



# THE AFFORDABLE CARE ACT, THE SUPREME COURT, AND HIV: WHAT ARE THE IMPLICATIONS?

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## INTRODUCTION

Assuring that all Americans living with HIV have access to quality health care has been a challenge since the earliest years of the HIV epidemic. The Affordable Care Act (ACA), signed into law by President Obama in 2010 (Public Law 111-148), aims to expand access to affordable health coverage and reduce the number of uninsured Americans. As such, when fully implemented in 2014, it is expected to significantly expand access for people with HIV, many of whom are uninsured or otherwise unable to access affordable and stable health care coverage. Access to care, particularly antiretroviral treatment (ART), is not only critical for the health of people with HIV, it also carries important public health benefits with recent research demonstrating that ART significantly reduces the risk of HIV transmission from an HIV positive to negative individual.<sup>1</sup> Soon after the ACA was passed, however, its constitutionality was challenged in federal court, and eventually heard by the Supreme Court, which issued a much anticipated decision on June 28, 2012, in the case of *National Federation of Independent Business v. Sebelius*.<sup>2,3</sup> This issue brief explores the implications of the ACA for people with HIV, taking into account the Supreme Court's recent ruling. It provides an overview of key ACA provisions of particular importance to people with HIV, the changes resulting from the Supreme Court's decision, and looks ahead at key remaining questions and opportunities.

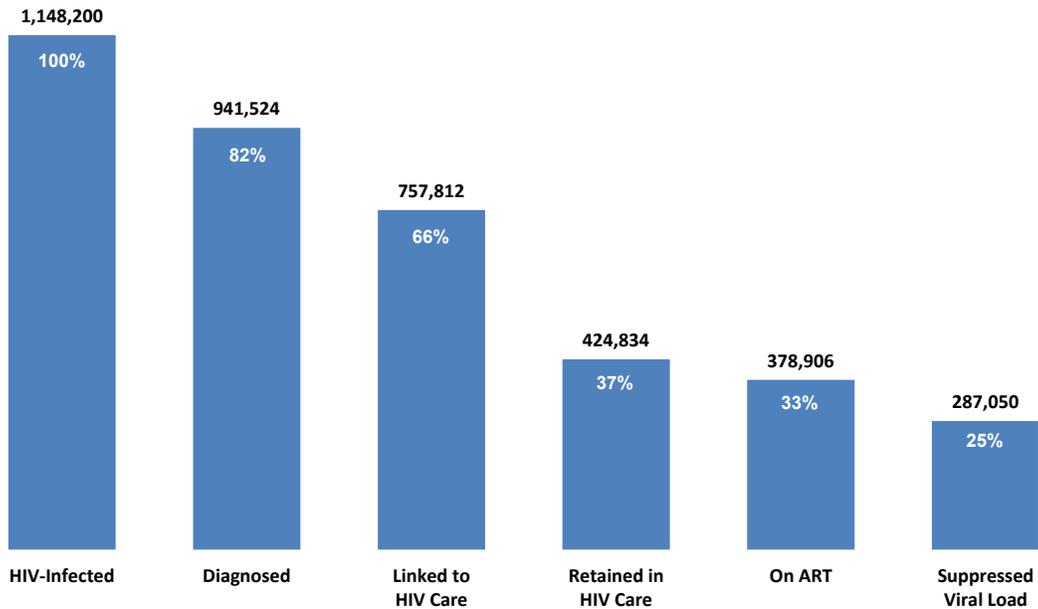
## BACKGROUND

HIV remains a serious public health challenge in the United States. More than a million people are living with HIV in the U.S. and roughly 50,000 become newly infected each year.<sup>4,5</sup> In addition, it is estimated that only 37% of people with HIV in the U.S. are retained in regular HIV care<sup>5</sup> – some are not yet diagnosed, but others are not yet linked to care or fall out of care, due to lack of adequate insurance coverage, access barriers, and other factors.

Compelling research has demonstrated the significant benefits of early HIV treatment. Results from the NIH-sponsored "HPTN 052" study found that early ART reduced the risk of HIV transmission from an HIV positive to negative partner by 96%.<sup>1</sup> For those with HIV, several studies have found that early ART also significantly delays the progression of their HIV disease, and reduces the occurrence of adverse health events and death.<sup>6,7,8,9,10</sup> As a result of these studies, federal HIV treatment guidelines were recently updated to recommend initiation of ART immediately after HIV diagnosis for all people with HIV in the U.S., regardless of CD4 count (a marker of immune system health).<sup>11</sup> Research has also demonstrated the effectiveness of pre-exposure prophylaxis (PrEP) – that is, HIV negative individuals taking ART before HIV exposure – in reducing HIV risk, prompting the Food and Drug Administration (FDA) to approve ART for this purpose in July 2012.<sup>12,13,14</sup>

Recently, researchers have begun to popularize the concept of an HIV "treatment cascade" which depicts the continuum of HIV care, from initial diagnosis of HIV through to maximal viral suppression.<sup>5,15,16</sup> The treatment cascade provides a useful framework for assessing the biggest drop offs, or "cliffs", along the care continuum and thus helps to identify opportunities for intervention. The latest estimates indicate that there are significant drop offs at each stage of the cascade (see Figure 1). Of those living with HIV in the U.S., approximately 82% have been diagnosed, 66% have been linked to care, and only 37% have been retained in care. Once retained in care, most (89%) receive ART, 76% of whom are virally suppressed. However, because of cliffs at each stage of the cascade, only 25% of people with HIV overall in the U.S. were fully virally suppressed. The biggest cliff occurs between linkage to and retention in care – more than 300,000 people with HIV are lost between these stages of the continuum.<sup>5</sup> This suggests that while policy attention is needed at each stage of the cascade, increasing the share of people with HIV who are retained in regular care is a critical point of intervention for maximizing public health and clinical benefits.

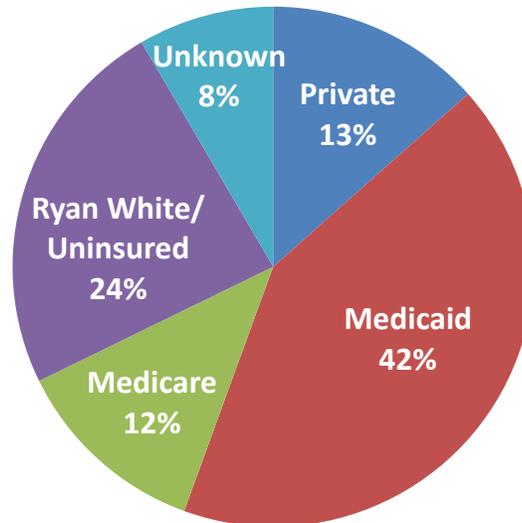
# Figure 1: The HIV Treatment Cascade



Source: Adapted from CDC "HIV in the United States—The Stages of Care" July 2012.

Health insurance coverage has been shown to make an important difference in improving such access, and ultimately health outcomes, for people in the United States, including those with HIV.<sup>17,18,19,20,21</sup> While reliable national estimates of the insurance coverage of people with HIV are not available,<sup>22</sup> a recent analysis of data from a network of high-volume HIV clinics found that only 13% of people with HIV in care were covered by private insurance, and a quarter (24%) did not have any coverage (see Figure 2).<sup>23</sup> Medicaid covered the greatest share (42%, including those with dual Medicaid and Medicare coverage); indeed, a national study of Medicaid and HIV found that Medicaid covered almost half of all people with HIV who were in regular care.<sup>24</sup> Many of those who lack coverage, or have insufficient coverage, rely on the Ryan White HIV/AIDS Program, the nation's safety net for people with HIV who are uninsured or underinsured. Yet, unlike Medicaid, Ryan White is not designed as an insurance mechanism that provides a promise of coverage for a defined set of benefits. Annual funding for Ryan White is subject to discretionary appropriations by Congress (and the states), which do not necessarily match the number of people who need services or the cost of their care, and the program has never been able to meet the needs of all people with HIV seeking services. Throughout most of the program's history, there have been waiting lists for drugs provided through Ryan White's AIDS Drug Assistance Program (ADAP), which provides prescription medications to people with HIV.<sup>25</sup>

**Figure 2: Insurance Coverage of Patients with HIV/AIDS, 2010**



Notes: Based on Patients with HIV Attending Medical Offices Participating in HIVRN; N=19,235.  
Medicaid includes those with Medicare coverage.  
Source: Data from K. Gebo and J. Fleishman, in Institute of Medicine, HIV Screening and Access to Care: Exploring the Impact of Policies on Access to and Provision of HIV Care, 2011.

## MAJOR HIV-RELATED PROVISIONS OF THE AFFORDABLE CARE ACT

The passage of the ACA in 2010 provided significant, new opportunities for expanding access and coverage to millions of people in the United States, including people with HIV. Soon after the ACA's passage, the White House released the first comprehensive national HIV/AIDS strategy for the U.S. with three primary goals – reduce the number of new infections, increase access to care, and reduce HIV-related health disparities – predicated in large part on using the ACA as a platform to help achieve these goals.<sup>26</sup>

While nearly all of the provisions of the ACA have some impact on people with HIV or their care, several are of particular relevance. These include provisions that have already been implemented, as well as others that will be implemented in 2014. They include expansion of health coverage and services in the private insurance market and through Medicaid, as well as an increased emphasis on prevention and health system improvements. **Table 1** includes key ACA provisions with the most direct relevance to people with HIV that will be implemented prior to 2014. **Table 2** includes those that will go into effect in January 2014. These are further described after both tables. This section is followed by an overview of the recent Supreme Court decision and its implications for these major provisions.

**Table 1: Key HIV-Related ACA Provisions Implemented Before 2014****EXPANSION OF COVERAGE OR SERVICES****Medicaid: Coverage for Childless Adults**

Creates a new state option (at regular Medicaid match) for states to cover childless adults with income up to 138% of the federal poverty level (FPL). (Effective April 2010. Since that time, 8 states have expanded coverage to adults either through the new option or a waiver.)

**Medicare: ADAP Counts Towards TrOOP**

Changes Medicare drug coverage policy so that AIDS Drug Assistance Program (ADAP) spending on HIV drugs is counted as true-out-of-pocket (TrOOP) costs for purposes of reaching the Medicare catastrophic drug coverage level. Permits limited ADAP resources to go further. (Effective January 2011.)

**Medicare: Closing the Drug Coverage Gap**

Provided \$250 rebate for Medicare beneficiaries that reached the drug coverage gap in 2010. Starting in 2011, also provided a 50% discount on brand-name drugs and 7% discount on generic drugs with discounts increasing annually through 2020, when the coverage gap is eliminated. (Effective January 2010.)

**Insurance Protections for Consumers: Lifetime Limits and Rescissions on Coverage**

Prohibits individual and group health plans from placing lifetime limits on coverage, rescinding coverage, and denying children coverage based on pre-existing medical conditions (Effective for plan years after September 2010.)

**Insurance Protections for Consumers: Pre-Existing Condition Insurance Plan (PCIP)**

Establishes a temporary program in every state to provide coverage for people with pre-existing medical conditions, such as HIV, who have been uninsured for six months and denied insurance coverage. (Effective July 2010. Program disappears when the other coverage expansions take effect in 2014; see Table 2.)

**Young Adult Dependent Coverage**

Extends dependent coverage for adult children up to age 26 in all individual and group plans. (Effective for plan years after September 2010.)

**PREVENTION****Prevention and Public Health Fund**

Creates a new fund for prevention, wellness, and public health activities. The ACA appropriated \$15 billion over 2010-2019 for the fund, subsequently reduced by law in February 2012 to \$10 billion. (Fund began in July 2010. In FY 2010, \$30 million was allocated for new CDC HIV prevention activities including the establishment of the Enhanced Comprehensive HIV Prevention Planning (ECHPP) Initiative and new investments in HIV surveillance, testing, and other areas.)

**Free Prevention Services and Annual HIV Screenings for Women**

Requires new health plans to provide prevention services with an A or B rating by the U.S. Preventive Services Task Force for free, which includes HIV screening for those at high risk.<sup>27</sup> (Effective for plan years after September 2010.) Also, the Secretary of HHS issued rules requiring insurers to provide free coverage for certain women's preventive services, including annual HIV counseling and screening for all sexually active women. (Effective for plan years after August 2012.) Under Medicare, eliminates cost-sharing for Medicare-covered preventive services that are rated A or B by the USPSTF (effective January 2011). Under Medicaid, provides a one percentage point increase in FMAP for states that offer Medicaid coverage with no cost sharing for preventive services rated A or B by the USPSTF (effective January 2013).

**HEALTH SYSTEM IMPROVEMENTS****Medicaid: Health Homes**

Creates a new state option to permit Medicaid beneficiaries with chronic conditions to designate a provider as a health home. States provided an enhanced federal matching rate of 90% for two years for health-home related services (Effective January 2011. To date, 6 states have taken up the option and 13 more have expressed interest. The ACA specifies a list of chronic conditions and also authorizes the HHS Secretary to expand the list. HIV is not on the ACA list, but HHS has indicated that it may be considered for incorporation into health home models, with further guidance forthcoming.<sup>28</sup>)

**Medicaid: Increased Payments for Primary Care**

Increases Medicaid payments for primary care services provided by primary care doctors to 100% of the Medicare payment rate for 2013 and 2014. (Effective January 2013. A proposed rule issued by HHS would define primary care doctors to include primary care subspecialists.<sup>29</sup> Given the complexity of HIV care and need for experienced HIV providers, HIV specialists often serve as their patients' primary care physicians.)

**Table 1, continued**

<b>Medicaid/Medicare: Integrated Care for Dual Eligibles</b>
Established a Medicare-Medicaid Coordination Office. A key activity of the office is to award grants to design person-centered models that coordinate primary, acute, behavioral, and long-term services and supports for persons dually enrolled in Medicaid and Medicare. (15 states awarded grants in April 2011.)
<b>New Investments in Health Centers and National Health Service Corps</b>
Permanently authorizes the federally qualified health center (FQHC) and National Health Service Corps (NHSC) programs and increases their funding for 2010-2015. (In October 2010, HHS awarded \$727 million in grants to update and expand 143 community health centers and in September 2011, HHS announced \$10 million in new planning grants to 129 organizations seeking to become FQHCs, including at least seven HIV/AIDS organizations.)
<b>Health Disparities Data Collection</b>
Requires enhanced data collection and reporting of data on race, ethnicity, sex, primary language, disability status, and for underserved frontier and rural populations. (Effective March 2012.)

**Table 2: Key HIV-Related ACA Provisions in 2014 and Beyond**

<b>Expanded Medicaid Coverage</b>
Expands Medicaid to nearly all individuals with incomes up to 138% FPL. Provides 100% financing to states for newly eligible beneficiaries from 2014-2016, 95% federal financing in 2017, 94% in 2018, 93% in 2019, and 90% in 2020 and beyond. All newly eligible beneficiaries will be guaranteed a benchmark benefits package that must include the essential health benefits (see below).
<b>Establishment of Private Health Insurance Exchanges</b>
Creates state-based American Health Benefit Exchanges and Small Business Health Options Program (SHOP) Exchanges, administered by a government agency or non-profit organization, through which individuals and small businesses with up to 100 employees can purchase qualified coverage.
<b>Health Insurance Premium and Cost Sharing Subsidies</b>
Provides refundable and advanceable tax credits and cost-sharing subsidies to eligible individuals. Premium subsidies are available to families with incomes between 100-400% of the poverty level to purchase insurance through the Exchanges, while cost-sharing subsidies are available to those with income up to 250% of the poverty level.
<b>Guaranteed Availability of Coverage: Prohibits Pre-Existing Condition Exclusions</b>
Requires guarantee issue and renewability of health insurance regardless of health status. Permits variation in premiums based only on age (limited to a 3 to 1 ratio), geographic area, family composition, and tobacco use (limited to 1.5 to 1 ratio) in the individual and small groups markets and the Exchanges.
<b>No Annual Limits on Coverage</b>
Prohibits annual limits on the dollar value of coverage.
<b>Essential Health Benefits</b>
Creates an essential health benefits (EHB) package that provides a comprehensive set of services across ten categories. Annual cost sharing is limited to the Health Savings Account limits (\$5,950/individual and \$11,900/family in 2010). Plans in the individual and small group markets both inside and outside of the Exchanges, Medicaid benchmark and benchmark-equivalent benefits packages, and the Basic Health Plan must include the EHB.
<b>Basic Health Plan</b>
Provides states with the option of creating a Basic Health Plan for uninsured individuals with incomes between 138-200% of the poverty level who would otherwise be eligible to receive premium subsidies in the Exchange. The Basic Health Plan must cover the EHB.
<b>Individual Requirement to Have Insurance</b>
Requires U.S. citizens and legal residents to have qualifying health coverage with certain exemptions and a phased-in tax penalty for those without coverage.

- Medicaid:** One of the most important components of the ACA for people with HIV is the Medicaid expansion. Medicaid is the largest payer of HIV care in the U.S. and a critical source of care and services, including ART and other prescription drugs, for people with HIV. Prior to the ACA, however, to qualify for Medicaid, a person had to meet both financial eligibility criteria and belong to a group that was “categorically eligible” for Medicaid (children, parents with dependent children, pregnant women, and individuals with disabilities). Federal law categorically excluded non-disabled adults without dependent children, unless a state obtained a waiver or used state-only dollars to cover them. This ran counter to HIV treatment guidelines and presented a “catch-22” for many low-income people with HIV who could not qualify for Medicaid until they were already quite sick and disabled, despite the fact that early access to treatment could help stave off disability and prevent further transmission. The ACA made several changes that are designed to significantly expand Medicaid eligibility. It established a new minimum Medicaid income eligibility level of 138% FPL<sup>30</sup> for citizens and legal residents<sup>31</sup> (thereby removing the categorical eligibility requirement and basing Medicaid eligibility solely on income) that will take effect in 2014 with an enhanced federal match rate of 100% from 2014 through 2016, scaling down to 90% by 2020. States also were provided with a new option to expand coverage to this group early, effective April 2010, at their regular federal Medicaid match rate. Since April 2010, eight states have expanded Medicaid coverage to adults either through the new option or a waiver.<sup>32</sup>

Even with the early option to expand, Medicaid eligibility remains quite limited for low-income childless adults today (see Table 3). Only nine states and the District of Columbia provide Medicaid benefits to this population, five of which limit eligibility to those with very low incomes ( $\leq 75\%$  FPL) or have closed their programs to new enrollees. An additional 17 states provide coverage that is more limited than Medicaid, though several of these programs are now closed to new enrollees. Twenty-five states provide no coverage at all for low-income childless adults.<sup>32</sup>

- Medicare:** Medicare is an important source of coverage for people with HIV who are under age 65 and disabled, and for those who are 65 and older. The ACA changed how the Medicare drug benefit works so that ADAPs can assist Medicare beneficiaries with HIV by temporarily paying their drug cost-sharing or providing drugs in the coverage gap until the individual reaches the catastrophic level of coverage. Previously, many ADAPs provided this type of assistance to ensure continuity of care, but had to make an open-ended commitment of support, as ADAP assistance did not count toward “true out of pocket costs” or TrOOP, to qualify for the catastrophic level of coverage. The law is also phasing out the coverage gap, but provided immediate assistance in the form of a \$250 rebate for persons in the coverage gap in 2010 and increasing levels of discounts for drugs in the coverage gap from 2011 until 2020 when the coverage gap is eliminated.
- Insurance Protections for Consumers:** Except in a small number of states, HIV has generally been considered an uninsurable, pre-existing health condition in the individual market<sup>33</sup> and, where available, often unaffordable. In addition, although the Health Insurance Portability and Accountability Act (HIPAA) created a right to purchase coverage for individuals that maintain continuous insurance coverage, insurers can still set premiums, which has rendered the guarantee of coverage effectively meaningless for those with high cost conditions such as HIV. Many health plans have also imposed lifetime or annual limits on coverage, which presented additional challenges for those with high cost conditions. The ACA provides both immediate new consumer protections, as well as more comprehensive protections in 2014, that will greatly benefit people with HIV and others with existing and costly medical conditions. Protections implemented in 2010 include prohibiting health plans from placing lifetime limits on coverage, from rescinding coverage, and from denying children coverage based on pre-existing medical conditions. For adults, the ACA creates a pre-existing condition insurance plan (PCIP) to serve as a temporary insurance program until 2014. As of 2014, health plans will be prohibited from placing annual limits on coverage and from denying coverage to adults or charging higher premiums based on pre-existing conditions.

- **Health Insurance Premium and Cost Sharing Subsidies:** Given that insurance coverage can still be prohibitively expensive, especially for persons with income slightly above the new Medicaid income standard, the law provides for premium subsidies beginning in 2014 for individuals and families with incomes from 100% up to 400% of poverty and cost-sharing assistance from 100% up to 250% of poverty. Individuals purchasing insurance through the exchanges will have access to various tiers of coverage. Premium subsidies will be tied to the second lowest cost plan in the silver tier of coverage.
- **Benefits Standards:** To ensure that coverage will be comprehensive, the law also created new benefits standards, calling for the establishment of an “essential health benefits” (EHB) package by 2014. Plans in the individual and small group markets both inside and outside of the Exchanges, Medicaid benchmark and benchmark-equivalent benefits packages, and the Basic Health Plan must cover the EHB. The EHB is to include 10 benefit categories: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. The HHS Secretary is charged with defining essential health benefits, and in December 2011, HHS released an EHB “informational bulletin”<sup>34</sup> outlining its proposed policies and approach to further define the EHB, but has not yet issued final regulations.
- **Individual Requirement to Have Insurance:** As of 2014, the ACA requires all U.S. citizens and legal residents to have qualifying health insurance, and, as mentioned above, bans discrimination in enrollment and in setting premiums on the basis of health status, making it possible for people with HIV to obtain affordable private insurance coverage. The ACA achieves this by supporting states in establishing insurance exchanges that will operate in every state (or through a Federal fallback exchange if states do not implement exchanges on their own).

## THE SUPREME COURT’S ACA RULING & IMPLICATIONS FOR PEOPLE WITH HIV

Soon after its passage, multiple challenges to the constitutionality of the ACA were initiated across the country. The Supreme Court heard a challenge brought by the state of Florida and twenty-five other states disputing the constitutionality of the individual mandate and the Medicaid expansion. This case was combined with a lawsuit by the National Federation of Independent Business (NFIB) and individual plaintiffs who do not currently have health insurance. In a much anticipated ruling, the Court upheld the individual mandate. While the Court also maintained the ACA’s Medicaid expansion, it limited the Secretary’s enforcement authority for the expansion. As such, if a state does not implement the expansion, the Secretary cannot withhold existing federal program funds. This change in enforcement authority may impact state decisions to implement the expansion.

### How will states respond?

In light of the Supreme Court’s ruling, states could choose to expand coverage in full or not to expand at all (and some states have asked whether partial expansions or expansions initiated after 2014 will be permitted<sup>35,36</sup>), and it is impossible to predict how states will react. On the one hand, twenty-six states were part of the Supreme Court lawsuit challenging the constitutionality of the ACA’s Medicaid expansion. On the other, thirteen states filed amicus briefs with the Court in support of the expansion (two states were on both sides)<sup>3</sup> and several states have already used the ACA’s early option to expand Medicaid to low-income adults.<sup>32</sup>

<b>Table 3: Medicaid Coverage of Childless Adults &amp; ADAP Waiting Lists</b>				
<b>STATE</b>	<b>MEDICAID COVERAGE</b>	<b>MORE LIMITED COVERAGE THAN MEDICAID</b>	<b>EARLY ACA MEDICAID EXPANSION</b>	<b>ADAP WAITING LIST (ANY TIME SINCE JANUARY 2010)</b>
Alabama				Yes
Alaska				
Arizona	Yes (closed)			
Arkansas		Yes		Yes
California		Yes	Yes	
Colorado	Yes		Yes	
Connecticut	Yes		Yes	
Delaware	Yes			
District of Columbia	Yes		Yes	
Florida				Yes
Georgia				Yes
Hawaii	Yes (closed)	Yes		Yes
Idaho		Yes		Yes
Illinois				
Indiana		Yes		
Iowa		Yes		Yes
Kansas				
Kentucky				Yes
Louisiana				Yes
Maine		Yes		
Maryland		Yes		
Massachusetts		Yes		
Michigan		Yes		
Minnesota	Yes	Yes	Yes	
Mississippi				
Missouri		Yes	Yes	
Montana				Yes
Nebraska				Yes
Nevada				
New Hampshire				
New Jersey		Yes	Yes	
New Mexico		Yes		
New York	Yes			
North Carolina				Yes
North Dakota				
Ohio				Yes
Oklahoma		Yes		
Oregon		Yes		
Pennsylvania				
Rhode Island				Yes
South Carolina				Yes
South Dakota				Yes
Tennessee				Yes
Texas				
Utah		Yes		Yes
Vermont	Yes	Yes		
Virginia				Yes
Washington		Yes	Yes	
West Virginia				
Wisconsin		Yes		
Wyoming				Yes
<b>Total</b>	<b>9</b>	<b>20</b>	<b>8</b>	<b>20</b>

Sources: Kaiser Family Foundation, [www.statehealthfacts.org](http://www.statehealthfacts.org) and NASTAD.

There are also significant financial incentives for states to expand their Medicaid programs under the ACA— the expansion is 100% federally funded from 2014 through 2016 and at least 90% federally funded thereafter. In addition, other provisions of the law will greatly reduce federal funding to states for uncompensated care, which will worsen the financial pressure on safety-net hospitals who have relied on such funding in the past to serve the uninsured (the ACA reduces these payments to states under the assumption that Medicaid coverage was expected to expand, as enacted in the law). Expansion will also provide offsetting reductions in state spending for mental health services for low-income populations, as well as wider positive impacts on employment and state revenues. Indeed, past experience has demonstrated that the availability of federal funds has been an effective incentive for states to provide coverage, even when states are facing financial constraints.<sup>37</sup> Still, expanding Medicaid requires a new, if proportionately small, expenditure of state funds and at a time when states face budget pressures, it is unclear how many states will opt for the expansion or how quickly.

#### What does this mean for people with HIV?

Given these uncertainties, it is hard to assess the ultimate impact of the Supreme Court's decision on people with HIV who are low-income and would qualify under the Medicaid expansion, although the ACA is still expected to greatly increase their health insurance coverage. Still, much like the HIV coverage landscape today, it will continue to vary significantly across the country, with some people with HIV finding themselves living in states that do expand, while others in states that do not (or perhaps do so only partially). Uninsured people with HIV that live in states that expand Medicaid will gain new coverage. Those that live in states that do not expand Medicaid may be left out of coverage, needing to rely on the Ryan White program, including ADAP, if they have no other options. They may find themselves caught in a new "coverage gap"; that is, having no access to Medicaid but incomes too low to qualify for exchange subsidies (subsidies to help purchase coverage through the new exchanges are available to those with incomes between 100% and 133% FPL.)

These coverage decisions will also have important implications for the Ryan White Program. In states that do expand Medicaid, financial pressure on Ryan White, including ADAPs, is expected to ease, although the need for the program will not disappear as evidenced by its current role in supplementing coverage for Medicaid beneficiaries and in serving those who are not eligible for any coverage at all. In states that do not expand Medicaid, Ryan White will need to fill a bigger relative gap. Already, those states that have faced strains in their Ryan White programs in the past tend to be those without childless adult coverage under Medicaid. This is illustrated in Table 3, which identifies the twenty states that have imposed ADAP waiting lists at some point since January 2010. All twenty are states that do not provide Medicaid coverage to childless adults (including one that did but has since closed enrollment); six provide coverage more limited than Medicaid. The majority (14) are states that provide no coverage at all to this population.

## **OPPORTUNITIES & CHALLENGES FOR USING THE AFFORDABLE CARE ACT TO IMPROVE HIV CARE**

Notwithstanding the challenges of implementing such a large and complex law and the uncertainty generated over whether all states will expand Medicaid, it seems clear that the ACA will greatly expand insurance coverage for people with HIV. Moving forward, there are several opportunities and challenges for using the ACA to improve HIV care. One general challenge is how to get the health system to pay appropriate attention to the unique issues of serving people with HIV given that they represent less than 1% of the U.S. population. Even within Medicaid, the largest source of financing for HIV care, HIV represents only about 2% of overall spending.<sup>24</sup> In addition to monitoring state activity with respect to the Medicaid expansion, other issues related to ACA implementation for people with HIV include the following:

### **Transitioning People with HIV to New Insurance Coverage**

Getting all people with HIV to understand whether or not they are eligible for new coverage, and whether they will have access to Medicaid or an exchange is critically important. Additionally, people will likely need assistance in assessing their plan options and enrolling in coverage. These issues may be more consequential for people with HIV than for some other populations because interruptions in care or delays in treatment could have more harmful effects. The Ryan White program is an important resource for supporting the transition to ACA coverage, and therefore offers a key opportunity for federal and state officials to work with Ryan White grantees and relevant stakeholders to develop strategies for transitioning all uninsured, but eligible people with HIV to new coverage.

### **Ensuring Adequate Benefits for People with HIV**

Beyond simply whether new coverage will be available, there are important questions about the scope and adequacy of health benefits for new enrollees in Medicaid and exchange health plans, as well as current Medicaid beneficiaries in the small number of states with limits on benefits, including hard limits on the number of drugs dispensed per month or year. As noted above, while the EHB is intended to set minimum standards, policy decisions that have yet to be made will determine whether the EHB is sufficient to guarantee access to the recommended standard of HIV care. Comprehensive access to prescription drug coverage, consistent with federal HIV treatment guidelines, is perhaps the most significant issue in this regard. The EHB informational bulletin issued last year by HHS indicates that the Department intends to require plans to offer at least one drug per drug class. The current standard of HIV care, however, includes the use of multiple antiretroviral medications, often from the same drug class or across drug classes, simultaneously.<sup>11</sup> While it is unclear how this will be addressed in the final EHB rules, HHS has indicated that it does not intend to adopt the protected drug class policy used in the Medicare Part D drug benefit; under that policy, all Part D drug formularies are required to cover “substantially all” drugs in six protected drug classes, including ARVs, a policy instituted in part to “mitigate the risks and complications associated with an interruption of therapy for these vulnerable populations”.<sup>38</sup> While there are multiple mechanisms through which policymakers could ensure pharmacy access consistent with federal HIV treatment guidelines, monitoring how this issue is addressed in final rules will be important.

Also unclear is whether people with HIV newly eligible for Medicaid under the ACA will be required to enroll in the benchmark plan. A number of groups will be exempt from this requirement, and will instead be offered the traditional Medicaid benefits plan (which may have more expansive benefits; for example, all state Medicaid programs currently cover all FDA-approved prescription drugs, although prior authorization or quantity limits may apply). Exempt groups include the disabled already eligible for Medicaid, dual eligibles, pregnant women, the medically needy, and the medically frail. While non-disabled people with HIV are not specifically listed, they could fall into the medically frail category, which, per final HHS rules, must at a minimum include people with “serious and complex medical conditions.”<sup>39</sup>

### **Ensuring Exchange Plans Implement Core Aspects of a Quality System for HIV Care**

HIV is a complex condition that raises some unique considerations as insurers set up new plans. Given issues of drug resistance and other factors that determine which ART regimens to prescribe for an individual patient, there may be less discretion for plans to manage the antiretroviral pharmacy benefit than for some other conditions. Additionally, ensuring that each person with HIV has access to an experienced HIV provider with current knowledge about the rapidly evolving HIV standard of care is more critical than for some other conditions. Many private insurers, including several national health plans, have been leaders in developing strong and effective HIV systems of care.<sup>40</sup> These entities can provide valuable lessons for others in the field. In addition, the HIV community, including medical providers, Ryan White program administrators, community based organizations and people with HIV, can offer insurers a diversity of experience and expertise to guide plan development. Finding opportunities for these stakeholders to share their relative expertise will be important for helping to develop health systems that include high quality HIV care.

### **Addressing Health Disparities and Ensuring the Health System is Responsive to the Communities Disproportionately Impacted by HIV**

Health disparities in the U.S. remain a critical challenge. They are particularly acute in HIV. For example, gay and bisexual men who make up roughly 2% of the U.S. population comprise an estimated 64% of new infections.<sup>4</sup> Further, HIV disproportionately impacts black and Latino Americans and other people of color. Expanded data collection under the ACA will enable monitoring of progress at reducing disparities. HIV organizations and medical providers have a high level of expertise at making health institutions culturally sensitive and welcoming to diverse populations including gay and bisexual men (including LGBT youth), transgender women, people of color, and low-income populations. Working within local communities, these HIV organizations could seek out opportunities to work with insurers, providers, and health systems to ensure that the expanded health system works for the populations most impacted by HIV.

### **Tracking HIV Clinical Indicators and Getting All Americans with HIV Maximally Virally Suppressed**

To realize the promise of effective HIV treatment for both clinical and public health outcomes, it is necessary to achieve viral suppression in as many people with HIV as possible. One necessary step in achieving this, at the population level, is to develop effective systems for monitoring performance along the treatment cascade. The White House Office of National AIDS Policy commissioned the Institute of Medicine (IOM) to convene a committee to identify critical data and indicators related to continuous HIV care and access to supportive services, as well as to monitor the impact of the National HIV/AIDS Strategy and the ACA on improvements in HIV care. In March 2012, the IOM's committee released the first of two reports on indicators and data systems.<sup>41</sup> The IOM report recommends nine key indicators for monitoring clinical HIV care, along with five additional indicators for monitoring mental health, substance abuse, and supportive services. In addition, the Department of Health and Human Services recently approved the use of seven common core indicators for monitoring HHS-funded HIV prevention, treatment, and care services, consistent with the IOM's recommendations.<sup>42</sup> HIV researchers, medical providers, and others could work with Medicaid programs, health systems, and health insurers to adopt some or all of the IOM's indicators for clinical HIV care and actively use these indicators to monitor and report on improvements in HIV clinical care.

### **Envisioning a new Role for Ryan White**

Finally, it will be important to consider a new role for the Ryan White HIV/AIDS program in the post-ACA world. Ryan White exists to fill in gaps left by the rest of the health system. First established in 1990 as an emergency response to the HIV epidemic, the program has grown into a critical part of the HIV health care delivery system, and the HIV response overall has benefitted from the program's investments in community infrastructure and building HIV-focused institutions and capacity. The Ryan White program has been reauthorized four times since first created and is due to be reauthorized again in 2013, providing an important opportunity to re-assess how to adapt its focus in light of the ACA. This will include consideration of how the Ryan White program can assist people with HIV in their transition to new coverage as well as its continued role in providing care to those who have limited coverage or remain ineligible for health coverage in the future. Maintaining the Ryan White program's flexibility and infrastructure will therefore be important to ensure that the current system of HIV care is not prematurely weakened as the ACA is implemented.

## **CONCLUSION**

The Affordable Care Act has already led to improvements in access to and quality of care for people living with HIV and, when fully implemented in 2014, is expected to significantly expand access even further. At the same time, there are several outstanding questions regarding the implementation of the ACA, and decisions that have yet to be made by the federal government and the states will affect its ultimate reach. There are also key opportunities for working to ensure that new systems of care will include high quality HIV standards for realizing the potential of the ACA to be a "game changer" in reducing the burden of the HIV epidemic in the United States.

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