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Service providers already feeling the loss

By Megan Broderick

WATERBURY — People with HIV and AIDS face losing medical services and supplemental assistance because Connecticut this spring lost federal funding for infected low-income residents. As service providers tally their losses from a statewide \$1.6 million or 8.65 percent funding cut, they're not certain where clients will go if they turn them away. That's troubling for people like Carmen Cruz, 51, of Waterbury, who found out three years ago she is infected with HIV.

Cruz relies on funding through New Opportunities, Inc. in Waterbury to help pay her electric bill and provide food for herself and her 18-year-old mentally disabled son. She believes she was infected by a dirty blood transfusion in Puerto Rico when her spleen was removed in the 1980s. She moved here in 2002 seeking better services for her son.

After years of aching bones, pneumonia and nosebleeds, Cruz was diagnosed during a visit to Saint Mary's Hospital. Because of her illness and her need to care for her son, she doesn't work. Her illness qualifies her for \$623 a month in Social Security disability benefits. Her monthly rent is more than \$400. Without help through New Opportunities, Cruz said, she fears she would be homeless.

Hundreds of low-income patients fear similar fates, whether the loss of their homes or of drug treatment and counseling that keeps them away from risky behavior, said Thomas Butcher, director of the Ryan White Title I office in New Haven. His office helps oversee federal AIDS funding distributed in Connecticut. When asked where people can go for help if turned away from current services, Butcher said, "That's part of the issue — we don't know."

The federal government distributes funding annually through the Ryan White Program, which helps states provide services to people with the virus who are low-income, uninsured or under-insured. The funding year for Ryan White runs from March 1 to Feb. 28.

Most of the funding comes in two rounds — first to two Connecticut regions where the majority of HIV and AIDS cases are concentrated, and second to services statewide. In December, Congress passed the Ryan White Modernization Act, which targets regions that saw 2,000

or more new AIDS cases in five years and changed the formula used to determine funding.

Connecticut's money went from \$18.4 million to about \$16.8 million.

While all services, from primary medical care to assistance with transportation, faced cuts, caregivers in this area were hit particularly hard partially because non-medical services, like the help Cruz receives, make up much of what they provide.

The new formula mandates 75 percent of funding be spent on core medical services including primary care, substance abuse rehabilitation and mental health services. That leaves even less to go toward services such as food assistance, emergency financial assistance, rent assistance and transportation. Funding reductions at several local service providers were far more drastic than 8 percent.

Caregivers worry losing these types of services will contribute to patients falling out of care, shortening their lives and spreading the virus. Help paying an electric bill or keeping food in the kitchen can prevent someone from becoming desperate for money and returning to the risky behavior that may have caused them to contract HIV in the first place, caregivers say. "This program does save lives," said Ric Browne, director of the AIDS/HIV Assistance Program at New Opportunities in Waterbury, which helped more than 200 people with HIV and AIDS in the past year. Browne is also co-chairman of the Greater Waterbury HIV/AIDS Consortium, a group of caregivers in Waterbury and the Naugatuck Valley.

"This place is a safety net where we can help these people maintain a good life."

Richard deJesus, 50, of Waterbury, learned he had HIV in 1988 and spent the next five years selling and using drugs with abandon, believing death was imminent. In 1992, he sold drugs to an undercover police officer and instead of prison was offered a treatment program. He said he has been clean since but would not stay that way without the support and services at New Opportunities. "I'd probably have to resort to crime to get money," said deJesus, who cares for an 11-year-old son and receives Social Security disability benefits.

Local losses

Local service providers have tallied these losses so far:

- Waterbury Hospital's HIV/AIDS clinic, which treats about 400 patients, has enough funding from the hospital and other sources to maintain primary care through the end of June. But it already has lost money for one-on-one substance abuse counseling, alternative therapies and a drug reimbursement program. It is relying on its connection with the hospital and receiving supplemental funds expected from the federal government soon to maintain the current level of primary care and case management after June.

- The AIDS/HIV Assistance Program at New Opportunities Inc. in Waterbury lost one of two staff members and will be able to provide case management to about 45 people as opposed to 144, food to 50 instead of 131 and transportation to 60 rather than 120 as of March 1. It lost \$7,700 it had last year to spend time going into the community to find people who have fallen out of care or not sought care. Last year, 32 people were helped through that outreach program

- Birmingham Group Health Services' Valley Mental Health Center in Naugatuck, the only Ryan White-funded program in the Naugatuck Valley, went from 1½ staff members to one. It is decreasing its clinical time where clients receive mental health and substance abuse services from 20 hours per week to four, case management from 70 clients to about 35 or 40. It received \$5,000 for a food pantry as opposed to \$15,000. It also lost funding for outreach.

- Staywell Health Care Center in Waterbury saw mental health services for HIV/AIDS patients reduced from 30 hours per week to 7.5 hours, primary care from 13 hours per week to four and their dental program funding reduced from about \$30,000 last year to \$6,050. It has started a waiting list for mental health services and patients may have to wait for several weeks for a primary care appointment.

- Connecticut Counseling Center Inc., which provides methadone treatment in the city, lost more than \$100,000 of its federal HIV/AIDS funding, but the center is planning to try to continue the services as usual by applying for other grants. The center serves 1,200 to 1,500 people monthly, with 15 to 20 percent of them HIV positive.

Waterbury's Health Department said it can absorb some of the people who lose case management. Last year, the health department provided case management to 134 people with HIV/AIDS. But officials there are unsure how many more they can take on before reaching capacity and the department commonly refers clients who need food and housing assistance to many of the organizations that have received cuts, such as New Opportunities.

Ripple effect'

The Modernization Act that changed the formula was approved by Congress in December.

Connecticut's congressional delegation wrote a letter recently to Gov. M. Jodi Rell saying they believe the problem stemmed from the way Connecticut's Department of Public Health submitted its number of current HIV cases to the federal government. HIV and AIDS caregivers also blame the state.

Rell wrote a letter in response to the congressional delegation saying the state was not at fault and is subject to federal guidelines. The federal Health Resources and Services Administration, which administers the Ryan White Program, follows the formula mandated by the law.

"Hordes of people with HIV and AIDS are going to look to other areas to try to get their services, so there is going to be a ripple effect," said Shawn Lang, director of public policy with the Connecticut AIDS Resource Coalition. "They're going to be put on waiting lists and have long waits for services that they may previously have had easier access to."

The cuts come at a time when health care for those living with the virus has been revolutionized, allowing people to live much longer than ever previously expected if they have access to the right programs. AIDS can now recede back to HIV and can become nearly undetectable in the body. Babies whose mothers are HIV-positive are rarely born with the virus because of drugs given to the mother while she is pregnant.

"The field has been revolutionized. People are living for decades" said Dr. Merceditas Villanueva, who specializes in infectious disease at Waterbury Hospital's HIV/AIDS clinic. "But HIV can be spread. It may not be treated because of funding cuts and the epidemic will just continue to grow."

Patients like Cruz and deJesus are speaking out, calling and writing to legislators and helping those with HIV and AIDS who might be hesitant to voice their opinions. "Sometimes they're afraid to speak because they don't want anyone to know," Cruz said. "I'm very open with my health and I'm speaking for them, too."

Sara Echevarria, 43, who found out she was HIV-positive in 1989 and was thrilled to have recently celebrated another birthday, sees now as a chance to remind people that HIV and AIDS are still a significant problem.

"I thought it was a death sentence," she said during a support-group meeting at New Opportunities recently. "This is a place to come and talk to someone where you can feel safe. It's scary to be alone. People are living longer, we still need a voice to say, 'It's still here.'"