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Economy Hurts Government Aid for H.I.V. Drugs

By KEVIN SACK

FORT LAUDERDALE, Fla. — The weak economy is crippling the government program that provides life-sustaining antiretroviral drugs to people with H.I.V. or AIDS who cannot afford them. Nearly 1,800 have been relegated to rapidly expanding waiting lists that less than three years ago had dwindled to zero.

As with other safety-net programs, ballooning demand caused by persistent unemployment and loss of health insurance is being met with reductions in government resources. Without reliable access to the medications, which cost patients in the AIDS Drug Assistance Program an average of \$12,000 a year, people with H.I.V. are more likely to develop full-blown AIDS, transmit the virus and require expensive hospitalizations.

Eleven states have closed enrollment in the federal program, most recently Florida, which has the nation's third-largest population of people with H.I.V. Three other states have narrowed eligibility, and two of them — Arkansas and Utah — have dropped scores of people from the program.

Last week, because of swelling numbers here in South Florida, the nationwide waiting list surged past record levels set in 2004, to 1,781 people, according to the National Alliance of State and Territorial AIDS Directors. The growth is expected to continue when Georgia starts deferring enrollment in its drug assistance program on July 1. Illinois may soon follow, and New Jersey plans to cut eligibility on Aug. 1, removing 600 of the 7,700 people on its rolls.

Louisiana capped enrollment on June 1 but decided against keeping a waiting list. "It implies you're actually waiting on something," said DeAnn Gruber, the interim director of the state's H.I.V./AIDS program. "We don't want to give anyone false hope."

Ten states' programs have stopped covering drugs that do not directly combat H.I.V. or opportunistic infections. Unless money is found by Aug. 1, Florida plans to pare 53 of 101 medications from its

formulary, including those for conditions that are often related to H.I.V., like diabetes, high blood pressure and anxiety.

In many states, there is a sense of reverting to the 1980s and early 1990s, before the development of protease inhibitors reversed the rise in AIDS deaths.

“The worry then was that there were no medications for AIDS,” said Dr. Wayne A. Duffus, medical director of the drug assistance program in South Carolina. “The worry now is that there are medicines, but you can’t afford them. A lot of patients are certainly old enough to remember what happens if you don’t get your medicines.”

For the moment, pharmaceutical companies have stepped into the breach, negotiating discounts for the state drug plans and accepting needy patients into programs that temporarily provide free medications. Although there is no data to prove it, state AIDS directors said a vast majority of people on waiting lists seemed to be getting medications one way or another.

But they concede that some patients may be going without, and that caseworkers are being diverted from critical tasks while navigating a thicket of cumbersome applications seeking drug companies’ help.

“The drug companies are trying their best to lower prices,” said Carl Schmid, deputy executive director of the AIDS Institute, an advocacy group. “But we cannot rely on them to finance the health care of poor people living with H.I.V. and AIDS.”

Tim Sweeney, 49, a Fort Lauderdale man who has depended on the assistance program for a dozen years, said he was put on Florida’s waiting list because he was four days late to re-enroll, as is required every six months. Mr. Sweeney, who has AIDS, takes six H.I.V. pills twice a day, as well as three other medications. Their total retail cost: \$4,500 a month.

Unemployed for 18 months, Mr. Sweeney said he spent three days filling out forms to apply for aid from pharmaceutical companies. While awaiting responses, he is being supplied with drugs, one week at a time, by the AIDS Healthcare Foundation, a social service agency.

The patchwork arrangement gives him little comfort. “My biggest fear,” said Mr. Sweeney, who credits the drugs with vastly improving his immune cell counts, “is that I’ve done all this hard work over 20 years and now I’m going to fall back.”

Scott Miller, 42, a northeast Florida truck driver who lost his health insurance in May along with his job, said he had never before sought assistance during five years with H.I.V. When his caseworker told him there was a waiting list, he asked what he was supposed to do.

“She just shrugged her shoulders and said, ‘I don’t know what to tell you,’ ” Mr. Miller said. After several days without drugs, Mr. Miller qualified for a free three-month supply of his medication, Atripla, from Bristol-Myers Squibb.

Dr. Helmut Albrecht, director of the infectious diseases program at the University of South Carolina School of Medicine, said he knew of one wait-listed patient who had died after a seizure while awaiting approval from drug company programs.

“In my world, there is never a certainty if meds would have prevented death,” Dr. Albrecht said, “but the fact remains that the wait certainly did not help.”

Drug assistance has grown since 1996 to become the largest component of the federal Ryan White program, which provides grants to states and localities. The drug program’s budget from all sources is now \$1.6 billion, with Washington contributing about 55 percent, states offering 14 percent and drug company rebates accounting for 31 percent, according to the state AIDS directors.

A confluence of factors has caused the strain. Enrollment has spiked during the recession, up 12 percent from June 2008 to June 2009, to about 169,000 people. The trend has probably accelerated since then. In Florida, monthly enrollments grew by a third between May 2009 and May 2010.

A renewed emphasis on testing is also driving up caseloads, and federal treatment guidelines now recommend an earlier start to drug therapy. Because the drugs are so effective, people often stay on the rolls for extended periods.

Meanwhile, federal financial support has stayed essentially flat, up barely 2 percent this year, while appropriations from state budgets have fallen 34 percent, according to the state AIDS directors. The drug companies increased their contribution by half, to nearly \$500 million, but it is still not enough.

Once fully implemented in 2014, the new health care law is expected to close the gaps by expanding Medicaid, subsidizing private insurance and requiring insurers to cover pre-existing conditions.

More immediately, two Republican senators, Tom Coburn of Oklahoma and Richard M. Burr of North Carolina, have proposed redirecting \$126 million from stimulus spending to the drug assistance program.

President Obama opposes taking money from stimulus projects but is “working to ensure” that the program gets adequate financing, said Shin Inouye, a White House spokesman. He did not provide details. Mr. Obama recommended a \$20 million increase in next year’s drug assistance budget.

In Florida, where AIDS deaths have dropped by two-thirds since the introduction of antiretroviral drugs, state officials cannot forecast how long the waiting list might be necessary. Unemployment stands at 11.7 percent, and there is no budget relief in sight. The list, which was begun on June 1, already holds 361 names.

“I know people are scared,” said Thomas M. Liberti, chief of the state H.I.V./AIDS bureau. “We haven’t had a waiting list in 14 years. Unfortunately, we did not outlast the recession.”

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