How Does Obamacare Affect People With HIV?

May 16, 2016

“People with HIV who gained health coverage under [the Affordable Care Act, or ACA] are more comfortable navigating insurance two years later, but problems persist, others remain uninsured.” Thus reads the headline of a press release summarizing findings of a new report by the Kaiser Family Foundation (KFF).

Two years into major coverage expansions of the ACA—a.k.a. Obamacare—the report finds that more people with HIV recognize their new benefits but continue to worry about affording coverage, while those in states that didn’t expand Medicaid are often uninsured.

As it did for the previous reports, KFF held focus groups in five states—California, Florida, Georgia, New York and Texas—this time in early 2016, to assess the experiences of HIV-positive people regarding their ACA coverage.

KFF hosted a panel discussion about these topics on May 4. You can watch that policy briefing here.

In the executive summary of the report, KFF lists these key findings:

- While in 2014, participants who gained insurance coverage were still in the early stages of figuring out how to use it, insured participants in this round of research reported using their coverage regularly to meet their HIV care and treatment needs. They reported that their health is easier to manage as a result of gaining coverage and appear better able to navigate using insurance than their 2014 counterparts. They have found relief and security in becoming covered.

- Still, despite some increased comfort with coverage, participants remain unsure of how to fully assess plan options and, as in 2014, put a lot of trust in case managers to help make enrollment

decisions. They continue to lack some basic insurance literacy, but unique to this round of research, many participants across the sites knew that access to health care varied across the country.

- Those with insurance recognized its benefits, but some worry about being able to maintain coverage. Those with private insurance worry about costs, and those with Medicaid find recertification stressful.

- Only a few participants have made changes to their plans since first enrolling. One individual switched to a different metal level plan by choice and was unexpectedly met with higher costs, and two others were moved into new coverage automatically.

- As was found in the 2014 groups, those who live in non-Medicaid expansion states and remain uninsured, largely because they fall into the coverage gap, feel that they can meet their HIV care and treatment needs through the Ryan White Program, which they say is lifesaving, but have many other health problems that are going unaddressed. When they learn that their state chose not to expand Medicaid, they are dismayed but not surprised. Almost all say if their state later expanded the program, they would enroll, especially those who have past experience with Medicaid coverage.

- More than gaining insurance, most report that their finances are the biggest stress in their lives; they struggle to make ends meet and many face substantial medical debt.

- Just as in 2014, many respondents report close relationships with their HIV providers. They say having a provider who is a specialist and who has a consistent role in their lives is important, and in seeking out new coverage many prioritize being able to maintain these relationships. Choice in pharmacies was also important, with respondents identifying a range of preferences regarding how they get their medications.

- The Ryan White Program continues to provide a crucial role in the lives of almost all the participants, especially the uninsured. Ryan White clients were enormously grateful for the program but, like Medicaid enrollees, faced challenges around recertification time. Unlike in 2014, those who have gained coverage tend to be less aware they are still connected to the program despite reporting using support services, like case management, that are funded by Ryan White.

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