



## Watchdogging the ACA for People with HIV

by Robert Greenwald

**T**he first open enrollment period of the Affordable Care Act (ACA, also known as Obamacare) ended on March 31, 2014. The good news is that we've made significant progress for many uninsured people, including those with HIV. More than eight million people signed up for private health insurance through the insurance marketplaces, and more than three million people signed up for Medicaid. In states that have expanded Medicaid under the ACA, almost all low-income people now have access to comprehensive health care.

Since 1996, the Treatment Access Expansion Project (TAEP) has been working to expand access to health care for low-income people with HIV, hepatitis, mental illness, and other chronic health conditions. Currently, TAEP is working to ensure that the promises offered by the ACA become a reality.

### Medicaid Expansion

The ACA fits together like a puzzle. Everyone up to 133% of the Federal Poverty Level (FPL) – about \$15,000 a year for an individual – could now be eligible for Medicaid. Under the old Medicaid program, in most states, you not only had to be poor, but you also had to be disabled to be eligible. People with HIV had to become sick and disabled by AIDS to qualify for Medicaid, instead of getting the treatment that could have prevented them from getting sick in the first place. The ACA Medicaid expansion eliminates the disability requirement – now, if you have a low income, you're in.

But, since the Supreme Court made Medicaid expansion optional for states, the sad reality is that where you live now makes a big difference, especially if you have a chronic health condition like HIV. That's distressing, given that in the past decade we've really made progress, particularly with the Ryan White program, to make sure there is a balanced distribution of resources. Now, our lowest-income people living in states that have not expanded Medicaid are just left out—an awful and unacceptable situation. Many of the non-expansion states are in the South, which has high numbers of people newly diagnosed with HIV. Without Medicaid expansion, the growing number of people with HIV who have poor health outcomes will only increase.

The ACA's subsidies for private health insurance cover people from 100% FPL to 400%. There's a little overlap: people who make between 100–133% of FPL can choose between subsidies to buy private health insurance or can enroll in Medicaid, if they live in a Medicaid expansion state. However, there are no subsidies for people who earn below 100% FPL. When the ACA was written, it was expected that everyone below 100% FPL would be covered through Medicaid expansion. So a person below 100% FPL in a state that has not expanded Medicaid can apply for a private marketplace plan, but will not get any subsidy to help them pay for it.

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We're hopeful that this situation will change. When Medicaid was first enacted in 1965, there were many states that resisted its implementation and held out for long periods of time. It took years for states like Texas and Arizona to sign on. But ultimately they came on board, and now all 50 states provide traditional Medicaid to all eligible residents. We are optimistic that, eventually, that will happen with the new Medicaid expansion.

People who live in states that have not yet expanded Medicaid are soon going to realize that not only are they being denied health insurance, but that their federal tax dollars are paying for coverage in other states. People are going to make their politicians feel the heat. Those elected officials are denying the citizens of their states access to care that is overwhelmingly federally

supported, just for their own political posturing and gain. That is unacceptable and they should ultimately face the choice of signing on to health reforms or losing their jobs.

Right after the last presidential election, many Republican governors changed their positions to support Medicaid expansion. Over time, this trend will continue as people in non-expansion states demand access to the benefits of health reform that are taking place in expansion states. So again, I'm optimistic that we're going to get many, many states onboard within the next five to ten years. We just need to stay the course and we will win.

## Marketplace Plans

It's also exciting that so many people with HIV now have access to private health insurance through the marketplaces. In addition to the subsidies for people from 100% to 400% FPL, the ACA includes many reforms to the health insurance system. Insurers can no longer exclude people or charge them more based on pre-existing health conditions. They can no longer impose annual or lifetime caps on benefits for a specific health condition. And now young adults can remain on their parents' health plans until they are 26.

In exchange for these new provisions, the ACA created the "individual mandate" – everyone who is not otherwise insured now has to buy insurance or pay a penalty. So the insurance companies, in exchange for no longer "cherry-picking" (trying to keep sick people out of their plans), are getting millions more customers.

In theory, the ACA's reforms to private insurance should mean that longstanding barriers to insurance coverage for people with HIV and other chronic conditions are now eliminated. But the reality is that the insurance industry is resistant to change. Insurers have spent billions of dollars for decades to keep sick people off their plans and to maximize their profits. That isn't going to change overnight – it would be naïve to think that they won't keep trying to do that in some way. In fact, that's what we're seeing: discriminatory practices that are intentionally designed to reduce enrollment by people with HIV and other expensive health conditions.

Here is a brief summary of some of the trends we are seeing used by insurers to restrict access to health insurance for people with HIV:

## Transparency

The ACA mandates that marketplace plans must clearly state what services they cover, what drugs they cover, what costs come with their plans, and which providers are part of their plans. Yet we are seeing a pattern of intentionally leaving HIV meds and HIV providers off these lists. The companies say, "Oh, the websites are a work in progress" or "We just forgot to include them."

The fact is, these practices effectively discourage people with HIV from enrolling in these plans, and that's discriminatory. By law, plans are not allowed to leave the HIV meds they cover – or any other meds they cover – off the public list of drugs covered by their plan. Every time TAEP sees this, we are holding them accountable, and we are working to ensure that government insurance regulators also hold them accountable.

We've made tremendous progress in getting insurers to be more transparent, as more and more plans now show the complete list of covered meds and network providers. However, there is still a lot of work to do to ensure that people get the information they need in an easy-to-read, standard format. That would make it possible for consumers to compare plans and make informed decisions as to which plan truly meets their health care needs.

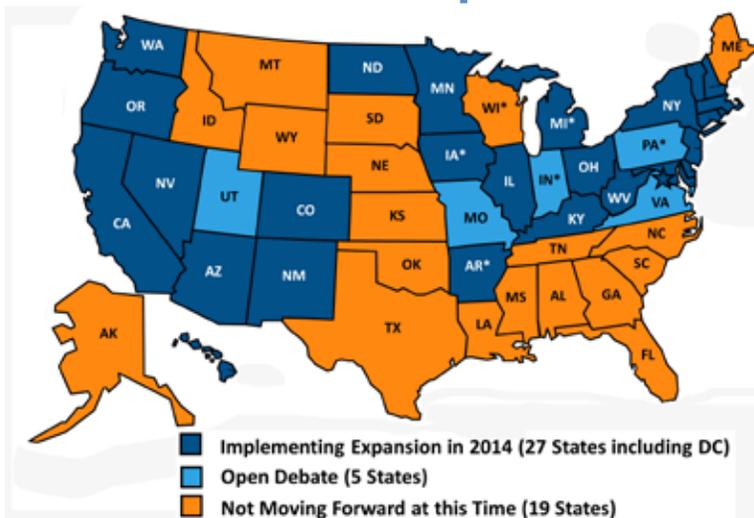
## Covered Medications and Services

Access to HIV drugs, specialists, lab tests, and other HIV-related services is important, but so are all of the other services people with HIV need – whether to treat diabetes, heart disease, or the other health conditions that arise as we get older. That's why access to private health insurance is an important step forward for many people with HIV, as they now have coverage for comprehensive health care beyond just treating their HIV.

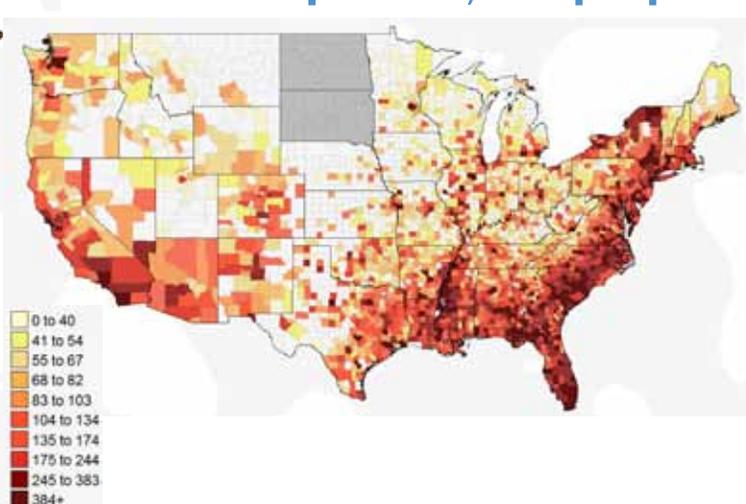
The ACA also requires that all plans sold on the marketplace provide essential health benefits (EHBs) including hospitalization, maternity care, mental health and substance use services, prescription drugs, rehabilitative services, lab tests, preventive care, chronic disease management, and other services.

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## Medicaid Expansion



## HIV Cases per 100,000 people



Source: Kaiser Family Foundation, March 26, 2014

Source: AIDSvu.org, 2010

Yet, despite the EHB requirement, we are seeing plans that keep some HIV medications, like single-tablet regimens, off their lists of covered meds, or that don't cover HIV genotype tests – another way for insurers to discourage people with HIV from enrolling. While we're making progress in these areas, as many insurers have agreed to add the missing HIV meds to their covered drug lists, there's a lot more work to be done. Many drugs and necessary services are still not covered by some insurance plans. Also, we must be continually on guard against new, similar attempts by insurers to get around the law and save money by denying needed services to people with HIV.

### Costs

While transparency and covered services have improved, one increasing cause for alarm is the trend in the new insurance plans to put HIV and other expensive medications into very high cost-sharing tiers. "Cost-sharing" refers to the amount that consumers have to pay for medications or services. Some companies have put every HIV med on the highest tier, charging 50% co-insurance. This means that consumers have to pay half of the price of the medication! So, even though people have insurance, they still have to pay thousands of dollars until they reach the out-of-pocket maximum allowed under the ACA, which is \$6,350 per year for people with incomes above 250% FPL. While the ACA does reduce the maximum out-of-pocket limit for people below 250% of the FPL, it can still be as high as \$5,200 for an individual, and that's also unacceptable. Charging 50% co-insurance for a med that has no generic alternative is simply a way to keep people with HIV from enrolling in their plan. It's discriminatory and will be challenged in the months ahead.

### The Speak Up Project

While tens of thousands of people with HIV now have increased access to health care, barriers continue to exist. Perhaps the most blatant effort by insurers to restrict access happened when insurers in both Louisiana and North Dakota tried to stop accepting third-party payments, including payments from the Ryan White Program that have for many years helped people with HIV meet their health care costs. When this happened, thousands of people with HIV could not enroll in new insurance plans, since the insurers refused to accept payments from the Ryan White Program.

Fortunately, our advocacy efforts first led a federal district court to stop the insurers from refusing to accept the payments, and then to the federal government issuing new rules requiring insurers to accept the payments. This shows the power of advocacy. The key is continued vigilance. We hope we won't have to go to court for each new barrier, but if that's what it takes, we will. And to make sure we know what the issues are for people with HIV across the country, we have created the "Speak Up" project, along with AIDS Foundation of Chicago and several other partners.

Speak Up is a website where people with HIV and their service providers can report problems with the new health plans. We want to hear about any issues with signing up for new health coverage (either Medicaid or private insurance). Once people have insurance, we want to hear about any problems getting care and treatment.

We are monitoring and analyzing all these problems. We use the information to educate officials about the needs of people with HIV, to show the need for improvements to the ACA, and to advocate for change. Whenever possible, we refer people facing barriers to local attorneys and advocates who can help them file grievances and appeals. We will also be reporting back to the community on what we learn.

To find out more about Speak Up or to report a problem with health insurance, go to [www.hivhealthreform.org/speakup](http://www.hivhealthreform.org/speakup).

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### Next Steps

While Speak Up is only a month old, we have already identified some key problem areas. Addressing these issues will require regulations that:

- Amend the Essential Health Benefits (EHB) rule to require coverage of all HIV medications, including fixed-dose combinations and single-tablet regimens, in accordance with HIV treatment guidelines.
- Require health insurance plans to provide complete and accurate health provider and coverage information (including which meds are covered) in a standard format, including the actual out-of-pocket costs that consumers must pay.
- Amend the EHB rule to prohibit coinsurance from exceeding 25% for HIV drugs that are widely accepted in treatment guidelines if there is no generic version.

We can win these reforms, but it will take advocacy. Otherwise, we'll see too many people with HIV falling through the cracks even though they have health insurance. There are also a few other advocacy issues that must be among our top priorities.

### Premium Assistance

We must help people with HIV in states that have not expanded Medicaid. In states with governors or legislators opposed to "Obamacare" the best hope may be to allow states to expand Medicaid through what is called "premium assistance." This means that the state uses Medicaid dollars to purchase private insurance for people who would be newly eligible for Medicaid. Several states, starting with Arkansas, have implemented this route to expansion.



TAEP supports this option as long as the state provides all the benefits and services of Medicaid at no additional cost to consumers. The political reality is that without it many low-income people, including many people with HIV, will lack health care. Too many politicians have pinned their political careers on opposing Obamacare. Premium assistance allows them to say, “I’m not doing Obamacare. Instead, I’m going to take their money and I’m going to privatize Medicaid and get people private health insurance.” If they want to spend millions of extra dollars to privatize Medicaid, and they are willing to guarantee that low-income people get the same benefits at the same cost as everyone else, we aren’t going to try to stop them. In fact, we spend a lot of time in Southern states working with legislators to help them see this as a path forward. And it appears to be working well in Arkansas and other states.

Stacey Bowser, the director of the Ninth Street Ministries Clinic in Arkansas recently said, “Because people are qualifying for insurance through the ACA, our free medical clinic will not be needed anymore. There was such a need for many years that we would have people coming through the medical clinic from the time the doors opened early in the morning all the way until 4:00 in the afternoon.” But over the past several months, the number of patients has dwindled to next to nothing. Only about 80 people came through the clinic in February. By March, that was down to just three people. “Our services won’t be needed anymore, and this will conclude our mission,” Bowser explained.

## Support for Ryan White

The success of the ACA for people with HIV also depends upon adequate levels of funding for the Ryan White Program. Despite their strengths, both Medicaid expansion and the marketplace private health insurance plans still have significant gaps in coverage. For example, they generally don’t include vision and dental care. They often don’t cover essential support services, like transportation, food, child care, and other services. These services, which are provided by Ryan White, are critical to ensuring that people with HIV achieve the viral suppression that improves both individual and public health. Without these services, we will not be able to address the challenges of HIV care.

Since its creation, the Ryan White Program was meant to be a safety net, filling gaps in health care. Because the holes were so big before the ACA, Ryan White essentially became the health system for uninsured people with HIV.

In addition, Ryan White can help with costs for people who are newly insured. Coinsurance is often extremely high and even with subsidies, the costs are out of reach for many low-income

people with HIV. Ryan White can help them meet their premium and copayment costs.

Perhaps most important, Ryan White remains the primary source of care for low-income people with HIV left out of new insurance options because they live in states that have not expanded Medicaid or because they are immigrants. For these people, Ryan White remains the sole source of health care, which is essential to address the HIV epidemic effectively. Ryan White reduces health care costs and improves individual and public health outcomes, since treatment is also prevention.

## The Beginning

The start of the ACA is not the end of the story, it’s the beginning. The foundation is in place, but the floor that has been set is not sufficient to meet the needs of all people with HIV. We must raise the floor to make sure that all of the health care needs of people with HIV in the U.S. are met. While there is no cure or vaccine for HIV, we do have the tools to keep people with HIV retained in care, virally suppressed, and healthy. We have what it takes to dramatically reduce the transmission of HIV and create an AIDS-free next generation – now it’s time to go out and do it. ■

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