

May 2017 | Issue Brief

What is at Stake in ACA Repeal and Replace for People with HIV?

Lindsey Dawson, Jennifer Kates

As debate continues surrounding repealing and replacing or transforming aspects of the Affordable Care Act (ACA), and as one such proposal has passed the U.S House of Representatives, questions remain about the potential impact of such changes on high needs populations, including people with HIV. Prior to the ACA, many people with HIV faced significant barriers to accessing health coverage despite national treatment guidelines recommending starting antiretroviral therapy at time of diagnosis.¹ Several of the ACA's key provisions addressed these barriers (see Table 1) and recent analysis demonstrates that the ACA significantly increased insurance coverage for people with HIV.²

Table 1. Key ACA Provisions Expanding Access and Eliminating Barriers to Coverage for People with HIV

Expanding Access
Creation of Marketplaces for purchasing private coverage (Including subsidies for those 100-400% FPL)
Medicaid expansion with eligibility based on income and residency alone (Effectively, state option. 32 states including DC expanded as of May 2017)
Eliminating Barriers
Prohibition of pre-existing conditions exclusions
End to rate setting based on health status
Elimination of annual and lifetime benefits limits
Creation of a benefits floor, including prescription drug coverage

This brief explores the potential implications of different ACA repeal scenarios and related administrative actions on people with HIV. In particular, it looks at the main policy areas under consideration that stand to affect people with HIV the most: (1) the future of the ACA's Medicaid expansion; (2) changes to the traditional Medicaid program; and (3) the pathway forward for private market reforms, including the ACA's health insurance marketplaces. (For a detailed overview of the major policy proposals that have been introduced to date, including the amended [American Health Care Act](#) (AHCA), see Kaiser Family Foundation's interactive ACA replacement plan comparison tool).³

Changes to Medicaid Would Likely Have the Biggest Impact on People with HIV

Medicaid is the single largest source of coverage for people with HIV in the U.S. and its role for those with HIV has significantly expanded under the ACA. Indeed, the Medicaid expansion provision is arguably the aspect of the law that has had the most far reaching effects on people with HIV, driving a nationwide increase in access

to insurance.⁴ Proposals that have been put forward, including the amended AHCA which has now passed the House, have sought to change both the Medicaid expansion and the traditional Medicaid program.

The Medicaid Expansion. Prior to the ACA, under federal law, individuals could not qualify for Medicaid based on income alone.⁵ Enrollees had to be *both* low income *and* fall into another category, known as “categorical eligibility,” such as disability, pregnancy, or being parents. This excluded most low-income childless adults from coverage and created a particular “catch-22” for many low-income people with HIV who could not qualify for Medicaid until they were already quite sick and disabled, often as a result of developing AIDS, despite the availability of recommended medications that could prevent such disease progression.⁶ The ACA fundamentally changed this, requiring states to expand their Medicaid programs to cover individuals below 138% FPL based on income and residency status alone; although a June 2012 US Supreme Court decision effectively made the expansion a state option. To date 32 states (including D.C.) have expanded their programs (where an estimated 62% of people with HIV live).⁷ As part of the expansion, the federal government offered states a historically generous federal match to cover this new population, with 100% federal funding for the first few years, gradually decreasing to 90% in 2020 and beyond.⁸ A recent analysis found that increased Medicaid coverage in expansion states drove a nationwide increase in coverage for people with HIV in 2014, the first year after the Medicaid expansion went into effect.⁹

As part of the repeal and replace debate, the Medicaid expansion has been a major focus because of the impact unraveling this source of coverage would have on the 32 states that have expanded and the millions enrolled through this pathway. The AHCA would retain the expansion but use the (less generous) traditional state match for new enrollees starting in 2020 and for existing enrollees without continuous coverage. A less generous match could mean states would be less willing to cover the new adult population in the years to come and in fact several states already have triggers in place to rescind coverage for the current group if the federal match declines to certain levels. It would also provide a disincentive for other states to expand in the future.

The Traditional Medicaid Program. Proposals to transform the current open-ended nature of federal matching funds to states for the traditional Medicaid program have also been part of the debate. Proposals, including converting the program to a block grant or per capita cap would fundamentally change the financing and structure of the program and shift costs to states.¹⁰ The AHCA proposes a per capita cap approach as a way to limit federal spending and increase state flexibility. However, such an approach could impact access for people with HIV. Under restructured and constrained financing, states would probably respond by reducing services or eligibility to accommodate a loss in federal dollars. Beneficiaries may see increased cost-sharing and providers, reductions in reimbursement rates. As these programs could be structured in a multitude of ways, it will be important to watch how proposals might impact access to coverage for people with HIV in terms of eligibility, benefits, cost-sharing, beneficiary protections, and enrollment requirements. These proposals to change per beneficiary spending would apply to the HIV disability population in traditional Medicaid as well as the newly eligible expansion population.

Administrative Actions. Apart from repealing the expansion or fundamentally changing the financing and structure of the Medicaid program through legislation, the administration can permit broader flexibility for states through the use of 1115 Medicaid waivers which allow states to experiment with new approaches that can result in significant changes. On March 14, 2017, Health and Human Services (HHS) Secretary Price and

Centers for Medicaid and Medicare Services (CMS) Administrator Seema Verma sent a letter to governors outlining the administration’s approach to Medicaid policy. It highlighted the flexibility the administration intends to provide to states with respect to state plan amendments and 1115 waivers. It specifically notes the potential for waivers to include higher beneficiary cost-sharing and adopt alternative benefit designs with features such as health savings accounts and work requirements, all provisions that could impact access to care and treatment for people with HIV.¹¹

Lessons from History

People with HIV have previously faced capitated health financing with respect to ADAP (the prescription drug component of the federal Ryan White Program). Through the program, states receive capped federal grants distributed by formula. For much of ADAP’s history, demand outpaced funding and the states instituted waiting lists. At their height, over 9,000 people with HIV were on waiting lists. Steps were taken to address the emergency (including culling formularies, changing eligibility, infusion of emergency funding, and receiving higher rebates from drug companies), but this experience demonstrated how block grant health financing is not necessarily sustainable or reliable and poses critical public health challenges in the infectious disease context.

Proposed Changes to the Individual Insurance Market Also Stand to Affect People with HIV

The ACA made significant changes to the private insurance market, removing many barriers to access and introducing new benefits and non-discrimination standards. Current legislative proposals and administration actions that seek to modify aspects of the law could scale back some of these changes.

Pre-existing condition protections and rate setting. Prior to the ACA, it was nearly impossible for people with HIV to access private coverage through the individual market. In most states, issuers were permitted to take health status and history into account when deciding whether to issue an individual policy, including under what terms, and in determining premium cost.¹² Most with HIV were considered “uninsurable” and either denied individual market coverage outright or, when offered, rates were typically unaffordable and/or policies included sweeping exclusions.¹³ Under the ACA, individuals are guaranteed access to health insurance through the individual market regardless of health, rates cannot be set based on health status, and lifetime and annual limits are prohibited. Retaining this provision had been a central feature of the original AHCA but doing so is difficult without the individual mandate. The AHCA’s approach is to require a surcharge for those without continuous coverage. The amended version of AHCA passed by the House would significantly erode this protection, permitting states to use a waiver to charge people with pre-existing conditions higher premiums and to sell policies without the Essential Health Benefits (EHBs – more discussion on EHBs below).¹⁴ Such changes could mean that access to coverage may again be more limited for those with HIV and other pre-existing conditions.

Financial Assistance. One of the key provisions in the ACA is the creation of health insurance marketplaces which offer a centralized way for consumers to purchase insurance coverage and financial assistance for those with incomes between 100-400% of the Federal Poverty Level (FPL). This includes Advanced Premium Tax Credits (APTCs), which make the cost of premiums more affordable and cost-sharing reductions (CSRs) which

limit out-of-pocket expenses for the subset with incomes between 100-250% FPL. People with HIV are significantly more likely to be low-income and thus these subsidies will have been particularly important for this population.¹⁵ Without access to APTCs and CSRs, which nearly 10 million enrollees have, many would not be able to afford insurance coverage, including those with HIV.¹⁶

The replacement policies that have been put forward would repeal or change the way financial assistance in the private market is provided. The AHCA would do away with cost-sharing reductions and offer a flat tax credit to be used towards premiums that vary by age but not by income; meaning those with the lowest incomes might have faced the greatest difficulty in affording coverage. Also, the credits would not vary by region (based on a benchmark plan) as they do under the ACA so those living in areas with very high premiums might face greater difficulty affording coverage.

Benefits Provisions. Prior to the ACA, there was no standardized federal benefit package in the private market. Under the ACA, individual and small group insurance policies must cover a suite of 10 “essential health benefits,” including prescription drugs (see full list in note);¹⁷ while whole health and comprehensive care is critical for people with HIV, access to antiretroviral treatment is the most fundamental benefit. Allowing states to obtain waivers of the EHB requirement, as is currently being discussed, would potentially limit coverage for HIV care and treatment. Even if the EHBs are retained, how those benefits are defined could be changed through rulemaking and redefining of EHBs could reduce access to care and treatment for people with HIV.

Administrative Actions. The administration can also reverse past and create new regulations through the rulemaking process or make and modify policy by issuing sub-regulatory guidance. Changes to rule making can impact how the ACA is implemented including through benefit design, cost-sharing, oversight, beneficiary protections, and market stability. For instance, HHS released a final Market Stabilization rule in April of 2017 that will change continuity of coverage requirements, shorten the open enrollment period, tighten special enrollment periods, loosen Actuarial Value (plan generosity) requirements, and pullback on network adequacy and essential community provider requirements and regulatory oversight.¹⁸ Loosening of the network and essential community provider networks in particular could be limiting for people with HIV as it may mean fewer Ryan White and infectious disease providers in plan networks.

Alongside the Market Stabilization rule discussed above, HHS released guidance on plan certification for 2018 and beyond.¹⁹ Building on an Executive Order, CMS detailed its plans to defer certain plan regulatory and oversight functions to states using the federal marketplace related to licensing, good standing, network adequacy (as also addressed in the final rule), and in some cases formulary review.²⁰ It is unclear how this shift towards state oversight will affect such access.

Lastly, starting in 2017 states are permitted to submit 1332 waivers requests, which like 1115 waivers allow states to experiment with coverage requirements and delivery but are specific to private health insurance and the marketplaces (rather than Medicaid). On March 13, 2017, Secretary Price sent a letter to the governors encouraging the use of 1332 waivers. Such waivers provide states with greater flexibility to shape their private markets including plan structure and marketplaces as insurance purchasing centers.

The Ryan White HIV/AIDS Program Will Likely Become Even More Important for People with HIV

The Ryan White HIV/AIDS Program is the federal health safety-net program providing primary HIV medical care, treatment, and support services for uninsured and underinsured people with the disease. Prior to the ACA, Ryan White supported about half of all people diagnosed with HIV and most already had some form of coverage (72% in 2013). Since the implementation of the major ACA reforms, the number of Ryan White clients has increased slightly and the share with coverage has also increased, suggesting that the program continues to play an important role in the lives of people with HIV regardless of insurance status.²¹

For those who gained coverage in the private market or through Medicaid under the ACA, Ryan White has been able to fill in the gaps in coverage and provide critical support services not typically covered by traditional payers, such as case management, transportation, and extended provider visits. In addition, in 2015 nearly 30,000 people with HIV receive insurance purchasing assistance through the Ryan White Program, an activity that has increased under the ACA as people with HIV had greater and more affordable access to the private market.^{22,23} For those who did not gain new coverage – largely because they live in a state that has not expanded Medicaid - Ryan White continues to provide their primary HIV care and treatment.

Under an ACA repeal, coverage gains that have occurred as a result of the law through the Marketplaces and Medicaid expansion could be lost. It is likely that individuals who lose coverage would return to Ryan White to meet their full HIV care and treatment needs, but it is unclear whether the program would be able to absorb clients into traditional HIV care and treatment with existing resources and without resorting to waitlists (see Text Box: Lessons from History). Additionally, Ryan White is not an insurance program and covers only HIV related care so those who have gained insurance coverage and transition back to Ryan White exclusively would face losing access to coverage for other health conditions and emergency services. While the program would still be permitted to assist clients with the cost of insurance, the ability of Ryan White to do so as commonly as it does today without the ACA's subsidies and rate setting protections is in question since by statute such arrangements must be cost-effective for the program.²⁴

In addition to the impact changes to the ACA would have on the program, the federal budget process also plays a critical role in the future of Ryan White. While the Trump Administration's "budget blueprint" or so-called "skinny budget" calls Ryan White out as a priority safety net provider, it also proposes an 18% cut for HHS overall. It is yet to be seen whether the full budget (expected in May) will preserve current levels of funding or propose cuts to the program and ultimately, how Congress will finalize FY18 appropriations. If cuts are realized, the Ryan White Program may not be able to sustain existing levels of service provision, especially if more individuals seek assistance from a program with less funding.

Endnotes

- ¹ Department of Health and Human Services. *Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.* 2016. Available at <https://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>
- ² Kates, J. and Dawson, L. Kaiser Family Foundation. *Insurance Coverage Changes for People with HIV Under the ACA.* February 2017. <http://kff.org/hiv/aids/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>
- ³ Kaiser Family Foundation. *Compare Proposals to Replace The Affordable Care Act.* 2017. <http://kff.org/interactive/proposals-to-replace-the-affordable-care-act/>
- ⁴ Kates, J. and Dawson, L. Kaiser Family Foundation. *Insurance Coverage Changes for People with HIV Under the ACA.* February 2017. <http://kff.org/hiv/aids/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>
- ⁵ Some states used a waiver to create an eligibility pathway with their own funds to cover this population.
- ⁶ Department of Health and Human Services. *Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents.* 2016. Available at <https://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf>
- ⁷ KFF analysis of data from CDC Atlas (HIV Prevalence, 2014) and Kaiser Family Foundation. *State Health Facts. Status of State Action on the Medicaid Expansion Decision.* <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22.%22sort%22:%22asc%22%7D>
- ⁸ In the traditional Medicaid program, the highest match a state receives is Mississippi's at 75.65% and the Median (including DC) match is Oklahoma's at 58.57%.
- ⁹ Kates, J. and Dawson, L. Kaiser Family Foundation. *Insurance Coverage Changes for People with HIV Under the ACA.* February 2017. <http://kff.org/hiv/aids/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>
- ¹⁰ For more information, on block grants and per capita caps see: – Robin Rudowitz. Kaiser Family Foundation. *5 Key Questions: Medicaid Block Grants & Per Capita Caps.* 2017. <http://kff.org/medicaid/issue-brief/5-key-questions-medicaid-block-grants-per-capita-caps/>
- ¹¹ Price, Thomas E. (Sec. HHS) and Verma, Seema (Administrator CMS). Letter to Governors. March 14, 2017. Available at: <https://www.hhs.gov/sites/default/files/sec-price-admin-verma-ltr.pdf>
- ¹² For a detailed look at pre-ACA insurance practices related to eligibility and rate setting see: Claxton, G., Levitt, L., and Pollitz, K. *Pre-ACA Market Practices Provide Lessons for ACA Replacement Approaches.* 2017. <http://kff.org/health-costs/issue-brief/pre-aca-market-practices-provide-lessons-for-aca-replacement-approaches/>
- ¹³ Pollitz, Karen. Sorian, Richard, and Thomas, Kathy. Kaiser Family Foundation. *How accessible is Individual Health Insurance for consumers in less-than-perfect health? How accessible is Individual Health Insurance for consumers in less-than-perfect health?.* June 2001. <http://kff.org/health-costs/report/how-accessible-is-individual-health-insurance-for-2/>
- ¹⁴ MacArthur amendment to the AHCA. Available: <http://www.politico.com/f/?id=0000015b-a790-d120-addb-f7dcoec90000>
- ¹⁵ Centers for Disease Control and Prevention. *Behavioral and Clinical Characteristics of Persons Receiving Medical Care for HIV Infection—Medical Monitoring Project, United States, 2013 Cycle (June 2013–May 2014).* HIV Surveillance Special Report 16. <http://www.cdc.gov/hiv/library/reports/surveillance/#panel2>. January 2016. <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-hssr-mmp-2013.pdf>
- ¹⁶ Marketplace Enrollees Receiving Financial Assistance as a Share of the Subsidy-Eligible Population. <http://kff.org/health-reform/state-indicator/marketplace-enrollees-eligible-for-financial-assistance-as-a-share-of-subsidy-eligible-population/?currentTimeframe=0>
- ¹⁷ The Essential Health Benefits package includes: While the benefits are not defined specifically, except with respect to certain preventative services, impacted plans must cover services related to the following categories: ambulatory services, emergency services, hospitalization, maternity and newborn care, mental health and substance use services (on par with other health services), prescription drugs, rehabilitative and habilitative services, laboratory services, preventive and wellness services, and pediatric services.
- ¹⁸ 82 *Fed. Reg.* 18346-18382 (April 18, 2017), available at <https://www.federalregister.gov/documents/2017/04/18/2017-07712/patient-protection-and-affordable-care-act-market-stabilization>.
- ¹⁹ Department of Health and Human Services. Centers for Medicare and Medicaid Services. *Guidance to States on Review of Qualified Health Plan Standards in Federally-facilitated Marketplaces for the Plan Years 2018 and Later.* April 13, 2017. <https://www.cms.gov/CCIIO/Resources/Regulations-and-Guidance/Downloads/OHP-Certification-Reviews-Guidance-41317.pdf>

²⁰ President Donald J. Trump. The White House. *Executive Order Minimizing the Economic Burden of the Patient Protection and Affordable Care Act Pending Repeal*. January 20, 2017. <https://www.whitehouse.gov/the-press-office/2017/01/20/executive-order-minimizing-economic-burden-patient-protection-and-affordable-care-act-pending-repeal>

²¹ Kates, J. and Dawson, L. Kaiser Family Foundation. *Insurance Coverage Changes for People with HIV Under the ACA*. February 2017. <http://kff.org/hiv/aids/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>

²² National Alliance of State & Territorial AIDS Directors (NASTAD). National ADAP Monitoring Project: 2016 Annual Report. 2016. <https://www.nastad.org/sites/default/files/2016-National-ADAP-Monitoring-Project-Annual-Report.pdf>

²³ Dawson, L. and Kates, J. Kaiser Family Foundation. *The Ryan White Program and Insurance Purchasing in the ACA Era: An Early Look at Five States*. 2015. <http://kff.org/hiv/aids/issue-brief/the-ryan-white-program-and-insurance-purchasing-in-the-aca-era/>

²⁴ Compared to the cost of directly purchasing medications.