Proposal to Shift Funding for HIV/AIDS Program Divides Legislators, Advocates

By Melissa Attias, CQ Roll Call

A bipartisan group of House lawmakers has introduced legislation to make changes to the Ryan White HIV/AIDS Program, but a number of advocates oppose the bill and are reluctant to delve into the law even though it’s technically months overdue for a reauthorization.

The advocates want some time to gauge the effects of the health care overhaul (PL 111-148, PL 111-152). They say they are comfortable sustaining the program, which provides medical services to low-income patients with HIV/AIDS, through the appropriations process in the meantime.

The Ryan White program’s most recent authorization expired at the end of September (PL 111-87), just as open enrollment began on the new health insurance exchanges.

“We think we need a year or so with the ACA under our belts,” said William McColl, political director for AIDS United and co-chairman of the Ryan White Work Group of the Federal AIDS Policy Partnership, referring to the health care law.

North Carolina Republican Renee Ellmers introduced the bill (HR 4260) last month with Democrats Eddie Bernice Johnson of Texas and Bennie Thompson of Mississippi, winning praise from the AIDS Healthcare Foundation. The group said in a news release that the measure would ensure the program’s funding distribution is evidence-based and that the money targets effective interventions.

According to information provided by Ellmers’ office, southeastern states including North Carolina have seen their populations of HIV-positive individuals grow over the last several years while they declined in cities that had large HIV-positive populations in the past.

But those cities still get more Ryan White dollars per patient, her office said, which means many southern states do not have the money to make sure patients get virus-suppressing drugs that control the spread of HIV.

The bill would require the Health and Human Services secretary to submit a report to Congress by Sept. 30 on the funding allocations and include a plan to keep each state’s funds per HIV/AIDS patient from varying by more than 5 percent from any other state.

The measure also includes provisions to set up projects that create Ryan White Savings Accounts. Also, it would require those who receive Ryan White services to be under the care of a primary care team led by an HIV medical provider.
“As a nurse, I have seen firsthand the pain and anxiety that an HIV-positive diagnosis can cause and look forward to seeing this bill quickly move through the House of Representatives,” Ellmers said in a statement.

But McColl said the bill currently lacks the community support that would allow advocates to build a large coalition around it and includes provisions that he thinks would be difficult for everyone to back.

In a recent newsletter, AIDS United said the bill conflicts with its position to wait to move forward until the health care law is implemented further and expressed concern about its provisions, including the savings accounts. While the organization does not support the bill, McColl said the larger Ryan White Work Group would see if there are pieces members can agree on for the next reauthorization.

Both Ann Lefert, director of policy and health care access for the National Alliance of State and Territorial AIDS Directors, and Carl Schmid, deputy executive director of The AIDS Institute, also said that it’s not the time to move forward. Lefert said NASTAD cannot currently support the bill, maintaining that advocates do not get a lot of opportunities to make adjustments to authorization measures.

“The Ellmers bill is not the place that NASTAD and I think the community would prefer to start in terms of our discussions about what Ryan White will look like in the future,” said Lefert, who also is co-chairwoman of the Ryan White Work Group with McColl.

Schmid said the bill is unnecessary because a provision that limited how much money areas could lose as part of the Ryan White funding allocations ended when the reauthorization expired, allowing funds to flow based on case counts. The best way for North Carolina and other southern states to help HIV patients would be to expand Medicaid, he added.

Asked about some advocates’ push to put off a reauthorization until more of the health care law is implemented, Ellmers spokesman Tom Doheny said the bill is not a reauthorization. It makes small changes to increase patient choice while directing HHS to examine how to make the funding formula more equitable, he said.

“Congresswoman Ellmers agrees [a reauthorization] would be inappropriate until we see how the changes to our healthcare system play out,” Doheny said in an email.

Named for an AIDS patient and advocate who died at age 18, the Ryan White program helps provide HIV-related services to low-income individuals by filling in gaps that other sources do not cover. Schmid said the program has, and always will, be the payer of last resort, noting that 72 percent of the people on Ryan White have some form of insurance coverage already, the largest source being traditional Medicaid.

Although Schmid said some Ryan White patients may be able to buy insurance on the exchanges, he said the Medicaid expansion is the most important because clients are largely very poor. One future issue will be the question of what to do with the states that do not expand, he said, such as whether their allocations should increase and the fairness of rewarding states for not expanding Medicaid.
“That’s going to be the issue that Congress and the administration have to deliberate over in the future,” Schmid said.

Lefert also noted that advocates do not yet know how many people will enroll and how well they will be able to access care under the health care law. In Massachusetts, advocates said Ryan White funding shifted under the state’s health overhaul from direct services like buying medication to helping with copayments and premiums.

But no matter what role the Ryan White program takes, supporters say they don’t see it going away in the foreseeable future.

“I think we will need a robust Ryan White program for a very long time,” said Jenny Collier, convener of the Ryan White Medical Providers Coalition.