

Puerto Rico's AIDS Care in Disarray Over Funds ^[1]

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Disclaimer: This article has been taken from the New York Times, online edition, written by Erick Eckholm, and published on June 5, 2007. [see article at [NY Times](#) ^[2]]. SAN JUAN, P.R. — His emaciated body advertises the damage wreaked by the AIDS virus. But over the last year, Rolando Warren González, 41, a former steel band member, has faced an extra challenge to his survival. From the shelter where he lives in Loiza in Puerto Rico's impoverished northeast, Mr. González travels an hour and a half by bus to reach the government clinic where he receives his "cocktail" of antiviral drugs. "But sometimes I go, and they just don't have the medicines," he said. Six times in the last year, he said, he has suffered two-week periods with no drugs, undercutting the life-prolonging benefits of modern therapies against H.I.V., the AIDS virus. Accounts like his — and worse — are repeated across this tropical territory of the United States, where hundreds of H.I.V. and AIDS patients are not receiving vital medical care, say a host of doctors, community groups and patients. The disarray in treatment reflects a stew of problems. An overstretched health care budget is accentuated by rivalries between the commonwealth and the San Juan city governments, which run separate AIDS programs. But federal officials and many local doctors say the main culprit is the island's poor management of the available money provided for AIDS care under the Ryan White Act, amounting to \$53 million last year. Clinics have not received drugs on time, and private groups that assist AIDS patients are often reimbursed six months late or more, causing some to cut services or even shut down. In sharp rebukes to the Puerto Rico Health Department and the City of San Juan, federal officials have put the AIDS grants under unusually

tight review and even threatened to halt some federal money. Because of disorganization, the officials say, the island has often failed to spend all its Ryan White aid, losing access to \$6.5 million over the last five years. Adding questions, in December the F.B.I. raided four San Juan Health Department offices, seizing 400 boxes of documents in a criminal investigation into possible misuse of Ryan White grants. Officials here deny misusing funds. They did have to establish a waiting list for new patients needing drug treatment in the fall, but say that any lapses in care have been brief and that their main worry, in an era when treating a single AIDS patient can cost more than \$25,000 a year, is a shortage of money. At a time when patients live longer and drug costs soar, the challenge is daunting. But doctors and patients here say the government has made poor use of its money. "The state of H.I.V. treatment here is a catastrophe," said Dr. José Varga Vidot, director of Community Initiative, a private group in San Juan that provides primary care to 1,600 patients including drug addicts, prostitutes and homeless people. Dr. Varga Vidot said he knew of at least 75 people who were unable to obtain all their drugs from government clinics for up to a month. In relation to its population of 3.9 million, Puerto Rico has the fifth-highest concentration of AIDS cases of states and territories, with 12,000 patients and estimates that as many more are infected with H.I.V. but are not yet ill. About half the patients were infected from shared heroin needles, posing special challenges because many are isolated and penniless. Although no studies have tried to link the spotty care with mortality, according to the latest comparative national data, 580 patients died here in 2003, indicating a mortality rate higher than that in states like New York known for good AIDS care. A majority of H.I.V. and AIDS patients are covered by the Puerto Rican version of Medicaid, known as Health Reform. That financially struggling program does not cover some crucial drugs. The \$53 million provided under the Ryan White law is supposed to fill the gaps. As a territory, "we don't get what we need," said Health Secretary Rosa Pérez-Perdomo. Federal aid to the Medicaid program here is capped at \$240 million, meeting 13 percent of the overall budget, Dr. Pérez-Perdomo said. On the mainland, poorer states receive up to 75 percent of their Medicaid money from Washington, giving them more leeway in treating low-income AIDS patients. Advocates for AIDS treatment in the United States, where the disease is increasingly concentrated among blacks and Hispanics, juxtapose President Bush's new call for \$30 billion to expand AIDS care abroad, a politically popular cause, with the stagnant financing of the Ryan White program for needy Americans. That has remained around \$2.1 billion for four years. "At a time of rising needs at home, especially among minorities, Puerto Rico and the states all have to compete for flat Ryan White funds," said Dennis DeLeon, director of the Latino Commission on AIDS in New York. The advocates say Washington should do more to reshape a dysfunctional care system on the island. The Health Resources and Services Administration, which administers the Ryan White money, has repeatedly pushed for streamlining the crushing bureaucracy here and sent many advisers, said Dr. Laura Cheever, deputy associate administrator at the agency. The F.B.I. raid, on Dec. 12, was part of an investigation into the misuse of Ryan White money that San Juan had received for its use and for 30 nearby municipalities, said a spokesman for the agency here, Harry Rodríguez. In 2006, the city received \$13 million. Even patients receiving top-quality care have to struggle with the disease, because H.I.V. can develop resistance, making patients switch to new, costlier drugs. Gaps in treatment can hasten the development of resistance. Doctors here also say that when they need to switch an ailing patient to a new regimen, approval from the central health department can take months and that the latest drugs are often not available. Angélica Segarra runs the shelter for homeless AIDS patients where Mr. González stays, a rambling house in Loiza. Ms. Segarra said that she provided medicines to 60 people before recent cuts in financing by San Juan forced her to stop and that many patients have searched in vain for clinics taking

new patients. One patient, Luis Torres, 42, was unable to secure medicines for three months. Another resident, Miguel Vásquez, 44, split his drugs with Mr. Torres because, he said, "it seemed like the right thing to do." In March and April, each took half the proper dose until the supply ran out. "Now I've had a month with no cocktail and I'm worried," Mr. Vásquez said. Cash shortages or errors in drug distribution by the commonwealth Health Department mean that patients sometimes receive five days' doses at a time or two antivirals instead of the prescribed three, a practice that can do more harm than good. The main San Juan AIDS clinic, one of the better equipped, serves 2,254 patients. Since late 2006, it has stopped accepting new ones, saying it cannot afford more. One problem is jurisdictional rivalries. Dr. Héctor Sorentini Méndez, health director of San Juan, said the commonwealth had refused to share its federal grants, \$22 million under the AIDS Drug Assistance Program, which pays for otherwise uncovered medicines under the Ryan White law. Sandra Molinias Rabe, 33, a former heroin addict in the mountains southwest of San Juan, is one of many cases who have slipped through the cracks. Ms. Rabe lives with her partner, Raymond Quiñones, in a squalid shack without running water, reached by an arduous climb up overgrown steps. A neighbor allows them to carry up buckets of water and run an electricity line to power a light bulb. Her medical condition is poor, and the doctor at Casa Joven del Caribe, an aid group, said she needed new laboratory tests to see whether she should switch medications. The aid group, which is in a dispute with San Juan over late disbursements, can no longer pay for her tests and drugs and sent her to an assigned Medicaid doctor in another town. That doctor said she would have to return in two weeks. In the meantime, she had no medicines. Antiquated equipment and poor communications have added to the problems. An audit by the comptroller of Puerto Rico published in November found that the Health Department records of drug stocks and deliveries to outlying clinics were grossly deficient, allowing mistakes and medicines to expire. Four of the eight main H.I.V. clinics lacked working bathrooms or computers, another report said in the fall. Héctor Figueroa, who directs a drug treatment program in Caguas, south of San Juan, said changes in federal priorities and a lack of action by the Puerto Rico government had led to sharp cuts in transportation aid and substance abuse treatment. At the two clinics in his region, Mr. Figueroa said, patients sometimes receive 15 days' medicines in a month. The Health Resources and Services Administration, citing problems in administration, patient access, and community participation, put the San Juan government on "restricted drawdown" status in 2005 and did the same for the commonwealth in 2006. The health agencies now have to submit all grant vouchers to Washington for approval before money is disbursed. Puerto Rico officials say the waiting list for drug assistance has declined, to 36 from 130 in the fall, and will soon be eliminated. A local group, AIDS Patients for a Sane Policy, said that its survey of clinics found 477 patients waiting to start therapy or to make necessary changes in their drug regimens. For a year, Puerto Rican and mainland groups, including the Congressional Hispanic Caucus, have called on federal authorities to take stronger action here. In a letter to Michael O. Leavitt, secretary of health and human services, Senator Tom Coburn, Republican of Oklahoma, has said he was "gravely concerned about the ongoing crisis taking place in Puerto Rico." In another letter, Senator Hillary Rodham Clinton, Democrat of New York, said mismanagement had "severely curtailed access to life-extending treatment" and called on the health administration to strengthen its oversight of Ryan White programs on Puerto Rico. Administration officials said that they had proposed transferring San Juan's Ryan White funds to a separate entity that would manage them, but that Mayor Jorge A. Santini Padilla had refused. "In the end," Dr. Cheever of the health administration said, "It's up to them to do the planning, allocations and administration, and what we can do in terms of sanctions is very limited by legislation."

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