral load suppression, and housing status) for federally funded HIV programs provide a roadmap for agencies as they retool for a changing response. "Agencies need to figure out how to track each of those numbers," Young advises. "For non-clinical providers, this means you are going to have to have a different relationship with your clinical partners."

Preparing to adapt to a changing landscape is more than just a good idea for AIDS organizations, Young believes. It may be essential to organizational survival.

"My advice to AIDS organizations at this stage is to count the number of providers in your area," Young says. "Look to your left, then look to your right, and hope that you're not the one who's gone in a couple of years."

# HARLEM UNITED INTEGRATING SERVICES IN A CAPITAL OF BLACK AMERICA

Harlem United was founded in 1988, as the epidemic was exploding in the neighborhood that many have long regarded as the capital of Black America. From its roots as a small paraprofessional organization, Harlem United is now a \$40 million, 400-employee agency and has one of the most expansive, integrated service portfolios of any AIDS organization in the country.

Harlem is among the neighborhoods most heavily affected by AIDS in the entire developed world. Today, nearly 3% of Harlem residents are living with diagnosed HIV infection, and the age-adjusted death rate for people living with HIV is nearly 50% higher in Harlem than for the Manhattan borough as a whole.<sup>24</sup>

As the epidemic has expanded and the AIDS landscape has evolved, Harlem United has distinguished itself by remaining ahead of the curve. Harlem United was among the first AIDS service organizations to venture into the delivery of adult day health care services, and the agency took early steps to diversify its funding by creating Medicaid-reimbursable services.

“Our philosophy as an organization has always been about how we continue to provide more services to our clients,” said Harlem United CEO Steven Bussey. “We want to have a holistic approach that ensures better outcomes, reducing the average length of stay in hospitals and the number of emergency room visits, as well as increasing viral load suppression and

CD4 counts. We continue to adjust our model as we understand better what our clients need.”

Throughout its history, Harlem United has emphasized programmatic integration and synergy. “We allow our services to feed off each other and support each other,” Bussey said. “It’s hard to ensure outcomes if you don’t have an ability to impact all areas affecting the client.”

Following the emergence of Highly Active Antiretroviral Therapy, Harlem United adapted its service offerings to capitalize on the treatment revolution. Harlem United’s adult day health care program was the first in New York State to offer directly observed therapy, comprehensive oral care, and a full continuum of mental health services. Harlem United helped found New



York’s only community-controlled special needs plan for people living with HIV. Recognizing the toll of late diagnosis on the health prospects of people living with HIV, Harlem United also led statewide advocacy to obtain state approval for regulations to streamline the HIV testing process.

Recognizing the critical role of stable housing in effective management of HIV, Harlem United moved early into the field of supportive housing. In 2012, the agency operated 586 units of supportive housing reserved for clients at risk of becoming homeless, offering primary care and other wraparound services specifically tailored to the needs of unstably housed individuals living with HIV. In 2007, Harlem United was awarded a Federally Qualified Health Center grant to provide health services to the homeless population.

“We saw early on what providing housing to clients would mean,” Bussey said. “How can you address health issues when your clients don’t have a roof over their heads and can’t get proper food and nutrition?”

Strategic alliances have helped

Harlem United respond to the multifaceted and widely varying needs of the community it serves. In 2007, Harlem United formed a strategic alliance with FROST’D to expand health care access to chronic substance users, HIV-positive formerly homeless persons, and young men who have sex with men. At the time this report went to press, Harlem United was actively exploring a potential merger with the organizations Housing Works and HELP-PSI, which if completed would establish a mammoth, integrated service system for the underserved that stretches from one end of New York City to the other.

Harlem United’s integrated, client-centered, community-grounded approach has achieved results. Six months after entering the agency’s supportive housing program, clients had 8% fewer emergency room visits and 17% fewer episodes of hospitalization, generating savings in acute care costs of \$900,000. By helping medically frail clients avoid costly nursing home care, Harlem United’s adult day health center saves New York’s Medicaid program an



estimated \$5 million a year. Clients enrolled in the agency's health center for the homeless have one-third the number of emergency room visits of similarly situated individuals who are not enrolled. Using geographic mapping to identify "hot spots," the agency's HIV testing initiative has proven effective in reaching a larger percentage of HIV-positive individuals, saving New York's taxpayers an estimated \$618,900 in 2009.

**H**arlem United's service continuum not only improves health outcomes for its clients, but it has also proven attractive to key funders because it saves taxpayers money. "For better or worse, governments focus on reducing costs to the system, particularly as it pertains to the Medicaid and Medicare populations," Bussey advised. Significantly, the attractiveness of the agency's service model to government funders has made Harlem United less dependent than many other service organizations dependent on philanthropic funding.

As the health care system has evolved, Harlem United has adapted its program models and organizational approaches to minimize risk and optimize results. When New York State launched a comprehensive redesign of its Medicaid program to improve

health care outcomes and enhance efficiency, Harlem United capitalized on the opportunity to highlight its model. Harlem United has been designated a Level 1 medical home, a status that will become increasingly important for both patients and providers as the Affordable Care Act is implemented.

In its ongoing programmatic and organization adaptation to clients' changing needs and the evolution of the broader environment, Harlem United has maintained a commitment to service quality. "The programs and services you provide have to be driven by data supervision, clinical supervision, and quality," Bussey noted. "And we couple that with fiscal responsibility and effective management, all integrated and tied together to help ensure that programs are running efficiently."

In many ways, Bussey believes we've only seen the tip of the iceberg when it comes to environmental shifts in the AIDS response. "Government's focus on reducing costs to the system creates a need for efficiencies," he said. "As a result, there is going to be less room for small organizations that make small or incremental changes to the cost structure. This will require organizations to have a bigger footprint in order to have a larger influence on the population they serve.

"This creates a huge risk in urban communities where you currently have a lot of small organizations performing very important tasks. These organizations are feeling threatened by cuts in prevention funding, a lack of support for their administration costs, and the focus of Obamacare on fully accountable care organizations. There is a real risk that smaller organizations won't have the resources to survive in this environment. The question on the table is whether we can convert a system that has been smaller, grassroots-based into the one desired by governments, with more consolidated tools and resources to address community needs."

Although the risks for small AIDS organizations are real, Bussey suggests that avenues exist to remain relevant—both for clients and for government funders. "With increasing pressures at the state, local, and federal level to reduce costs to the system, we are going to see increasing challenges to the care model that has long been used in the AIDS field," Bussey said. "We need to ask ourselves what is going to be the most efficient way for us to continue to provide the services our clients need. This is going to force people to explore strategic alliances, joint ventures, and consolidation. It's going to be harder and harder for agencies to survive when they are providing only one service."

# NOTES

1. Fauci AS (2011). AIDS: Let Science Inform Policy. *Science* 333:13.
2. AVAC, amfAR (2012). An Action Agenda to End AIDS. Available: <http://www.avac.org/ht/a/GetDocumentAction/i/44984>.
3. CDC (2012). HIV Incidence. Available: <http://www.cdc.gov/hiv/topics/surveillance/incidence.htm>.
4. CDC (2012). HIV among African Americans. Available: <http://www.cdc.gov/hiv/topics/aa/index.htm>.
5. Cohen MS et al. (2011). Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med* 365: 493-505.
6. Gardner EM et al. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis* 52: 793-800.
7. Hall HI et al. (2012). Continuum of HIV care: differences in care and treatment by sex and race/ethnicity in the United States. Presented at 2012 International AIDS Conference, Washington D.C. (USA), 22-27 July, oral abstract FRXB05.
8. Hall HI et al. (2012).
9. Millett GA et al. (2012). Comparisons of disparities and risks of HIV infection in black and other men who have sex with men in Canada, UK, and USA: a meta-analysis. *Lancet* 380:341-348.
10. Henry J. Kaiser Family Foundation (2012). U.S. Federal Funding for HIV/AIDS: The President's FY2013 Budget Request. Available: <http://www.kff.org/hiv/aids/upload/7029-08.pdf>.
11. Schackman BR et al. (2006). The lifetime cost of current human immunodeficiency virus care in the United States. *Med Care* 44:990-997.
12. Henry J. Kaiser Family Foundation (2012). Fact Sheet: Black Americans and HIV/AIDS. Available: <http://www.kff.org/hiv/aids/upload/6089-10.pdf>.
13. White House (2010). National HIV/AIDS Strategy for the United States. Available: <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>.
14. Bureau of Labor Statistics (2013). Economic News Release: Employment status of the civilian population by race, sex and age. Available: <http://www.bls.gov/news.release/empsit.t02.htm>.
15. U.S. Census Bureau (2011). Overview of the Uninsured in the United States: A Summary of the 2011 Current Population Survey. Available: <http://aspe.hhs.gov/health/reports/2011/cpshealthins2011/ib.shtml>.
16. CDC (2012). HIV in the United States: The Stages of Care. Available: <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.
17. Sullivan PS et al. (2011). Time to first annual HIV care visit and associated factors for patients in care for HIV infection in 10 US cities. *AIDS Care* 23:1314-1320.
18. Crowley JS, Kates J (2012). The Affordable Care Act, the Supreme Court, and HIV: What are the Implications? Henry J. Kaiser Family Foundation. Available: <http://www.kff.org/hiv/aids/upload/8363.pdf>.
19. Kohn J (2012). The South is the epicenter of new HIV infections in the United States. *Washington Post*. July 20. Available: [http://articles.washingtonpost.com/2012-07-20/news/35486202\\_1\\_hiv-infections-jonathan-mermin-aids-prevention-division](http://articles.washingtonpost.com/2012-07-20/news/35486202_1_hiv-infections-jonathan-mermin-aids-prevention-division).
20. Department of Health and Human Services (2010). Federal Financial Participation in State Assistance Expenditures. *Federal Register*, Nov. 20. 75:69082-69084.
21. NeighborhoodInfo DC (2012). DC 2012 Ward Profile: Ward 7. Available: [http://www.neighborhoodinfodc.org/wards/nbr\\_prof\\_wrd7.html](http://www.neighborhoodinfodc.org/wards/nbr_prof_wrd7.html).
22. Henry J. Kaiser Family Foundation (2012). Fact Sheet: The HIV/AIDS Epidemic in Washington, D.C. Available: <http://www.kff.org/hiv/aids/upload/8335.pdf>.
23. Gardner EM et al. (2011). The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. *Clin Infect Dis* 52:793-800.
24. New York City Department of Health and Mental Hygiene (2011). HIV Epidemiology & Field Services Seminannual Report, Vol. 6, No. 2. Available: [http://www.nyc.gov/html/doh/downloads/pdf/dires/2011\\_2nd\\_semi\\_rpt.pdf](http://www.nyc.gov/html/doh/downloads/pdf/dires/2011_2nd_semi_rpt.pdf).

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