Health Reform’s Uncertain Impact on HIV Patients

By Jason Kane
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In 2014, many HIV patients who receive medication through state-based drug assistance programs will be shifted to other forms of health coverage.

It’s an uncertain time for most HIV patients in the United States. A full two-thirds of them rely on government-subsidized health insurance — or else have none — and the health care reform law is about to shake things up.

Starting in 2014, when the major provisions of the law kick in, many of the HIV-positive patients who currently receive medication through state-based AIDS Drug Assistance Programs will be shifted onto the Medicaid rolls; others will receive subsidized coverage through their state’s health insurance exchange.

As most AIDS advocates see it, that means better access to comprehensive health care for their patients, which most agree is an undeniable good thing. So why are so many AIDS program managers losing sleep over the full implementation of the health care reform law?

A new report in the journal Health Affairs shows widespread confusion among the program managers concerning the law and its implications for the services they provide.

“Many said that they were overwhelmed by the complexity of the Affordable Care Act, and some expressed fear that state AIDS Drug Assistance Programs would be eliminated entirely,” the report states.

Primarily, many fear that if policymakers see the AIDS Drugs Assistance Programs as unnecessary or duplicative after 2014 — and pull funding for the programs as a result — patients could be left to navigate the complicated new health care landscape on their own. In states that decide not to expand Medicaid, a funding reduction for the AIDS Drug Assistance Programs could mean that some patients would lose access to affordable medications entirely.

Erika Martin, principal author of the study and assistant professor at Rockefeller College of Public Affairs & Policy at the University at Albany and fellow at the Rockefeller Institute of Government, interviewed AIDS Drug Assistance Program managers in 22 states to assess the way the health reform law will impact their services. She joined the PBS NewsHour to discuss her conclusions about how those program managers are — or should be — planning for such an uncertain future.

NEWSHOUR: Erika Martin, thank you so much for joining us. Let’s start broadly. How will the health reform law change coverage for patients with HIV?

MARTIN: Prior to health reform, there was a patchwork of public programs and fewer than a third of people living with HIV had private insurance. People could receive Medicaid if they were low-income and met some other categorical eligibility requirements such as disability. People with long-term disability could move to Medicare after a couple of years.

The Ryan White HIV/AIDS Program was a “payer of last resort” for people who were HIV-positive but not yet disabled or not
low-income enough to qualify for these other programs.

Health reform will do a couple of big things, including the Medicaid expansion which will allow people whose incomes are up to 133 percent of the federal poverty level to qualify regardless of these other categorical requirements. In addition, individuals with income between 133 to 400 percent of the poverty level can access private health insurance on new state health insurance exchanges at a subsidized rate.

And then there’s also some new consumer protection rules on private health insurance. People can stay on their parents’ plans until age 26, which is important for young adults who are newly infected with HIV. There are no more lifetime or annual coverage limits. Previously, a health insurance company could limit the amount of reimbursed benefit. And health insurance plans can no longer deny coverage due to pre-existing conditions such as HIV. Health insurance plans that are offered on the exchanges also have to offer a minimum set of essential benefits. In addition, there are provisions to encourage primary care and preventive medicine.

**NEWSHOUR:** All of these changes will have major impacts for organizations currently providing services to HIV patients. What are the fears of program administrators?

**MARTIN:** Currently, about a quarter of all people living in the U.S. with HIV have drug coverage through the AIDS Drug Assistance Program, one component of Ryan White. One fear is that Ryan White will be defunded, thereby eliminating AIDS Drug Assistance Programs. The Ryan White program gets reauthorized every three to five years, with a re-authorization scheduled this summer, the year before all these big coverage changes are set to happen. Policymakers might perceive that the “problem” of HIV care has been solved due to new coverage options.

Other fears are that clients might still continue to fall through the cracks. Although there is federal funding for new consumer assistance programs to help patients navigate the new environment, a lot of HIV patients are very vulnerable and have a lot of competing needs, and it might be very confusing to figure out what programs they qualify for, how to get on health insurance and how to use that health insurance.

Out-of-pocket costs are pretty sizable. Currently, patients who are in these AIDS Drug Assistance Programs might not need to pay large — or any — copays on medication. Now, as they’re being moved to new sources of coverage, there might be some pretty sizable copays and deductibles, in addition to high premiums. So it’s not as affordable as one might hope.

Finally, the law is incredibly complex — over 900 pages — and states are ultimately responsible for implementing many of the provisions. That means that program managers need to interpret federal guidance and regulations within their state context. For example, some states may have insurance regulations that are more stringent than federal guidelines, and other states may require legislative permission to enact major changes to their AIDS Drug Assistance Programs. AIDS Drug Assistance Programs in states that choose to use the federally-run insurance exchange (rather than setting up their own state-run exchanges) will need to coordinate with the federal government.

**NEWSHOUR:** How these programs adapt to help with these new needs?

**MARTIN:** In theory, many AIDS Drug Assistance Program clients should be eligible for Medicaid, which will be expanded in some states, or subsidized health insurance through insurance exchanges. AIDS Drug Assistance Programs can help people transition to different sources of coverage, and staff will work as navigators to help patients understand the new system and how to enroll in these different programs. Rather than paying directly for drugs and services for patients, now these programs can pay for health insurance premiums or copays, which will still be expensive. AIDS Drug Assistance Programs can also provide “wrap around” coverage for services not reimbursed by the primary source.
of insurance, as well as direct services to patients who fall through the cracks.

NEWSHOUR: How much will these services vary based upon the home state an HIV-positive patient?

MARTIN: I chatted with program managers before the Supreme Court decision in 2012, which says that states cannot be forced to expand Medicaid. Before the decision, they were talking about needing to find new ways to offer services to clients — things like navigating the new environment, helping patients pay for health insurance, or paying for the premiums and deductibles, etc. Now, I imagine that how state programs need to adapt depends on the state.

In a state like New York, which will expand Medicaid and is thoughtfully considering how to set up its exchange, the adaptation might have more to do with thinking about what specific services are not being covered by Medicaid or private insurance, and how to assist clients with purchasing and using insurance. In contrast, in a state that’s not going to expand Medicaid, the program will to continue to directly provide medications.

NEWSHOUR: Even in states that will expand Medicaid, there will still be some HIV-positive patients who aren’t able to access care through health reform, correct? Theoretically, these patients would still need to rely on the AIDS Drug Assistance Programs for basic medication and treatment services.

MARTIN: Yes, that’s true for immigrants and individuals who are unable to afford adequate coverage, even with the subsidies. Lawfully residing immigrants cannot receive federal benefits for at least five years and will be ineligible for key provisions of health reform.

Undocumented immigrants are also unable to access the federally funded programs. However, the AIDS Drug Assistance Programs are not prohibited from providing services to recent and undocumented immigrants. That’s important for the overall fight against HIV. Unlike most other chronic diseases, HIV is also an infectious disease. Treating patients is important for reducing future infections, thereby averting future medical costs.

Some citizens may also continue to rely on AIDS Drug Assistance Programs. The price of the health insurance plans on the exchange — even with the subsidies — is pretty high when you consider the premiums, deductibles and copays. Some program managers that I talked to predicted that the tax penalty for not buying insurance will be less expensive than buying insurance, and that insurance will remain unaffordable for many low-income patients. And then you have some folks who might not enroll because their lives are very complex and getting insurance can be overwhelming. They may have other co-morbid conditions, have social services needs, and getting insurance might not be their top priority. So they just might not be willing or able to get insurance.

For all of these groups, AIDS Drug Assistance Programs will still be important.

NEWSHOUR: So do you think the upcoming changes and uncertainty could lead the U.S. in the wrong direction in the HIV fight?

MARTIN: But I do think that there could be one major unintended consequence. Health reform pushes us in a lot of positive directions, but it also has a lot of gaps. The law is still not going to provide perfect coverage, or reduce the cost of health insurance as much as it should, and I think the mistake would be thinking it’s going to solve all problems with the health care system when it doesn’t. If in 2014 — as Medicaid expands in some states and the health reform exchanges go live — if policymakers start to defund Ryan White and other discretionary programs for vulnerable populations, that could have major repercussions.

If all states were to expand Medicaid, I don’t think it would be inappropriate if Ryan White funding would eventually decline over time. Many of these services would then be offered elsewhere. But the main concerns from program managers is that they would need to have Ryan White funding in the short-term, at least through 2016, to get people through this transition. As one of the program
managers said very colorfully, “It’s not like people will wake up on Jan. 1, 2014, and all of a sudden they will have health insurance and know what to do with it.” It’s going to take several years to transition people to different coverage sources. In addition, there’s a very real concern in some states — especially the ones that won’t expand Medicaid — that if Ryan White funds dry up, they will still need to provide the services they do now but they will have far fewer resources to do so.

NEWSHOUR: What’s the takeaway here?

MARTIN: Overall, I think it’s a very exciting time in the HIV fight, with great opportunities. There’s a mathematical possibility that if you put everyone living with HIV on medication, you can substantially reduce the number of new infections and eventually eliminate the epidemic. But what a lot of people — and I think many policymakers — don’t realize is that this requires a very long-term commitment. With appropriate therapy, people who are living with HIV can stay alive for nearly a full life span. Even if there are minimal new infections, there will continue to be a large number of people who need to stay on their medications for at least 40 years into the future.

My fear is that we will become over-confident that we have “solved HIV,” and that, in turn, will pull funding away from Ryan White and Medicaid and other programs that provide important services to low-income patients. That would cause the number of new HIV infections to rise again in the future. We also need to continue to invest in HIV prevention programs even if new infections decline, simply because treating people alone is not going to eliminate the epidemic.

Overall, I would say that we have a lot of new tools to address the HIV epidemic and evidence that these tools are very effective when implemented well, but the main challenge is to maintain our focus and commitment to continuing to fund these important programs.

NEWSHOUR: Erika Martin, thank you so much for joining us.

MARTIN: Thank you.