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Obamacare: Not So Affordable for People With HIV and Hep C

Getting Obamacare passed and up and running was just the first round in the struggle to bring universal health care to people living with HIV and hepatitis C.

March 1, 2014 By Benjamin Ryan

After years of fighting for universal health care in the United States, advocates for people living with HIV and hepatitis C virus (HCV) are waging a new uphill battle against the often harsh reality found within the tangled web of Obamacare's insurance marketplace plans. Myriad insurers across the country have designed Affordable Care Act (ACA, or Obamacare) plans that leave out the "affordable" angle and leave those with chronic health conditions with prohibitively expensive out-of-pocket costs as well as restricted medication and health provider options.

This is troubling news for the estimated 23,000 people with HIV who are expected to sign up for the insurance marketplace plans during the current open enrollment period that continues through March 31. (Another 26,000 are expected to gain health care access through expanded Medicaid programs.) Those Americans with lower incomes do of course qualify for government subsidies to help pay for premiums, and in some cases copayments and coinsurance as well. And there are caps on out-of-pocket health care expenditures in these plans. But these safeguards are often insufficient to make care accessible to those with a chronic health condition.

"What we're seeing here is trends that are disturbing us and that we want to nip in the bud," says Anne Donnelly, director of health care policy at Project Inform in San Francisco.

Donnelly is among those who contributed to a call to arms issued by the Fair Pricing Coalition in February. The group highlighted a series of egregious practices and policies on the part of private insurers that are often critically limiting options for those with HIV and HCV.

While the ACA stipulates that no insurer may deny coverage to someone with a pre-existing or chronic health condition, the FPC argues that some private insurers are attempting to skirt this element of the law by putting up barriers that amount to discrimination against those with HIV and HCV. For starters, some plans exclude first-line HIV medications from their formularies as well as the widely prescribed single-tablet regimens.

Many insurers have placed both HIV and HCV drugs in the most expensive copay or coinsurance tiers, the latter of which requires paying a percentage of the drug's cost as opposed to a flat fee. The data analysis firm Avalere analyzed numerous bronze and silver plan formularies, which have the least expensive monthly premiums but more expensive cost sharing than the gold or platinum levels (silver also qualifies for government assistance with cost sharing for those who make between 100 and 250 percent of federal poverty level), from plans across the country. The group found that 91 percent of these plans had "specialty drug tiers," in which certain drugs require greater out-of-pocket expenditures, compared with just 23 percent of employer-based insurance plans.

Avalere also found that, out of the four major categories of HIV medications, an average of just 72 percent are covered in the plans included in the group's analysis. An average of 81 percent of branded drugs with no generic equivalent are on the formularies. Meanwhile, just over half of branded HIV drugs that have no generic equivalent require coinsurance. The average coinsurance is 35 percent of the drug's cost.

According to the Fair Pricing Coalition, the result is that many people with HIV or HCV will hit their maximum out-of-pocket cap within the first few months of their insurance plan's policy year, a figure that can be as high as $6,350 for those with relatively larger incomes.

Confusion also abounds when it comes to choosing a health plan for those with chronic conditions. Formularies are often inaccurate or inaccessible, and deducing the cost sharing associated with any particular drug may be impossible during the selection process.

Louisiana has become a battleground in the question of whether people with HIV who are insured by marketplace plans have the right to have the federal Ryan White HIV/AIDS Program pay for their monthly premiums. In February, the state's Blue Cross Blue Shield program announced its intentions to reject all third-party premium payments, citing guidelines issued in November by the Centers for Medicare and Medicaid Services (CMS) that advised insurers not to accept them.

This move is especially critical for those people with HIV who make less than 100 percent of the poverty level, because they do not qualify for insurance premium subsidies from the federal government and Louisiana has refused to expand its Medicaid program.

CMS has since clarified that the November directive does not include the Ryan White premium payment program. Nevertheless, BCBS, the largest commercial insurer in Louisiana, is sticking to its guns. Two other state insurers, Louisiana Health Cooperative and Vantage Health Plan, have followed suit in rejecting Ryan White payments. This leaves just one state marketplace plan, which operates in only one parish, that still accepts them.

"Blue Cross is playing discrimination pure and simple, trying to see if they can get away with it," says Lynda Dee, spokesperson for the Fair Pricing Coalition.

BCBS representative John Maginnis claimed in a statement that the move to reject third-party payments does not only affect one group of people and that it is intended to thwart fraud—for example, to keep a medical equipment supplier from offering to subsidize the premiums for a plan from which that supplier would be more likely to benefit financially.

On February 20, the LBGT group Lambda Legal filed a class action lawsuit in U.S. District Court for the Middle District of Louisiana against the three insurance companies, seeking a reversal of their policies with regards to the Ryan White funds. The court has scheduled a March 10 hearing to decide upon whether to place a preliminary injunction that would force the insurers to continue to accept Ryan White payments for premiums until it can render an ultimate decision. Otherwise, the insurers plan to stop accepting all third-party premium payments in April.

On the national front, an army of AIDS service organizations and other concerned parties are mobilizing to put pressure on insurers, pharmaceutical companies and the federal and state governments to address Obamacare's apparent alienation of many people living with HIV and HCV.

Andrea Weddle, executive director of the HIV Medicine Association (HIVMA), says of the current realities of the Affordable Care Act: "Now is the opportunity to see how it's playing out and to work to address it and really make it work as well as it can for people with HIV."

Along with the American Academy of HIV Medicine, the HIVMA has issued a release urging insurance companies to reduce cost sharing, to cover single-tablet HIV regimens, not to require cumbersome prior authorization of ARVs, and to ensure convenient access to medications through pharmacy networks.

Covering similar territory, the Fair Pricing Coalition has issued its own series of guidelines for fighting barriers to coverage for people with HIV and HCV. The group advocates for including HIV and HCV diagnoses as a qualification for enrolling in a marketplace plan, or switching to a new one, outside of the open enrollment period.

Robert Greenwald, director of the Center for Health Law and Policy Innovation at Harvard Law School and Maura Calsyn, director of health policy at the Center for American Progress, have collected sign-ons from nearly 300 regional and national organizations to a letter urging U.S. Department of Health and Human Services Secretary Kathleen Sebelius to address the marketplace plan status quo as it pertains to people living with HIV. The letter pressures the secretary to require insurers issuing these polities to: accept third-party premium payments, limit coinsurance to no more than 25 percent for specialty drugs, publish complete and accurate formularies that specify out-of-pocket costs, and require coverage of widely preferred specialty medications that have no generic equivalent.

All this quagmire aside, Project Inform's Donnelly for one does not want people with chronic health conditions to lose sight of the forest for the trees.

"First and overriding, health care reform as a whole, with all of its troubles and everything, is a huge step forward for folks with HIV," she says. "And so now our work is to bring it home and do all the changes that need to happen in order to make it really work.”

For information about how to obtain health insurance if you are HIV positive, click here. If you have hepatitis C, click here.