

# THE AFFORDABLE CARE ACT, MEDICAID, THE RYAN WHITE PROGRAM, AND ONGOING HEALTH REFORMS

## Reducing Barriers to Care and Treatment in the Fight Against AIDS

Health care access is important to increase the number of people living with HIV who are retained in care and to **prevent future transmissions of HIV**



### Ensure Effective Implementation of the Affordable Care Act

According to the Centers for Disease Control and Prevention (CDC), more than 1.2 million people are living with HIV in the United States, but only 40% receive regular medical care, due in part to being unaware of their HIV status, and barriers to treatment and care including affordability, stigma, and lack of adequate facilitative services like transportation and housing.<sup>1</sup> Lack of treatment and care for HIV results in poorer health outcomes, higher long-term medical expenses for our health system, and increases the likelihood of future HIV transmissions.

The Affordable Care Act (ACA) has significantly improved access to coverage and care for people living with HIV. The ACA requires insurers to cover a minimum set of benefits and prohibits previously allowed discrimination based on pre-existing conditions or health status. Many people living with HIV have been able to acquire health insurance for the first time through the ACA-created Insurance Marketplaces and Medicaid expansion.

Despite 18 million Americans receiving health insurance coverage under the ACA, attempts to dismantle the law continue. We urge members of Congress to defend the ACA and all it has accomplished while promoting further health reforms to address ongoing unmet need, including advancing the triple aim of all health reforms—better care for individuals, better health for populations, and lower per capita costs.

### Protect the Medicaid Program and Ensure Continued Opportunities for States to Expand

Medicaid is the single-largest source of health insurance for people living with HIV in the U.S., covering half of all people living with HIV who regularly receive treatment.<sup>2</sup> Proposals to end Medicaid's entitlement status threaten the health not only of people living with HIV, but for all of the 69 million people

who rely on the program. Spending caps and block grants shift costs onto states and would likely result in states cutting critical optional services, such as prescription drugs, and further limiting already restrictive provider networks. Spending caps or block grants would also hinder states' ability to respond to public health emergencies (such as disease outbreaks) and provide access to new, effective cures or treatments for serious or chronic health conditions.

Medicaid coverage historically was limited to those who had progressed to an AIDS diagnosis. Under Medicaid Expansion, access to critical services are made available to those living at 138% of the Federal Poverty Level (FPL), no longer requiring them to first progress to AIDS before accessing support. This improves health outcomes for individuals and provides long-term cost-savings for society at large. Full implementation of Medicaid expansion would provide 115,000 previously uninsured people living with HIV with consistent, reliable insurance coverage.<sup>3</sup> Altering Medicaid's structure threatens the potential to expand the program and could lead states to reverse prior expansion decisions. Although Medicaid expansion is now optional for states, full funding of the program will demonstrate an ongoing federal commitment to Medicaid and encourage state participation in Medicaid expansion.

As more states consider improving coverage for their poorest residents, we ask Members of Congress to support legislation that would allow states that expand Medicaid coverage now, and in the future, to receive the same three-year period of full federal support followed by the same gradual phase-down as states that have already implemented Medicaid expansion. This would incentivize states to provide Medicaid coverage and would benefit people living with HIV, many of whom are too low-income to afford marketplace coverage. Combined with other efforts to ensure effective implementation of the ACA, this will increase the number of people who know their HIV status and are retained in care, improving individual health and reducing future HIV transmissions.

AIDSWatch is organized by the Treatment Access Expansion Project (TAEP), United States People Living with HIV Caucus (HIV Caucus), & AIDS United, and made possible by the generous support of the following sponsors.



## Continue Investing in the Ryan White Program

The Ryan White HIV/AIDS Program continues to play a critical role in addressing coverage gaps and affordability of health care for people living with HIV. It also ensures access to care and treatment for those who remain uninsured. Ryan White remains the largest source of federal funding exclusively dedicated to HIV-related treatment, care, and support services, serving 536,000 people with HIV each year.<sup>4</sup> Continued investment in this program will help reduce future transmissions and contain HIV care costs.

Ryan White is a payer of last resort and an important safety net for low-income people living with HIV, particularly in states that have not expanded Medicaid under the ACA. People who have health insurance also count on the program for access to uncovered, yet essential, health care services or for help with premium and cost-sharing payments. Integrating Ryan White's coverage and affordability completion services with health reforms can help end the epidemic. One example of this is Massachusetts, where residents with HIV are twice as likely as the national average to be retained in care and virally suppressed. Higher levels of viral suppression dramatically reduce the ability to transmit HIV and have contributed to a 37% decrease in HIV transmission in the state since 2002, while other states have seen flat or increased rates of transmission.<sup>5,6</sup>

are expected to be approved in 2016.<sup>7</sup> These innovative drugs are often specialty medications, the type of medications that many people living with HIV need to stay healthy. Many insurers have intentionally tried to limit access to these medications in a variety of ways, such as posting misleading or intentionally vague formularies on marketplace websites, making it difficult for people to determine whether a plan covers their medications, or placing these treatments in specialty tiers that require the greatest co-pay and co-insurance costs. Some plans also exclude essential HIV medications, such as single-tablet regimens, from drug formularies altogether, or place drugs needed by people living with HIV on formulary tiers with extremely high cost sharing.

- Congress should examine methods to control treatment access issues related to formulary transparency, coverage of essential medication, and the high cost of prescription drugs.
- Congress should enact a federal law limiting cost sharing for specialty medications; for example \$100 or \$150 per prescription per month or \$1,000 annually. California, Maryland, Delaware, Louisiana, Maine, Maryland, New York, and Vermont have already passed similar bills, but to ensure that everyone across the country has access to more affordable prescription drugs, a federal law is needed.
- Congress can also increase transparency by requiring issuers to display or link their full formularies on marketplace websites and include the true out-of-pocket cost for prescriptions.
- Additionally, Congress should prohibit issuers from altering their formulary once the open enrollment period to select plans has ended. Congress could also pass legislation requiring Medicare to use its bargaining power as a major purchaser to negotiate with pharmaceutical companies for better prices—a practice banned by current law.

Implementing these reforms will ease the burden of prescription costs on consumers, enable better adherence to treatment regimens, and ultimately save lives.

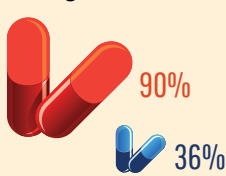
## Massachusetts vs. The U.S.

COMPARING RESULTS OF TWO HEALTH CARE SYSTEMS

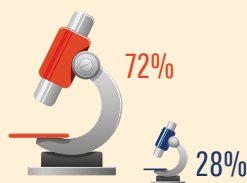
In Medical Care



Taking HIV Medications



Virally Suppressed



## Enact Laws to Reduce the Burden of Rising Drug Prices

One of the public's urgent health care concerns is the affordability of prescription drugs. In 2015, the FDA approved the largest number of first-of-a-kind medications, and more

<sup>1</sup> Centers for Disease Control and Prevention. *Today's HIV/AIDS Epidemic*. July 2015. Available at: [www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf](http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/todaysepidemic-508.pdf).

<sup>2</sup> Kaiser Family Foundation. *Medicaid and HIV*. March 5, 2013. Available at: <http://kff.org/hiv/aids/factsheet/medicaid-and-hiv-aids/>.

<sup>3</sup> Kates, J and Garfield, R. The ACA and People living with HIV: The ACA's Impact and the Implications of State Choices. *Health Affairs*. March 3, 2014. Available at: <http://healthaffairs.org/blog/2014/03/03/the-aca-and-people-with-hiv-the-acas-impact-and-the-implications-of-state-choices/>.

<sup>4</sup> Health Resources and Services Administration, HIV/AIDS Bureau. About the Ryan White HIV/AIDS Program. n.d. <http://hab.hrsa.gov/about/aboutprogram.html>.

<sup>5</sup> Freyer FJ. State's Steps to Control HIV Seen as Model for Nation. *The Boston Globe*. January 15, 2015. Available at: [www.bostonglobe.com/metro/2015/01/15/massachusetts-residents-with-hiv-twice-likely-have-illness-under-control/4mhlp5hdBathDyh4wckbZM/story.html](http://www.bostonglobe.com/metro/2015/01/15/massachusetts-residents-with-hiv-twice-likely-have-illness-under-control/4mhlp5hdBathDyh4wckbZM/story.html).

<sup>6</sup> Lewis, S. Massachusetts Department of Public Health, Office HIV/AIDS. Care Cascade Presentation: Ryan White Part A Boston EMA, HIV Health Services Planning Council. January 9, 2014. Available at: [www.bphc.org/whatwedo/infectious-diseases/Ryan-White-HIV-AIDS-Services/boston-planning-council/meeting-materials/Documents/Care%20Cascade%20presentation%20Boston%20Planning%20Council%20Jan%202014.pdf](http://www.bphc.org/whatwedo/infectious-diseases/Ryan-White-HIV-AIDS-Services/boston-planning-council/meeting-materials/Documents/Care%20Cascade%20presentation%20Boston%20Planning%20Council%20Jan%202014.pdf).

<sup>7</sup> Perone, M. The First of a Kind Drug Approvals Continued Rise in 2015. *Associated Press*. January 4, 2016. Available at: [www.washingtonpost.com/business/first-of-a-kind-drug-approvals-continued-rise-in-2015/2016/01/04/df38f622-b2f3-11e5-8abc-d09392edc612\\_story.html](http://www.washingtonpost.com/business/first-of-a-kind-drug-approvals-continued-rise-in-2015/2016/01/04/df38f622-b2f3-11e5-8abc-d09392edc612_story.html).