

# BLACK AIDS INSTITUTE

## THE STATE OF HEALTHCARE ACCESS IN BLACK AMERICA

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The Black AIDS Institute, founded in 1999, is the only national HIV/AIDS think tank in the United States focused exclusively on Black people. The Institute's mission is to stop the AIDS pandemic in Black communities by engaging and mobilizing Black leaders, institutions, and individuals in efforts to confront HIV. The Institute 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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Ver. 1.1

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# RANIYAH COPELAND A NEW FAMILY MEMBER PROVIDES A REMINDER OF WHY THE ACA IS SO IMPORTANT

In April 2017, Raniyah Copeland and her husband Bryce rejoiced at the birth of their second son, Aidan.

Their three-year-old son, Ahmad, is so thrilled to have a brother that he insists on helping Raniyah and Bryce with caring for Aidan.

Aidan's birth reminds Raniyah how lucky she is. As she and her family have good private health insurance, she knows that Aidan will have the healthcare he needs in his early months of life.



As Director of Programs at the Black AIDS Institute, Raniyah receives excellent health coverage through BAI's plan. "One of the huge perks of my job is my health plan," she says. "It's a Cadillac plan, and it's amazing that I don't have to pay for my health plan out of every pay check. The Black AIDS Institute's culture prioritizes healthcare for all of our employees."

Bryce works in the financial end of a major entertainment studio in Los Angeles. Ahmad and Aidan are covered under Bryce's plan because it has a lower cost for adding dependents. However, co-pays for the boys' healthcare can be considerable, Raniyah reports.

"For me, having kids is a life-changing experience—sometimes traumatizing, but also beautiful. Having children is the hardest but also best thing that Bryce and I have ever done. The challenges presented by parenthood make you grow and test

your patience. These kids are a physical and emotional manifestation of the two of us, and I'm incredibly grateful for them. Having two little Black boys is something I treasure. We're a family now!"

But the experience of having a family has also made Raniyah think about health coverage in new ways. "One thing you don't want to have to think about is having a sick child and worrying what that might mean," she says.

Aidan was born with jaundice, which required intensive care for the first week of his life. He's fine now, because he was able to receive the care he needed. "I can't imagine what it would mean if we hadn't been able to pay for that care," Raniyah says.

Raniyah and her family also experience first-hand the benefits of the ACA. When Aidan was born, before the ACA had been fully implemented, Raniyah was forced to pay the considerable cost for a breast pump, because her insurance plan didn't cover it at the time. "But with Obamacare, the pump was covered!" she said. "To think about these things being rolled back is disappointing and scary."

Although Raniyah was in the third trimester of pregnancy when the healthcare debate was heating up in Washington, she nevertheless followed it closely. And she wasn't pleased with what she heard.

"As a woman, what I heard is a long line of attacks against me, whether it is about when and whether I want to have children. I'm appalled that other people are saying what I can and can't do with my body. It's as if who I am is a pre-existing condition because of my gender.

"I can't stress how important health coverage is—for individuals and for us as a community. Healthcare is a right we all deserve. It is disheartening to see something so fundamental turned into a political ploy. Preserving the ACA is how the Black community stays alive and keeps our legacy moving forward."

# ACCESS DENIED

## THE STATE OF HEALTHCARE ACCESS IN BLACK AMERICA

By Phill Wilson  
President and CEO  
Black AIDS Institute

In late July, efforts by Republican leaders to snatch healthcare access from millions of Americans was stymied in the most dramatic fashion possible when Senator John McCain of Arizona walked up to the front of the Senate floor and with a thumbs-down motion effectively killing the Affordable Care Act “skinny repeal” bill. This temporary reprieve for the ACA by the thinnest of margins highlights how vulnerable healthcare access in this country is for millions of Americans, including those living with or at risk of HIV, and especially Black communities. The foundering of these ACA repeal efforts means we have dodged a bullet, but the threat to healthcare access remains real and ongoing.

With all the intense scrutiny and media attention on efforts to “repeal and replace,” and eventually just to repeal, the ACA on the part of the Trump Administration and the Republican Congressional leadership, there has been scant discourse on the specific and unique impact diminishing or repealing the ACA would have on Black communities.

### A Vital, Necessary Report

This report provides an update on where we are in efforts to repeal and/or replace the ACA; provides a primer for Black communities on the ACA with the aim of closing knowledge gaps about the ACA and dispelling myths and misunderstandings about the program; and finally, introduces a strategy to begin to lay the ground

work for increasing healthcare access knowledge, and building the infrastructure and capacity in Black communities to respond to the current and future attacks on healthcare access.

### Milestones in Jeopardy

The fight against AIDS in the U.S. has included important turning points in national policy—the courageous decision by former Surgeon General C. Everett Koop in the 1980s to circulate a frank AIDS awareness pamphlet to every American household; the establishment of the first Presidential AIDS Commission; the enactment of the Ryan White Care Act; the creation of the Office of AIDS Research at the National Institutes of Health; the launch of the Minority AIDS Initiative; the creation of the White House Office of National AIDS Policy; and the authorization of the National HIV/AIDS Strategy. Yet throughout the entire history of the AIDS fight in this country, few milestones stand taller than the enactment in March 2010 of the ACA (popularly and appropriately known as Obamacare).

After routinely relying on emergency rooms for basic care, or just going without, many Black Americans do not fully comprehend the value of preventive care or supportive services or how the ACA has expanded access to these services. People who, in the past, could only afford bare-bones coverage through insurance risk pools may not understand the essential benefits to which they

are entitled under the ACA. Many Black Americans remain unaware of the availability of subsidies for the purchase of insurance or of the difference between Medicaid and Medicare. Few people in the U.S. truly understand how the ACA is funded, how it fits together, and how removal of particular aspects of the legislation would affect the financial viability of the program as a whole.

If the current administration is successful in undermining the ACA through executive order, legislative or regulatory action, the power of the appropriation process, or active negligence in administering the program, healthcare in Black communities will take a devastating hit and any hope of ending the HIV epidemic in our lifetimes will be lost.

Recognizing the urgency of the matter, the Black AIDS Institute proposes to facilitate a national call to action that raises awareness, educates, and mobilizes Black communities to respond to the changing environment.

## A Living, Collaborative Process

This report is a living, iterative work in progress. As the debate on the future of the ACA and healthcare access evolves, the report will evolve as well to address the issues, challenges and proposals that emerge.

To develop the report, the Black AIDS Institute, our partners and steering committee analyzed information from a broad variety of sources, including datasets and authoritative reports. In addition, the writer, advisors, and editors drew on scientific modeling and analyses from experts working in diverse institutions, including the Henry J. Kaiser Family Foundation, Johns Hopkins Bloomberg School of Public Health, George Washington University's Milken Institute of Public Health, Harvard University's Center for Health Law and Policy Innovation, the National Health Law Program, the Center on Budget and Policy Priorities, National Black

Justice Coalition, and Georgetown University's O'Neill Institute for National and Global Health Law.

As is always the case in our reports, "The State of Healthcare Access in Black America" is designed to be particularly accessible to Black people. It is written and designed with us in mind. The only way to assure that our interests are included is for us to be engaged and involved in the process. Our own health, and the health of our households and communities, is our business.

## An Initiative that Looks to the Future

This report is a part of a larger Institute-led healthcare access initiative being launched by a coalition of HIV/AIDS organizations and advocates. This initiative is designed to identify, recruit, train, mobilize, and activate a national network of motivated Black advocates, activists, thought influencers, and policy makers prepared and equipped to play a robust role in resisting the current efforts to repeal and replace the Affordable Care Act and efforts to undermine healthcare access through administrative, regulatory, or appropriation processes that might take place in the future.

It is not going to be easy. The deck is stacked against us. Our own President wants to pull the security afforded by the ACA out from under us.

But together we can win this fight. To do so, we'll have to bring our best game. Let's get to it.

Yours in the Struggle



Phill Wilson



# BLACK AMERICA AND THE THREAT TO THE ACA

## HEALTHCARE ACCESS REMAINS IN JEOPARDY

The national healthcare debate that has unfolded in Washington D.C. over the last several months has generated anxiety from one end of America to the other. As the racial and ethnic group that stands to lose the most from the repeal of the Patient Protection and Affordable Care Act (ACA), commonly referred to as Obamacare, Black Americans have had particular cause to be concerned.

Thus far, efforts to repeal and/or replace the ACA have stumbled on Capitol Hill, and Senate and House leaders have taken discussions regarding the future of America's healthcare system out of the public's view. But the threat to healthcare coverage for millions of Americans is not over. The peril facing the ACA is only dormant and almost certain to return. Indeed, the Trump Administration, regardless of whether Congress takes action, has threatened to severely weaken the insurance market through regulatory decisions, effectively undermining the ACA even if the repeal of Obamacare lacks the votes in Congress.

Media coverage of the ongoing push to repeal the ACA has focused considerable attention on various technical issues and on the political jockeying in Washington. But, in truth, there is only one reason why Congress has thus far failed to repeal the ACA: In the face of a profound threat to basic healthcare access, Americans made their voices heard. As Americans have become more informed about the ACA during this year's healthcare debates,



## Key Messages

■ For Black Americans, passage of the ACA represented a critical step in our long, far-from-complete national journey toward realizing the Constitution's vision of equal opportunity for all.

■ The ACA has cut the number of uninsured Black Americans in half. An additional 2.1 million Black Americans now have health coverage as a result of the ACA. Today, for the first time, the uninsured rate among Black Americans is roughly equivalent to the Black share of the national population.

■ Although efforts to repeal the ACA have not succeeded to date, the threat to healthcare access remains real, as ACA opponents have vowed to return to the issue in the future. In the meantime, the Trump Administration is slashing funding to facilitate insurance enrollment through the ACA and studying possible regulatory steps to weaken the program.

■ Efforts to repeal, replace or radically weaken the ACA threaten to roll back health gains for Black Americans, including progress in narrowing the life expectancy gap between Black and white people. Repeal of the ACA would increase the number of uninsured Americans by 15 million to 24 million and result in the needless deaths of up to 10,000 Black Americans each year.

■ The ACA's prioritization of preventive services has enormously enhanced the ability of Black America to combat diseases that disproportionately affect Black people, including many cancers, HIV, cardiovascular disease and diabetes. The majority of Black people who have obtained coverage as a result of the ACA say they are using preventive health services that would otherwise have been unaffordable.

■ For the sake of Black America and all other Americans, Congress and the Administration should focus on improving, rather than scrapping, the ACA.

■ Across the country, Black communities urgently need to mobilize to educate community members about the critical importance of the ACA and advocate with their elected officials to combat any threat to expanded healthcare access.

■ The foundering of ACA repeal efforts thus far also presents potentially transformative opportunities. In states that have yet to expand Medicaid as provided under the ACA, Black activists should join with other state and local partners to encourage their governors and legislators to expand Medicaid.

they have learned to love the ACA. In August 2017, a majority of Americans had a favorable view of Obamacare, with the number of ACA supporters (52%) substantially outweighing ACA opponents (39%).<sup>1</sup> Nearly 4 out of 5 Americans now want the Trump Administration to try to make the ACA work rather than make good on its threats to undermine the program.<sup>2</sup>

There is good reason for this outpouring of support for the ACA, as the program has driven the percentage of Americans with health insurance to record highs.<sup>3</sup> As a result of expanded healthcare access under the ACA, tens of thousands of deaths are averted each year.<sup>4</sup>

Of all racial and ethnic groups in the United States, none has benefited from the ACA more than Black America. The proportion of Black Americans without health insurance has been cut almost in half as a result of the ACA, and the insurance coverage gap between Black and white Americans, once enormous, has been radically reduced.<sup>4</sup> The ACA is helping continue and quicken the reduction in disparities in life expectancy between Black and white Americans. As a result of expanded access to care under the ACA, Black America now has the means to more effectively manage health problems that have disproportionately affected Black communities, such as HIV, hypertension, cancer, diabetes and infant mortality. The ACA represents an important step in our country's still-incomplete journey towards the vision of equal opportunity for all

enshrined in our Constitution.

This report speaks to Black America. It encourages vigilance in the face of continuing threats to the ACA. The voices of diverse communities need to be amplified in the coming months. Already, the Trump Administration's undermining of the ACA has destabilized insurance markets, increasing the cost of insurance premiums and reducing coverage options for consumers in many parts of the country. As the Trump Administration's hostility towards the ACA diminishes the efforts of the federal government to attract new ACA enrollees, Black communities need to step into the breach, educating fellow community members about health coverage available under the ACA and developing community-centered strategies to facilitate enrollment.

But the failure thus far of ACA repeal efforts also presents critical new opportunities, and this report addresses these as well. In particular, states that have thus far refused to expand Medicaid may now be willing to reconsider, especially as the federal government foots the vast majority of expansion costs. This opportunity is especially important in the South, where only two states have expanded Medicaid under the ACA.

One of the most noteworthy characteristics of our national healthcare debate this year has been the relative absence of a focus on the needs of Black America. Politicians and the media have closely examined the potential impact of anti-ACA efforts on numerous constituencies, including the insurance and pharmaceutical industries, the chronically ill, and working-class white people. Yet much less attention has focused on Black Americans, who have disproportionately experienced the gaps and ills of our healthcare system. This report seeks to correct this gap by clearly and indisputably describing why the continuation and strengthening of the ACA is an imperative for Black America.

As the fight for healthcare access will be ongoing in the coming months and years, *this report will be a living document*. As developments occur and new threats and opportunities

arise, the report will be revised so that advocates, community leaders and other stakeholders have ready access to the latest information on the ACA's future.

## America's Healthcare System: Who is Covered and Who Pays

Health coverage in the U.S. involves a mix of private and public sector approaches.

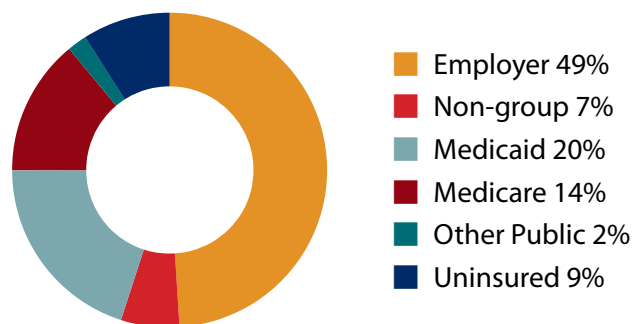
■ **Private Health Insurance:** Employer-based coverage remains the largest source of health coverage (Figure 1). Over the last two decades, however, the percentage of employers offering health coverage to workers has declined.<sup>5</sup> In addition, as experience in the recent Great Recession underscores, increases in unemployment and under-employment (part-time workers, seasonal workers, and contract workers) inevitably lead to increases in the number of uninsured, as job loss usually means loss of health insurance. Compared to those with employer-based coverage, a smaller proportion of consumers purchase private insurance on their own, in what is known as the non-group, or individual, market.

■ **Medicaid:** Medicaid covers more than 70 million Americans and is the primary source of coverage for nursing home and long-term care.<sup>6</sup> Designed to address the needs of low-income Americans, Medicaid is co-financed by the federal government and the individual states and the District of Columbia, with states retaining substantial flexibility in how they structure and administer the program.

■ **Medicare:** More than 55.5 million people look to Medicare for health coverage. Medicare, funded and operated by the federal government, primarily serves elderly people as well as people with disabilities.

■ **Other Payers:** A small fraction of Americans depend on other programs that provide health services. These include the Veterans Affairs Administration, Indian Health Services and federal and state correctional systems.

**Figure 1. Source of health coverage in the United States, 2015**



Source: Henry J. Kaiser Family Foundation





## Basic Facts About the ACA

It's frequently been said that the ACA functions as a three-legged stool.

■ **First leg—*Guaranteed Issuance*:** Under the ACA, everyone who pays his or her premiums must be enrolled by an insurance carrier, regardless of the individual's medical history. All insurance policies must meet basic standards and provide a standard package of health services.

■ **Second leg—*Individual Mandate*:** Every person is required to have health coverage. This helps ensure that younger, healthier people don't wait until they get sick to obtain health insurance, which in turn spreads the financial risks associated with illness across as broad and diverse a pool as possible. For individuals in need of health insurance, the ACA authorizes health insurance marketplaces that allow consumers to compare plans and select the one that is right them.

■ **Third leg—*Subsidies*:** Recognizing that the market price for health insurance is beyond the means of many households, the ACA uses the tax system to provide incentives to lower-income people to buy coverage. The ACA also provides subsidies to health insurers to compensate them for limiting out-of-pocket costs for lower-income households.

Just as a stool collapses if one of its legs fails, the ACA cannot function as intended if one or more of its key components is lost or undermined. As just one example, requiring health insurers to offer coverage to individuals with pre-existing conditions (first leg) will prove untenable without the individual mandate (second leg), as young, healthier people will be less likely to purchase insurance in the absence of the mandate, which in turn will make risk pools sicker overall and lead to spiraling increases in insurance premiums for remaining consumers.



## The Threat to the ACA: Where We Stand

This report went to press in early September 2017, only weeks after the ACA survived repeal by the narrowest of margins.

In neither the House nor the Senate were public hearings held this year to examine the wisdom of repealing the ACA. Yet, in each house of Congress, the leadership made a determined effort to end a program that has vastly expanded health coverage. In both the House and Senate, members were asked to vote on legislation many had not read, let alone digested, analyzed and discussed with their constituents.

One of the most damning statements on the push to repeal the ACA is the opposition to repeal of virtually every major medical, public health and consumer group. In short, almost no one who is involved in the delivery of health services supported repeal of the ACA.

In May 2017, after failing the first time to muster a majority of members in favor of ACA repeal, the House of Representatives voted by a narrow margin—217-213—to pass the American Health Care Act, which dismantled key provisions of the ACA, including the Medicaid expansion.



Even though the Congressional Budget Office had determined that the bill would increase the number of uninsured Americans by more than 20 million, President Trump celebrated House passage in a Rose Garden ceremony, calling the legislation “a great bill.”

Recognizing that the House bill to dismantle the ACA was deeply unpopular—with only about 1 in 5 Americans expressing support for the legislation—the Senate determined to start from scratch and write its own legislation. Senate Majority Leader Mitch McConnell (R-KY) assembled a working group of Republican Senators—all white men—to draft, in secret and without hearings, a Senate bill that could obtain at least 50 votes (as Vice President Mike Pence, in his role presiding over the Senate, would be available to break any 50-50 tie vote in favor of the Republican bill).

Despite the Senate’s expressed desire to start fresh in drafting health-care legislation, what emerged in the Senate was functionally similar to the discredited House bill. The Congressional Budget Office determined that the Senate legislation would, like the House-passed American Health Care Act, vastly increase the number of uninsured Americans.

A remarkable national revolt, uniting Democrats and Republicans, greeted the original Senate proposal. Governors and Senators from both sides of the aisle sharply criticized the Senate bill, including its repeal of the ACA’s Medicaid expansion. Senator Susan Collins (R-ME), for example, said the bill was “unacceptable.”

Eventually, the Senate considered and rejected a series of proposals to dismantle the ACA, failing in each instance to assemble a majority in favor of repeal. Finally, the Senate took up the leadership’s last-ditch effort—a “skinny repeal” that would repeal the ACA but not provide a replacement. That bill failed in the early morning hours of July 27, when Senator John McCain (R-AZ) provided the decisive “no” vote.



After months of anxiety—when households wondered if their families would have health coverage—failure of ACA repeal efforts in the Senate generated an extraordinary sense of relief across the country. But the high drama of the last several months also leaves us with a disquieting realization: The future of health coverage for millions of Americans continues to hang by a thread. Key House and Senate members remain determined to roll back the ACA, and the death, disability or resignation of a single member of the Senate could revive efforts to cripple the ACA.

In the next Congress, the math could be even more dire for the ACA’s future. In the 2018 mid-term Congressional elections, Democrats will defend 23 Senate seats versus only 9 currently held by Republicans. Even a strong election result for the Democrats may not prevent the loss of one or more Senate seats, potentially delivering a majority of the Senate in favor of ACA repeal.

Moreover, through its control of the regulatory apparatus, the Trump administration has the potential to dismantle the ACA. Indeed, the President has expressed a desire to watch the ACA “collapse.” Especially concerning are questions regarding the Administration’s plans to continue subsidies to insurance companies to offset costs associated with low-income enrollees. Although the Administration has thus far continued making the payments to insurers, uncertainty regarding the availability of these access-enabling payments has contributed to increased insurance premiums in some states and reportedly even prompted some insurers to leave the individual insurance market.

Now, in other words, is not the time for celebration or even to draw comfort. Now is the time to educate, advocate, and mobilize against what is certain to be continued assaults on the ACA.



# HILARY BEARD

## HOW ACCESS TO HEALTH COVERAGE ALLOWED ONE WRITER TO FOLLOW HER DREAM

Being able to rely on having health insurance has allowed Hilary Beard to follow her dream—as an award-winning writer.

But now Hilary is worried that she and others like her are going to suffer badly if efforts to repeal or undermine the ACA eventually succeed.

Hilary is 55, single, and self-employed, and she has a pre-existing condition that might make her ineligible for coverage.



“When I was younger I took my health for granted,” Hilary says. “But now I’m 55.”

Like many other Americans, Hilary assumed that the ACA was permanent. Now she’s worried about whether she’ll be able to afford insurance if the ACA is repealed, especially as some repeal proposals would allow radically higher prices for older consumers.

“What if my health insurance bill goes up? I already decided to go down to a silver plan from a gold I had because the price went up. What if my bill now doubles [if the ACA is repealed?]”

For Hilary, the ability to afford health insurance has enabled her to live the life she loves. In the early years of her professional life, she was on a fast track with a major corporate job, but she wasn’t feeling especially fulfilled.

And she had always dreamed of being a writer.

“I was exploring myself spiritually and began wondering why I was given certain talents if I wasn’t using them. I did not want to look back on my life and say I never used these talents. I could live with finding that I couldn’t make a living with my talents, but I couldn’t live with not trying to find out.”

After her parents passed away, Hilary took “the plunge,” striking out on her own as a writer. Today, Hilary is nationally known for her writing work on health, education, parenting and psychology, and now she is working increasingly as a professional coach.

“I don’t think I would be comfortable being self-employed without knowing that I would have access to health insurance,” she said. “As a writer, I have been communicating information about how communities can be more healthy and empowered. Without knowing that I had access to health insurance, that information would not have made it out into the world, certainly not off my pad.”

After helping care for her parents in their last years and following the news in the years before the passage of the ACA, Hilary also learned how difficult it can be for many people to obtain the healthcare they need and deserve.

“In the run-up to Obamacare, I learned that many insurance policies weren’t worth the paper they were written on,” Hilary recalls. “At the time, I didn’t really know that truth from my own personal experience, because up to that time I really hadn’t needed my health insurance a lot. It was shocking and disconcerting to learn that your health insurance could prove to be worthless as soon as you need it.”

In 2017, Hilary, like tens of millions of other Americans, are wondering if proposed rollbacks of the ACA will once again make insurance worthless for many.

# THE ACA HAS BROUGHT HEALTH COVERAGE TO MILLIONS OF BLACK AMERICANS

WITHOUT THE ACA,  
COVERAGE LOSSES COULD  
CLAIM THE LIVES OF 10,000  
BLACK PEOPLE ANNUALLY

In 2011, prior to approval of the ACA, one in four adults in the United States lacked health coverage at some point during the year.<sup>7</sup>

Immediately before passage of the ACA, 26.2% of Black adults lacked health coverage, compared to 16.1% of white adults.<sup>7</sup>

Black Americans' disproportionate struggle to obtain health coverage stems in large part from economic inequalities and lack of job opportunities, as health coverage is closely associated with household income.<sup>7</sup> Black people are more than 2.5 times as likely to be living in poverty as white people.<sup>8</sup> The unemployment rate among Black Americans is twice as high as among whites.<sup>9</sup> While the median adjusted income for white-headed households in 2014 was \$71,300, the median for Black-headed households was only \$43,300.<sup>10</sup> When it comes to wealth—i.e., the inter-generational accumulation of assets—the disparity is even starker, with the net worth of white-headed households roughly 13 times greater than for Black-headed households.<sup>10</sup>

The ACA has helped transcend the country's legacy of economic inequality, sharply reducing the ranks of the uninsured and ensuring a more solid foundation for households of lesser means. From 2010 to 2016, the number of people lacking health insurance declined by more than 20 million.<sup>3</sup> At no time in American history has such a sudden reduction in the number of uninsured occurred (Figure 2).<sup>11</sup> Today, as a result of advances under the ACA, more than 90% of Americans have

health coverage.<sup>12</sup> Studies confirm that the ACA is responsible for this unprecedented decline in the percentage of Americans lacking health coverage.<sup>13</sup>

Coverage gains have been especially noteworthy in Black America. From 2013 to 2015, the proportion of Black adults (ages 19-64) lacking health coverage fell from 24% to 15%.<sup>14 15 3</sup> Extrapolating from Census Bureau data on the age distribution of the Black population in the U.S., this 9% reduction in the uninsured indicates that 2.1 million Black Americans who were previously uninsured now have health coverage as a result of the ACA. As Figure 3 illustrates, the fall in the proportion of uninsured households has been greater for Black Americans under the ACA than among whites. Three-quarters of Black people who obtained health coverage through an ACA marketplace or Medicaid expansion reported having used this coverage to access health services, with 6 out of 10 saying they would not have been able to afford such services without the ACA.<sup>16</sup>

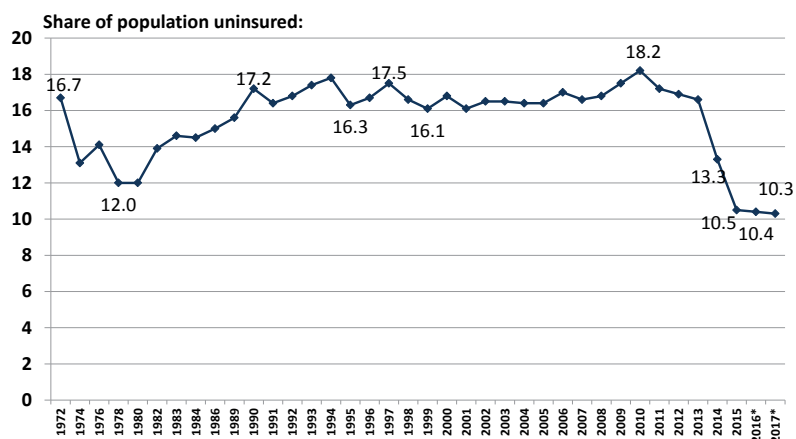
Since 2010, the proportion of Black Americans who are uninsured has been cut almost in half (Figure 6). Increases in insurance coverage have been especially marked for lower-income Black households (annual income under \$48,500), with the proportion of uninsured among these households falling from 31% in 2010 to 14% in 2016.<sup>17</sup>

Coverage gains are helping overcome historic disparities in health access. Today, the proportion of Black people among the uninsured population is equivalent to (or, according to some surveys, even below) the Black share of the U.S. population as a whole.<sup>18</sup> In short, the ACA is likely the most important single piece of legislation for Black America since the civil rights bills of the mid-1960s.

## How the ACA Expanded Health Coverage

The ACA has enhanced health coverage for Black Americans by

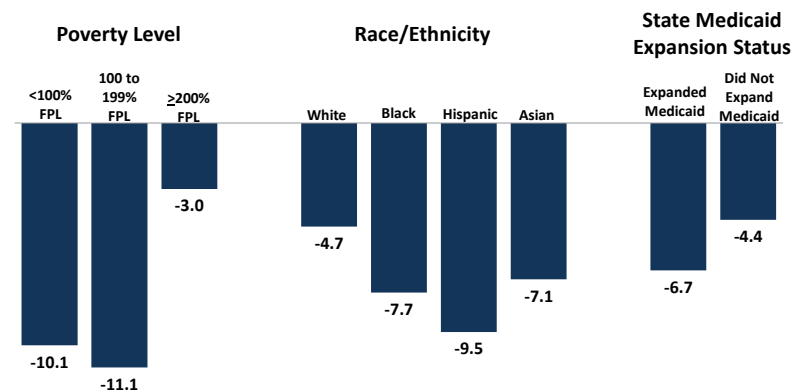
**Figure 2. Uninsured rate among the nonelderly population, 1972-2017\***



NOTE: 2017 data is for Q1 only. SOURCE: CDC/NCHS, National Health Interview Survey, reported in [http://www.cdc.gov/nchs/health\\_policy/trends\\_hc\\_1968\\_2011.htm#table01](http://www.cdc.gov/nchs/health_policy/trends_hc_1968_2011.htm#table01) and <https://www.cdc.gov/nchs/data/nhis/earlyrelease/insur201708.pdf>.



**Figure 3. Percentage point change in uninsured rate among the nonelderly population by selected characteristics, 2013-2015**



NOTE: Indiana, New Hampshire and Pennsylvania are included as non-expansion states during 2013 and 2014 and as expansion states in 2015. SOURCE: Cohen RA, Martinez ME, Zammit EP. Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, 2015. National Center for Health Statistics. May 2016. Available from: <http://www.cdc.gov/nchs/data/nhis/earlyrelease/insur201605.pdf>.



affecting two key components of the health financing system.

### Expanding Access to Private Insurance

First, the ACA has made private health insurance more accessible. The ACA requires employers with at least 50 full-time workers to provide health coverage. For individuals lacking access to health coverage through their jobs, the ACA provides credits

to individuals and households under 400% of the federal poverty line (\$98,400 for a family of four in 2017, or \$48,240 for a single person) for the purchase of health insurance through the marketplaces. These refundable tax credits can be paid directly to the insurance company, reducing the premium that lower-income households must pay. Maximum premium contributions are geared to a sliding scale based on household

# Black America and the South

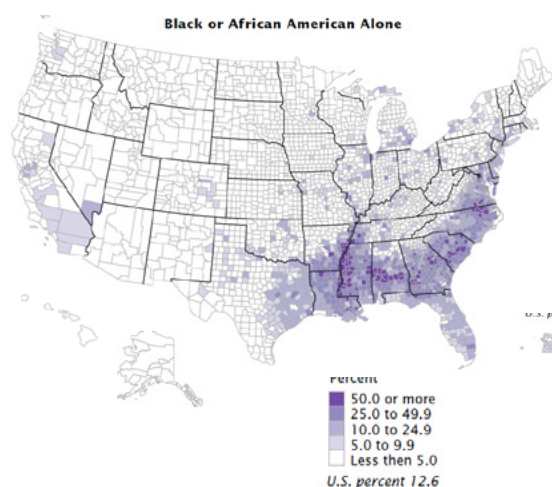
Like America itself, Black America stretches from Maine to Alaska and Hawaii. But its heaviest concentration is in the South (Figure 4). Most (55%) Black people in the U.S. live in the South, and Black people comprise a majority of the population in 105 counties in the South.<sup>39</sup> Nationally, of the 317 counties in which Black people make up 25% to 49.9% of the population, the South accounts for all but 17.<sup>39</sup>

Moreover, this concentration of the Black population in the South is increasing over time. While the proportion of Black people among the population either declined or stayed the same from 2000 to 2010 in the Midwest, Northeast and West, it increased in the South.<sup>40</sup>

Unfortunately, the South is also home to some of the weakest health safety nets in the country. When the millions of low-income Black people living in the South need health services, they find far too often that few, if any, affordable services are available.

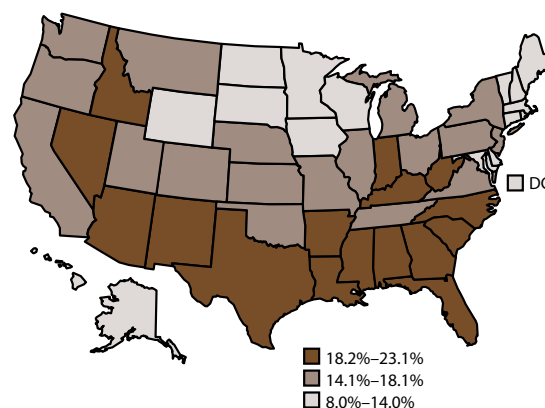
In every state in the South, the proportion of the population with health coverage is lower than the national median.<sup>41</sup> To date, all but two Southern states have opted not to expand Medicaid under the ACA. Nationally, the South is home to 90% of people who fallen into a “coverage gap” due to their states’ failure to expand Medicaid.<sup>42</sup> Not surprisingly, across the South, cost is a common barrier to healthcare access (Figure 5).<sup>41</sup>

**Figure 4. Black or African American population as a percent of country population, 2010**



For information on confidentiality protection, nonsampling error, and definitions, see [www.census.gov/prod/cen2010/doc/p194.pdf](http://www.census.gov/prod/cen2010/doc/p194.pdf)

**Figure 5. Age-standardized\* prevalence estimates of cost barrier to healthcare need during preceding 12 months† among adults aged 18-64, Behavioral Risk Factor Surveillance System, United States,§ 2014**



Abbreviation: DC = District of Columbia

\*Age standardized to the 2000 projected population for the United States.

†Survey question used to access cost barrier to healthcare need during preceding 12 months: Was there a time in the past 12 months when you needed to see a doctor but could not because of cost?

§States are divided into tertiles.

income. Subsidies are also available, on a sliding scale, to reduce cost-sharing for households of moderate income.

Black Americans account for 14% of people enrolled in private marketplace plans—a proportion greater than their share of the national population (13%).<sup>18</sup> From 2012 to 2014, the proportion of Black people living

with HIV who were privately insured rose from 21% to 25%.<sup>19</sup>

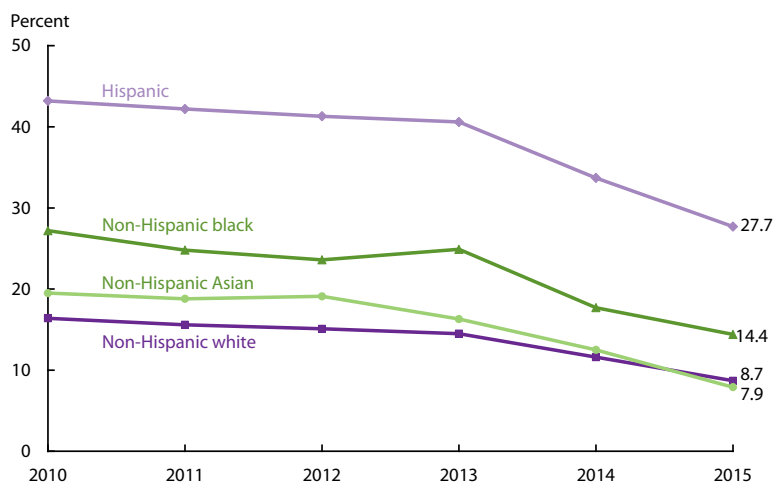
## Expanding Medicaid

The second means by which the ACA has increased health coverage is by expanding Medicaid eligibility to cover all persons with incomes under 138% of the federal poverty line (\$33,948 for a family of four in 2017,

or \$16,642 for a single person). This expansion replaced the program’s earlier approach that limited Medicaid eligibility to specific categories (pregnant women, children, people with disabilities, parents of dependent children, and people aged 65 and older). In the pre-ACA era, non-disabled single-adults were in large measure effectively excluded from



**Figure 6. Percentage of adults aged 18-64 who were uninsured at the time of interview, by race and ethnicity, U.S., 2010-2015**



NOTE: Data are based on household interviews of a sample of the civilian noninstitutionalized population. SOURCE: NCHS, National Health Interview Survey, 2010-2015, Family Care component.

participating in the Medicaid program and as a result often unable to access healthcare.

Under the ACA, the number of Americans benefiting from Medicaid has risen from 56.8 million prior to the ACA to 74.6 million as of March 2017.<sup>20</sup> Specifically as a result of the ACA's

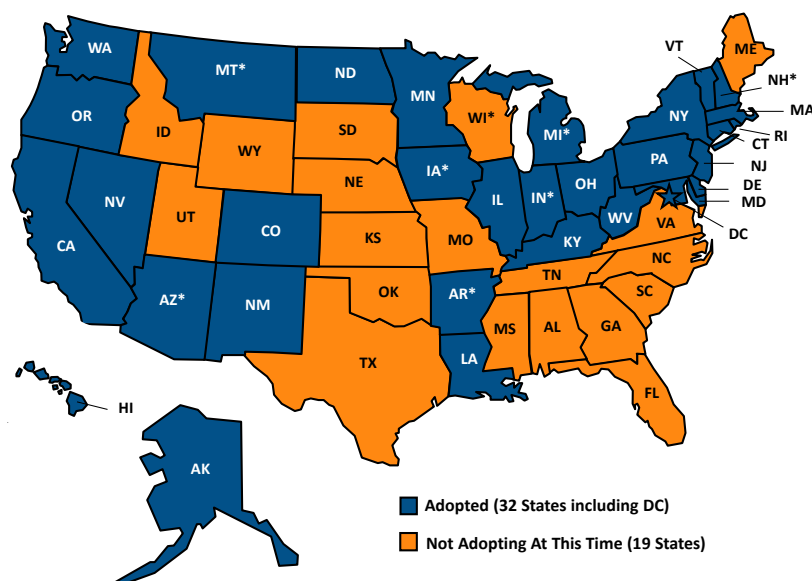
Medicaid expansion, an additional 12 million people who were previously uninsured now have health coverage.<sup>21</sup> From 2013 to 2015, the proportion of low-income, childless adults who lacked health coverage declined from 45.4% to 16.5% in states that expanded Medicaid.<sup>22</sup>

Although white Americans account for the largest proportion of nonelderly Medicaid recipients (42% in 2015, the last year for which comprehensive demographic information is available), Black people represent 19% of nonelderly Medicaid recipients.<sup>23</sup> More than 14 million Black people in the United States currently depend on Medicaid for healthcare.

As enacted, the ACA required all states to expand Medicaid in the manner outlined in the law, with the federal government footing 100% of the costs of this expansion in the early years of the ACA and 90% of costs in future years. However, in 2012, the Supreme Court held that states had the right to opt out of the Medicaid expansion. In 2017, 31 states and District of Columbia have opted to expand Medicaid under the ACA, while 19 states have declined (Figure 7). Had all states expanded Medicaid as originally intended by the ACA, between 4.3 million and 5.2 million additional people who currently lack health coverage would today have coverage.<sup>24</sup>



**Figure 7. Current status of state Medicaid expansion decisions**



NOTES: Current status for each state is based on KCMU tracking and analysis of state executive activity. \*AR, AZ, IA, IN, MI, MT, and NH have approved Section 1115 waivers. WI covers adults up to 100% FPL in Medicaid, but did not adopt the ACA expansion.

SOURCE: "Status of State Action on the Medicaid Expansion Decision," KFF State Health Facts, updated January 1, 2017.

<http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act>



## ACA Repeal Would Result in the Needless Deaths of Up to 10,000 Black Americans Each Year

For Black Americans, as for all others, lack of health coverage leads to preventable illness and death. People who lack health coverage are seven times as likely as the insured to forgo health services they need.<sup>30</sup> By contrast, expanded health coverage encourages consumers to avail themselves of needed health services, including preventive care that can prevent a health problem from worsening and avert expensive health spending down the road. From 2013 to 2015, as the ACA was implemented, the share of adults reporting having avoided a needed visit to the doctor due to costs declined in 38 states and the District of Columbia.<sup>15</sup>

If the ACA is repealed, up to 93,000 additional deaths will occur in 2019 alone due to the loss of health coverage now guaranteed under the ACA.<sup>4</sup> As Black Americans need health services the most and have benefited the most from the ACA's coverage expansion, it is certain that Black people will

## Why Vigilance Against ACA Repeal Efforts Is Essential: Without the ACA, Millions of Currently Insured Black Americans Will Lose Health Coverage

Proposals to repeal, replace or radically weaken the ACA would roll back one of the most important achievements in Black America's long struggle for civil rights and equal opportunity. These proposals would enact radical changes to the two main drivers of increased health coverage under the ACA—the private insurance market and Medicaid expansion.

### ACA Repeal Would Vastly Increase the Ranks of the Uninsured in Black America

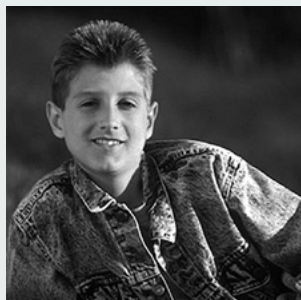
The proposals offered to date by ACA opponents would result in a cata-

strophic reduction in health coverage. The Congressional Budget Office estimates that various approaches to the repeal of the ACA offered by Republicans in the House and Senate would increase the number of uninsured by between 15 million and 26 million over the next decade.<sup>25 26 27</sup> These proposals wouldn't merely erase the gains made under the ACA, but would actually cause the number of uninsured to be higher in 2019 than it was when the ACA was first adopted.<sup>28</sup>

Repeal of the ACA would have especially acute effects in many states with large Black populations. For example, in South Carolina, where nearly 30% of the population is Black, removal of the ACA's protections will increase the number of uninsured by more than 58%.<sup>29</sup> In South Carolina alone, repeal or replacement of the ACA would cause 82,000 Black people who are presently insured to lose health coverage, including 6,000 Black children.<sup>29</sup>



# The Enduring Importance of Ryan White and Other Safety-net Programs



In addition to the publicly funded health programs that cover more than one in three Americans, various additional federal programs are also in place to address specific health challenges. One of these is the Ryan White HIV/AIDS Program, which has provided health and social services to people living with HIV for about 25 years. Creation of Ryan White reflected Congressional recognition that HIV is not merely another disease but, as a communicable, life-threatening condition, a public health challenge that demands a tailored, intensified, holistic response.

Experience with Ryan White since passage of the ACA underscores the continuing importance of such specialized health initiatives, which have greater flexibility than entitlement programs or private insurance to provide services that help extend the reach and impact of health coverage. Under the ACA, utilization of Ryan White services has actually increased<sup>19</sup>, especially as numerous Ryan White providers have focused on assisting uninsured people living with HIV in accessing coverage available under the ACA. Even as health coverage has increased, Ryan White's flexibility to support innovative health-enhancing support has remained critical to the national response to AIDS.

represent a disproportionate share of these preventable deaths if the ACA is repealed. Extrapolating from the share of Black Americans among the newly insured as a result of the ACA, up to almost 10,000 Black Americans could die each year if the ACA's coverage expansions are repealed.

## ACA Repeal Would Devastate the Private Insurance Market

In the event that the ACA is repealed or catastrophically weakened, loss of coverage would affect both the privately insured and those who rely on Medicaid. For those who currently have private insurance, repeal of the ACA would have especially dire consequences in the individual (i.e., non-group) health insurance market<sup>31</sup>, which provides a lifeline for people who are self-employed, work part-time or work for small companies that are not legally required to offer health coverage to workers. Were the

ACA repealed, older consumers and those living in rural areas would likely experience marked increases in non-group insurance premiums.<sup>32</sup> Ending the ACA would over the next decade reduce the number of people with private health insurance by at least 6 million.

While the individual market would feel the greatest effects were the ACA to be repealed, people who rely on employer-based insurance would also be affected. By removing the requirement that companies provide their workers with health coverage, these proposals would renew and accelerate the long-term decline in employer-based coverage that occurred prior to the ACA. Likewise, removal of the ACA's caps on out-of-pocket costs and requirements for coverage of essential health benefits would inevitably diminish the value and meaningfulness of many employer-based plans.<sup>33</sup>

## ACA Repeal Would Visit Its Harshest Effects on the Poor and Most Vulnerable

One of the most damaging aspects of ACA repeal proposals would be the dismantling of the country's historic approach to Medicaid. Under proposals championed by the House and Senate leadership, Medicaid would no longer be an entitlement, but instead states would be given much broader discretion to structure program eligibility and benefits as they see fit. In place of the current Medicaid financing approach, which allows funding to grow as eligibility and needs increase, states would experience per capita limits on federal Medicaid support. Like block grants, proposed per capita limits primarily function as a strategy for drastically reducing funding for Medicaid.<sup>34</sup> For example, the per capita cap in the House-passed American Health Care Act would siphon \$880 million out of the Medicaid program over 10 years<sup>35</sup>.

In the face of the stark funding reductions that would result from per capita caps, states would have little choice but to sharply reduce Medicaid benefits and/or curtail Medicaid eligibility.<sup>36</sup> Reform proposals would permit states to withhold Medicaid from unemployed adults, impose more onerous income tests for eligibility, limit benefits, impose work requirements and require greater cost-sharing among Medicaid recipients. If implemented, these proposals would reduce the number of people receiving Medicaid by 14 million, or by 17%, effectively wiping out the gains in Medicaid coverage achieved under the ACA.<sup>35</sup> The leading proposals for a per capita Medicaid cap would ironically impose the most severe financial constraints on state Medicaid programs that are already the weakest, as prior spending per-enrollee is likely to be a key factor in establishing each state's per capita cap.<sup>37 38</sup> Already-bare-bones Medicaid programs, such as in Texas, will become even more parsimonious if these health reform proposals are signed into law.<sup>37</sup>

# THE ACA HAS MADE HEALTHCARE AFFORDABLE FOR MILLIONS OF BLACK AMERICANS

WITHOUT THE ACA,  
INSURANCE PREMIUMS WILL  
SOAR, HITTING POOR AND  
MODERATE-INCOME BLACK  
HOUSEHOLDS THE HARDEST

Healthcare costs more in the U.S. than in any other highly developed country.<sup>43</sup> In the pre-ACA era, the cost of health insurance was the primary reason people went without health coverage (Figure 8)<sup>44</sup> and the number one cause of personal bankruptcy.<sup>45</sup>

The ACA has eased consumers' financial difficulties associated with healthcare. Indeed, the reductions in insurance premiums under the ACA have exceeded original projections by the Congressional Budget Office (Figure 9).<sup>46</sup>

According to a national survey by the Commonwealth Fund, the number of adults having problems accessing needed care and filling prescriptions due to costs declined from 80 million in 2012 to 63 million in 2016.<sup>17</sup>

## How the ACA Made Health Coverage More Affordable

The ACA includes several measures to enhance the affordability of healthcare:

■ *Medicaid Expansion:* By expanding Medicaid, the ACA reduced out-of-pocket spending among low-income Americans.<sup>47</sup> Whereas prior to the ACA millions of low-income Black Americans who could not afford private health insurance were also excluded from Medicaid, the ACA opens the door to comprehensive health coverage for poor and near-poor households.

■ *Subsidies for the Purchase of Insurance:* The ACA offers credits to consumers of modest incomes (from



133% to 400% of the federal poverty line) to help with the purchase of health insurance in the marketplaces.

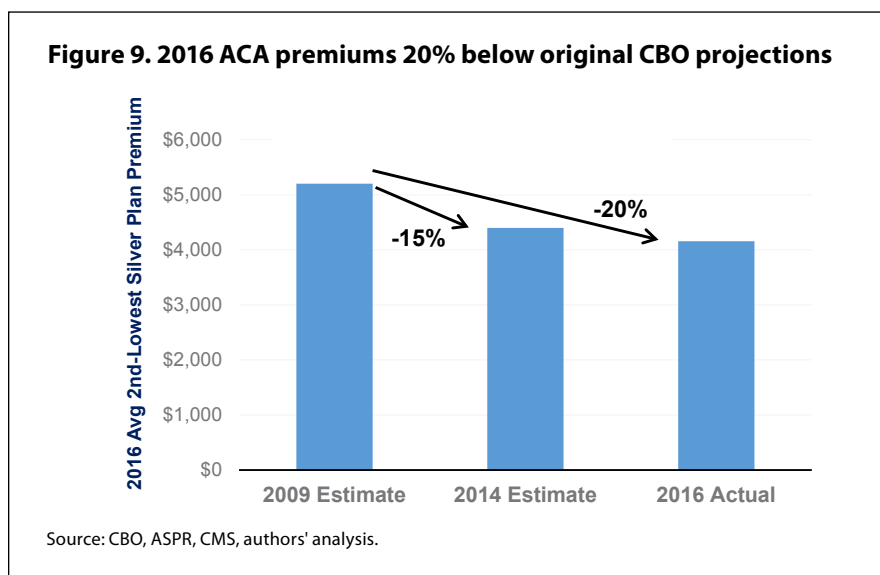
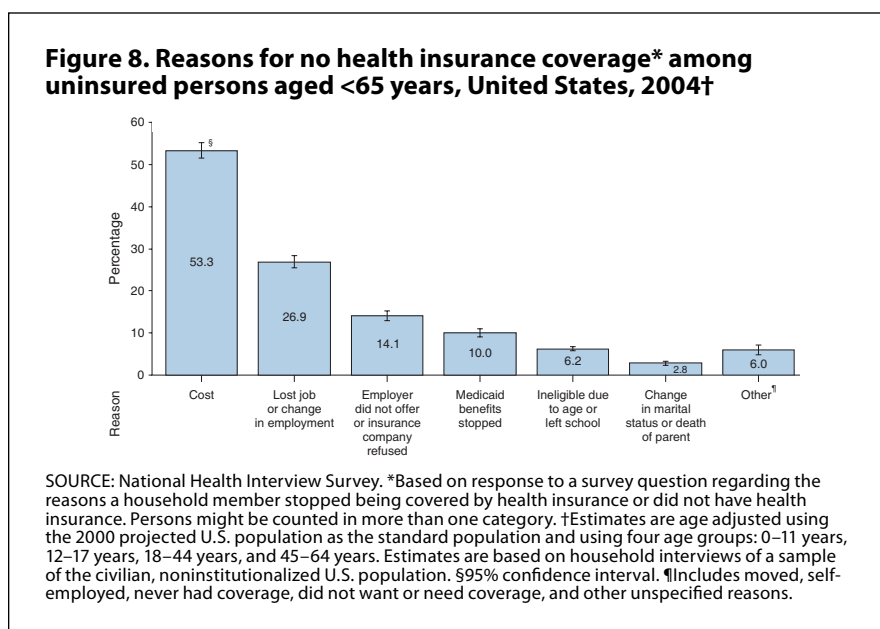
■ **Caps on Out-of-Pocket Costs:** Consumers' out-of-pocket expenses for in-network covered benefits cannot exceed \$7,000 annually for an individual. This cap extends not only to marketplace plans but also to employer-provided insurance. People with modest incomes also receive breaks on out-of-pocket costs. In 2017, 58% of people who purchased insurance through the marketplace qualified for reductions in their copayments and deductibles.<sup>48</sup>

■ **Consumer Empowerment:** ACA marketplaces enable consumers to compare plans by cost, and a majority of consumers surveyed said the marketplace made it easy to do so. Insurers participating in insurance marketplace must offer at least one plan with moderate cost sharing.

## Why Vigilance Against ACA Repeal Efforts Is Essential: Without the ACA, Millions of Black Americans Would Find Healthcare Unaffordable

Removing the ACA's affordability provisions would cause substantial financial harm among Black Americans and likely make insurance unaffordable for millions.

Removal or relaxation of the ACA's premium pricing controls—such as permitting insurance underwriting (i.e., allowing insurers to charge higher premiums for consumers who are sicker) and allowing much higher premiums for older adults (up to five times the cost for a 21-year-old)—would inevitably lead to sharp increases in premiums for the sick and elderly. The likely loss of healthy, younger enrollees due the repeal of the individual mandate—combined with the loss of federal subsidies to insurance companies and supports to consumers for the purchase of insurance—would, in the view of many experts, inexorably lead to a



deterioration and collapse of the individual market. According to analysts, increases of 9–27% in premiums for the more modestly priced plans in the individual market would be likely.<sup>49</sup> The “skinny repeal” bill that fell one vote short in the Senate, for example, would have increased insurance premiums by 20%, according to the Congressional Budget Office.<sup>27</sup>

In addition, repeal of the ACA would void the program's limits on out-of-pocket costs. This would inevitably usher in a “back to the future scenario” in which much higher deductibles and co-payments

increase households' risk of financial catastrophe in the event of illness.

While reducing the number Black Americans with access to Medicaid, repeal of the ACA would also increase the financial vulnerability of the low-income Americans who would still receive Medicaid. Whereas premiums have long been prohibited for Medicaid recipients and cost-sharing limited to nominal amounts, proposals advanced by those who want to repeal the ACA would grant states greater leeway to impose cost-sharing requirements for Medicaid beneficiaries, who by definition are poor.

# THE ACA HAS ENSURED THAT BLACK CONSUMERS HAVE THE HEALTH BENEFITS THEY NEED

WITHOUT THE ACA,  
BARE-BONES PLANS  
WILL MAKE INSURANCE  
MEANINGLESS FOR  
MILLIONS

Before the ACA was enacted, 62% of insurance plans in the individual market lacked maternity care, 34% precluded coverage for substance abuse treatment, 18% excluded coverage for mental health services, and 9% covered no prescription drugs.<sup>31</sup> In the pre-ACA era, private insurance policies for an estimated 105 million consumers included lifetime limits on coverage.<sup>50</sup> These lifetime limits posed particular perils for people with severe, chronic diseases, who ran the risk of running out of coverage and experiencing household financial catastrophe.

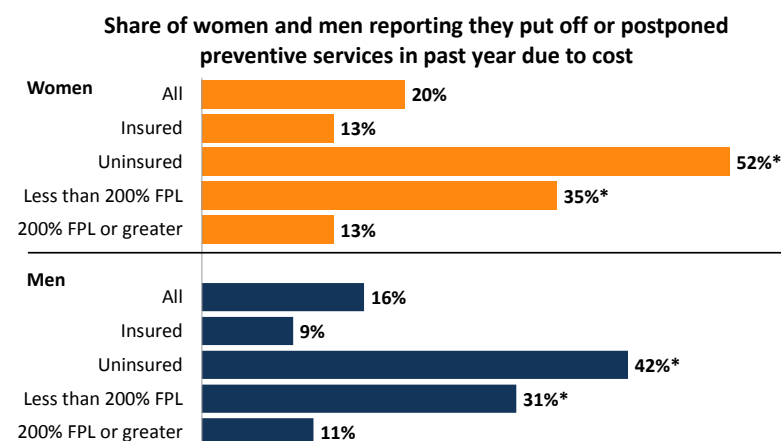
Before the ACA was implemented, insurance policies often shortchanged preventive services. In the pre-ACA era, many insurance policies routinely covered costs associated with the treatment of serious sickness but not the preventive services that could have averted illness in the first place. Due to cost, many consumers delayed preventive services prior to the implementation of the ACA (Figure 10).

## How the ACA Made Coverage More Comprehensive

Recognizing that healthcare is meaningful only if it covers the services people might need, the ACA mandated that all insurance plans (including employer-based coverage, marketplace plans and Medicaid) cover 10 essential health benefits:

- Ambulatory patient services,

**Figure 10. Cost barriers to use of preventive services for women and men**



NOTE: Among women and men ages 18-64. Federal Poverty Level (FPL) was \$19,530 for a family of three in 2013.\*Indicates a statistically significant difference from Insured and 200% FPL or greater,  $p < .05$ .  
SOURCE: Kaiser Family Foundation, 2013 Kaiser Women's Health Survey.



- Emergency services,
- Hospitalization,
- Maternity and newborn care,
- Mental health and substance use services,
- Prescription drugs,
- Rehabilitative and habilitative services and devices,
- Laboratory services,
- Preventive services and chronic disease management, and
- Pediatric services.

The ACA requires private insurers to cover recommended preventive services without imposing out-of-pocket costs by consumers (such as co-payments or deductibles). The ACA's emphasis on prevention has saved lives, leading, for example, to an

increase of 8,400 diagnoses of early-stage colorectal cancer.<sup>51</sup> In addition, the ACA prohibits lifetime caps on coverage.

## Why Vigilance Against ACA Repeal Efforts Is Essential: Without the ACA, Millions of Black Americans Would Lose Essential Health Services

Opponents of the ACA are united in their desire to relax or lift altogether requirements that insurance plans cover a package of essential services. Were these proposals to pass, the risk

avoidance practices that characterized private health insurance prior to the ACA would be certain to return. More households would be on the hook for all costs associated with maternity care, and fewer households would be able to obtain the prescription drugs they need.

For Black America, the proposed removal of the ACA's benefits mandate is especially perilous. Allowing insurers to impose cost-sharing requirements for preventive services that are now free under the ACA would inevitably undermine national efforts to manage chronic conditions that disproportionately affect Black Americans, such as many cancers, HIV, hypertension, diabetes and asthma.

Removal of the ACA's benefits mandates would also result in long-term and potentially irreparable damage to the insurance system. In the absence of a requirement to include a full range of coverage, insurers would undoubtedly offer low-benefit, "bare bones" plans for younger consumers. This would leave a diminished market for comprehensive insurance consisting of a patient pool that is sicker and more expensive, resulting in an upward cost spiral for the soundest insurance plans.

# THE SICKEST BLACK AMERICANS HAVE BENEFITED THE MOST FROM THE ACA

## REPEAL OF THE ACA WOULD DEVASTATE CHRONICALLY ILL BLACK AMERICANS

A key test for any healthcare system is how it responds to the needs of patients who require healthcare to stay alive or to live with an acceptable quality of life. This is a particular concern for Black America, as Black people on average have greater healthcare needs than white Americans and experience poorer outcomes on key health indicators (Figure 12).<sup>52</sup> Black people are 50% more likely than white people to die of cardiovascular disease, and the infant mortality rate for Black children is more than double the rate for white children.<sup>48</sup> Black Americans are 60% more likely than white Americans to be diagnosed with diabetes<sup>48</sup>, more than seven times more likely to die of AIDS<sup>53</sup>, and almost twice as likely to rate their health as fair or poor.<sup>48</sup>

Until passage of the ACA, insurers in most states could deny coverage to people with previous health issues. In 2013, nearly one in five applicants for insurance were denied coverage based on a pre-existing condition.<sup>54</sup> Nationally, 27% of adults have health conditions that would have made them uninsurable under rules that applied prior to the ACA. Before the ACA came into effect, insurance companies routinely charged much higher premiums to individual-market customers with health utilization records that included prior use of antidepressants, treatment for common infections (i.e., sinus) or prior surgery.<sup>31</sup> Before the ACA banned exclusions of pre-existing conditions, some states had established high-risk insurance



# Black People Living with HIV and the Future of the Healthcare System

ACA repeal would hobble Black America's capacity to fight AIDS, which remains a leading cause of death among African Americans.

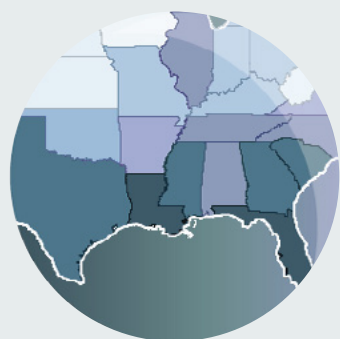
America's HIV epidemic, the largest and most serious among developed countries, is primarily an epidemic of Black people. Although Black people account for 13% of the U.S. population, they represented 44.3% of new HIV diagnoses in 2015 nationally.<sup>53</sup> The population-based prevalence of HIV diagnosis is nearly seven times higher among Black Americans than among white Americans.<sup>53</sup>

There is a broad scientific consensus that the tools exist to end AIDS once and for all. These tools include antiretroviral therapy, which dramatically reduces the risk of illness or death among people living with HIV and also effectively blocks HIV transmission, and pre-exposure antiretroviral prophylaxis (PrEP), which has efficacy approaching 100% for uninfected people who take it daily.

However, hopes for ending AIDS depend on a functional, accessible, consumer-friendly health system that facilitates and drives uptake of these essential HIV tools. This need is especially acute for Black Americans living with HIV, who tend to have fewer personal resources than white people living with HIV, limited access to care, and increased risk of key socioeconomic factors that increase vulnerability (e.g., violence, unemployment).<sup>57</sup>

Prior to the ACA, Medicaid's general exclusion of coverage of non-elderly adults without dependent children undermined efforts to link people living with HIV to essential health services. These barriers were particularly severe for young Black gay and bisexual men, who are at highest risk of becoming infected with HIV.

Given how health access barriers have long impeded an effective AIDS response in Black America, passage of the ACA was greeted as a godsend by Black AIDS advocates. Indeed, effective implementation of the ACA was quickly understood to be an essential pillar of hopes for ending AIDS in Black America.<sup>58</sup> As a result of the ACA, the proportion of Black people living with HIV who are uninsured fell from 21% in 2012 to 14% in 2014.<sup>19</sup>



Unfortunately, the refusal of 19 states to expand Medicaid has unacceptably limited the ability of Black America to accelerate progress towards ending AIDS. Among the estimated 115,000 uninsured, low-income Americans living with HIV who became eligible for Medicaid as a result of the ACA, more than half (60,000) live in states that have not expanded Medicaid.<sup>59</sup> In states that have thus far refused the Medicaid expansion, little if any improvement in coverage rates was seen from 2012 to 2014.<sup>19</sup> In 2014, nearly two-thirds of Black Americans newly diagnosed with HIV lived in the South, where all but two states have opted not expand Medicaid (Figure 11).

Because Medicaid services in the South are inaccessible for most non-elderly Black people living with HIV—and private health insurance remains unaffordable

for many—uptake of essential HIV health services continues to lag in many Black communities. Among people living with HIV in 2014, Black people were less likely than white people to be linked to care within one month of HIV diagnosis (71.6% vs. 79.0%), less likely to remain engaged in care (53.5% vs. 58.2%) and less likely to achieve viral suppression (48.5% vs. 62.0%).<sup>60</sup> Among people at high risk of acquiring HIV, Black people are notably less likely than white people to obtain PrEP.<sup>61</sup>

**Figure 11. Number of Black persons newly diagnosed with HIV, 2014**

**19,436**

**AFRICAN AMERICANS**  
were newly diagnosed  
with HIV in 2014

**&**  
**NEARLY TWO-THIRDS**  
**LIVE IN THE SOUTH**

0-2 3-4 5-6 7-12 13-20 21-40 41-66 67-102 103-462 463+

Source: [aidsvu.org](http://aidsvu.org) and the U.S. Centers for Disease Control and Prevention

pools, ostensibly to expand coverage for otherwise uninsurable high-need clients, but these plans proved in practice to be exceedingly costly for states to administer, unaffordable for many consumers, and actually used by a mere fraction of patients with pre-existing conditions.<sup>55</sup>

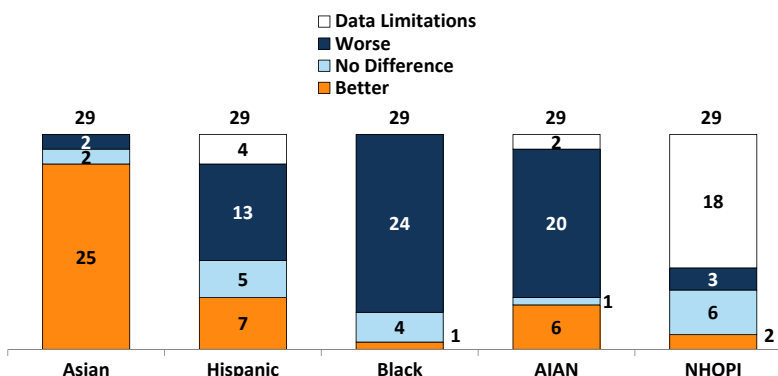
## How the ACA Has Helped High-Need Patients

The ACA largely swept away the insurance practices that made millions of consumers potentially uninsurable if they left their jobs or otherwise experienced a gap in coverage. By barring higher premiums or coverage caps for people with pre-existing conditions, the ACA also prevents insurers from penalizing individuals who have the misfortune to get sick. Ensuring access to care is essential for effectively managing the most serious public health problems in Black America, including HIV (see box). As a result of the ACA's protections, about 2.2 million individuals with pre-existing conditions currently receive coverage through the individual market.<sup>56</sup>

## Why Vigilance Against ACA Repeal Efforts Is Essential: Without the ACA, The Sickest Black Americans Would Lose Coverage

Proposals to repeal or weaken the ACA imperil Black America's ability to manage its most serious health problems and, if enacted, would inevitably increase the cost of coverage for the sickest Black consumers. For many Black Americans with chronic illnesses, health coverage would be unaffordable, and episodic charity care would serve as a poor, life-threatening substitute for the uninterrupted, high-intensity care and medical monitoring these patients need. If these proposals are implemented, many of the sickest

**Figure 12. Number of health status and outcome measures for which groups fared better, the same, or worse compared to whites**



NOTE: Better or Worse indicates a statistically significant difference from White population at the  $p < 0.05$  level. No difference indicates there was no statistically significant difference. Data limitations indicates data are not available separately for a racial/ethnic group, insufficient data for a reliable estimate, or comparisons not possible to Whites due to overlapping samples. AIAN refers to American Indians and Alaska Natives. NHOPI refers to Native Hawaiians and Other Pacific Islanders. Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic.



people in Black America will become disabled or die prematurely due to conditions that could be properly managed with good, continuous health coverage.

The health plan approved by the House would allow states to waive prohibitions against charging higher premiums for individuals or households with a pre-existing



# Repairing the ACA: How Bipartisan Cooperation Could Strengthen the ACA and Ensure Its Sustainability

Although the ACA represents momentous progress toward a healthier and more just country, it is not a perfect program. Healthcare costs continue to increase faster than the inflation rate, many consumers still face insurance premiums that are unaffordable (in part because too few young, healthy people have signed up for coverage), and millions of Americans remain uninsured.

These flaws are hardly surprising in a program that has been in place less than four years. Every major social program—from Social Security to Medicare—has required adjustments to address problems and make it work more efficiently. Contrary to claims by President Trump that the ACA is “failing,” it is beyond dispute that the ACA has accomplished what was intended—increasing health coverage, reducing the ranks of the uninsured, moderating the increase in health costs, protecting households against catastrophic financial losses associated with illness, and improving health outcomes.

But this good program can be made even better for American health consumers. In the aftermath of the failure of Congressional efforts to repeal the ACA over the summer of 2017, interest has grown regarding the possibility of bipartisan efforts to tweak the ACA to address gaps or weaknesses that have emerged.

Particular interest has focused on steps to shore up insurance markets, with several possible approaches available. Subsidies to health insurers might be increased to offset costs associated with high-need enrollees, and reinsurance or other strategies could be used to protect insurers against financial losses. To inject greater competition in insurance markets, Congress should consider creating a “public option,” a government-run insurance plan that would compete with other insurance plans on such criteria as quality, affordability, and provider network. Raising the penalty for foregoing insurance coverage could increase the number of young, healthier people who enroll in health insurance, helping further diversify the insurance risk pool and thereby moderating the costs of premiums. To reduce overall health costs, various consumer-friendly cost containment measures should be considered, such as the kind of government-led price negotiations for pharmaceutical products that are in place in many other developed countries.

Other potential ACA “fixes” might include a clear and firm reiteration by Congress regarding the federal government’s long-term commitment to pay the lion’s share of costs associated with Medicaid expansion. This could encourage the 19 states that have yet to expand Medicaid to do so. (In this regard, it is worth remembering that Arizona only began participating in Medicaid in 1982—17 years after the program was created. As the health and economic value of Medicaid expansion becomes clearer—and as the ACA’s status as an essential feature of American life is solidified—states that initially refused Medicaid expansion may well reconsider.)

The nation’s health should not be a partisan issue. America’s history of responding to AIDS demonstrates the value of a bipartisan approach, as Democrats and Republicans joined together to create and fund the Ryan White program, to support breakthrough HIV research at the National Institutes of Health, and to establish the history-making President’s Emergency Plan for AIDS Relief (PEPFAR). Everyone in Congress, regardless of party affiliation, should join together to build on the accomplishments of the ACA by making the program even better.

condition. Although the legislation ostensibly permitted higher premiums only for individuals who have a gap in coverage, the inevitable effects of these waivers would be to drive costs up for all individuals with a pre-existing condition.<sup>32</sup> Younger, healthier consumers who experienced a gap in coverage would, under the Republican plans, have had access to much less expensive insurance policies, effectively removing them from the risk-sharing pool on which sicker

patients rely and leading inexorably to higher (and, for many, unaffordable) insurance premiums for people with pre-existing conditions.<sup>32</sup>

As experience has already taught, high-risk pools would be wholly insufficient to make up for elimination of the ACA’s prohibitions on discrimination against people with chronic illnesses. Experts project that replacement of the ACA with risk pools at the capitalization proposed in the House and Senate bills would

reduce by 70% the number of people with pre-existing conditions who are able to obtain health coverage in the individual market.<sup>56</sup>

ACA repeal proposals would gut protections for high-need patients in other ways. By removing the requirement that all insurance plans provide a package of essential benefits, insurers would presumably be free simply to exclude coverage for expensive treatments, such as cancer chemotherapy.

# ACTING NOW TO PRESERVE AND EXPAND HEALTHCARE ACCESS

## MAKING SURE THE HEALTH SYSTEM WORKS FOR ALL AMERICANS

The potential consequences of the ongoing healthcare debate for Black America could hardly be greater. Black America needs to mobilize now—to preserve the ACA and to press decision-makers to further expand healthcare access.

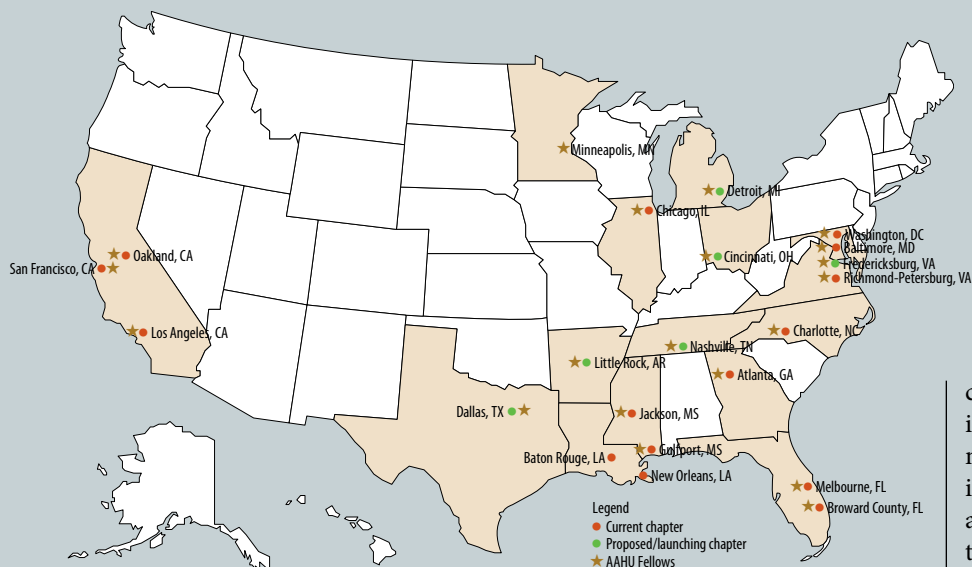
The Institute proposes a multi-component national effort to mobilize to beat back the threat to healthcare access. This new initiative aims to leverage and build on this report and its subsequent iterations, which serve as a national call to action to recognize and respond to the dangers posed by efforts to repeal or undermine the ACA.

Although national in scope to address a clear national threat, this initiative aims to take into account the need for focused, tailored approaches to address healthcare access challenges in different states. For example, communities in states that have yet to expand Medicaid may focus much of their advocacy on state governments, in the hopes of encouraging state-level leadership to strengthen the state and local healthcare safety net. While the Institute is launching this new initiative in collaboration with other national partners, it is the Institute's hope and expectation that local communities will be the initiative's primary owners and shapers.

To help catalyze grassroots action, the Institute will focus first on building healthcare advocacy capacity in the high-prevalence cities and regions where its Black Treatment Advocacy Network (BTAN) chapters are located.



**Figure 13. Black Treatment Advocates Network (BTAN)**



These chapters consist of people living with HIV, people at high risk of HIV, representatives from state and local health departments, AIDS service organizations, community-based organizations, faith-based organizations, clinical providers, and other key stakeholders.

## ACA-Focused Trainings

To educate constituents about the ACA and mobilize communities to understand and respond effectively to threats to the ACA, BAI will conduct ACA-focused trainings in five regions of the country through its BTAN chapters:

- *Midwest, Medicaid-expanded:* BTAN Chicago, BTAN Detroit, Cincinnati, and surrounding areas;

- *West, Medicaid-expanded:* BTAN Bay Area, BTAN Los Angeles, and surrounding areas;

- *South, Medicaid-expanded:* BTAN Maryland, BTAN Louisiana, Washington DC, and surrounding areas;

- *South, Medicaid not-yet-expanded:* BTAN Atlanta, BTAN Richmond-Petersburg, BTAN Charlotte, and surrounding areas;

- *Gulf, Medicaid not-yet-expanded:* BTAN Mississippi, BTAN

Melbourne, BTAN Broward, Texas, and surrounding areas.

In each region, BTAN chapters will host two-day trainings with up to 20 attendees per training. Those interested in training should visit the Institute's website in the coming days and weeks, where these trainings will be advertised and applications or expressions of interest sought.

During the trainings, attendees will receive content on topics such as Advocacy 101, State of HIV/AIDS in America, Resource Mobilization and Networking, etc. These weekend trainings will build the capacity of Black communities, the HIV workforce, and other key stakeholders in efforts to mobilize and advocate in their respective communities and local jurisdiction on the concerns of repealing and replacing ACA. To support these trainings as well as advocacy by communities unable to attend one of the trainings, the Institute will discuss various advocacy tools, including a community mobilization toolkit.

The Institute is in the process of creating a portal on its website specifically devoted to defense of the ACA and healthcare access. The new web portal will include weekly updates and notifications of new developments to BTAN chapters, partners and Black

communities. In addition to providing information to partners and communities, the ACA web portal will also include a moderated discussion forum, allowing partners and communities to share information and to request tools or resources to support their own advocacy and community mobilization efforts. On this web portal, the Institute will share information regarding advocacy coalitions or opportunities at both the national and state and local levels.

Drawing from lessons learned from the Institute's pioneering survey of the HIV workforce on HIV science and treatment issues, the Institute will also conduct a national survey of the knowledge, attitudes and behaviors of Black Americans regarding the ACA. The findings of this survey will be used to influence key decision-makers to keep the needs of Black communities in mind as decisions are made regarding the future of the ACA and healthcare access. Survey results will also feed into ongoing community mobilization and advocacy strategies, and help identify new opportunities to strengthen the fight to preserve health care access for Black America.

The Institute expects that this initiative will evolve over time, as communities develop their own mobilization and advocacy strategies and as new challenges and opportunities emerge. By remaining up-to-date on the latest healthcare access developments and by educating and mobilizing our communities, Black America can help preserve and further expand healthcare access.

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