

The future of AIDS Drug Assistance Programs: The 'days ahead are very dark'

By [Marcos Restrepo](#) | 02.11.11 | 10:59 am

If Kenneth Keeton, a Lake Placid man who describes himself as “borderline full-blown AIDS right now,” had to rely on Florida’s AIDS Drug Assistance Program, an underfunded system that provides HIV/AIDS drugs to low-income patients, or the charity of a private pharmaceutical program, he says the consequences would be dire.

“I would probably get sick and die,” he says.

Keeton, the sole caretaker for his ailing mother, spoke at the AIDS Drug Assistance Program (aka ADAP) [emergency funding summit](#) in Fort Lauderdale two weeks ago, discussing the lack of AIDS organizations in his area and how three friends died while on the Drug Assistance Program waiting list.

A [temporary solution](#) to the current Drug Assistance Program funding crisis to secure HIV/AIDS medication for more than 6,500 Florida patients was signed last week.

Keeton tells the Independent that after speaking at the Drug Assistance Program summit, he hasn’t “been able to reach anybody or heard from anybody about these issues.”

Florida has reduced the medications available through its Drug Assistance Program, not offering drugs that deal with opportunistic infections, which leaves patients on their own to deal with AIDS-related illnesses.

For Michael Rajner, legislative director of the [Florida GLBT Democratic Caucus](#), what prompted the state’s funding crisis was a combination of factors: rising unemployment and poverty, government funding not rising to match the need and a decision by the Crist Administration to not take advantage of medication rebate programs.

Rajner also says that the state legislature that has not adopted a science-based understanding of the problem, instead basing its plans on Christian beliefs and conservative views.

“The current state legislature and administration doesn’t want to humanize the issue,” Rajner says. “They only care about money.”

Keeton has never been on Florida's lengthy Drug Assistance Program waiting list, but did use program services about a decade ago. "I needed AIDS meds and had no insurance," he says.

Today, housing is Keeton's priority, "I've been on Social Security and get \$837 a month and an apartment starts at \$650," Keeton says, arguing that in Lake Placid it is hard to get medical assistance. "You get no other help than the health department, and you get minimal care there."

Keeton also worries about other services for people living with HIV and AIDS.

"We don't receive the services like areas where there are AIDS services organizations," Keeton says. "There are no lawyers here who offer help for things like advanced directives and your will and last testament."

"People don't have enough help to access medication," Rajner says. "In the AIDS community, some focus too much on ADAP. We are going to face issues with funding for HIV/AIDS prevention. We have a bigger fight on our hands than ADAP."

Rajner says "Democrats are struggling to address real dire needs of Americans" as Republicans "have tried to eliminate funding for programs the rest of Americans need, including health care."

He points to the Affordable Care Act, adding that without it, "the payout for HIV/AIDS medications will be greater, the hardship will be greater, you'll find preexisting conditions, people won't qualify for health care coverage, you'll find more people will not be able to afford health care coverage."

Joey Terrill, domestic testing manager for the [AIDS Healthcare Foundation](#), says the focus is on how to keep the Drug Assistance Program funded till Affordable Care Act provisions kick in in 2014. But he adds that nobody really knows the impact the Care Act will have on current HIV/AIDS programs.

"The administration has given indications that people living with HIV will be included in high-risk insurance pools, but nothing is set in stone," Terrill says.

What is sure, he says, is that state and federal agencies will be cutting spending in the near future.

Terrill points out that at the state level, departments of health services need to cut bureaucracy and administrative costs as a way to endure till 2014. His organization's advocacy has focused on the federal government and especially the drug companies, the only ones left to do something about the Drug Assistance Program crisis.

According to Terrill and Rajner, AIDS activists have become too complacent.

"Feeling that our work has been done, those spirited activists have been absorbed by agencies funded by the pharmaceutical companies so they are not as inclined to criticize," Terrill says. "There are organizations that offer support services for people with HIV without being fired up about advocacy to contain the epidemic."

Terrill also says it is apparent that the disease moves among the urban and rural poor, the African-American and Latino communities, and that many of these folks had not participated in any advocacy around HIV/AIDS and due to a heavy cultural stigma have been reluctant to speak out on their own behalf.

According to the 2009 Bureau of HIV/AIDS [update](#) in Florida, "more blacks are living with HIV than any other racial or ethnic group."

Rajner says the "days ahead are very dark."

"Unless people begin to engage in these debates, we won't see any change," he says.

Keeton says that many “have not gotten tested because of fear.” “The whole thing is about stigma: It is a gay man’s disease,” Keeton says. “Testing should be a normal part of health care.”

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