Island Fever

Puerto Rico’s economic crisis threatens critical progress on HIV.

September 25, 2017 By Rod McCullom

EDITOR’S NOTE: This article was completed before Puerto Rico was devastated by Hurricanes Irma and Maria. Stay tuned for updates on how the storms have further challenged people living with HIV on the island. Click here for suggestions from Lambda Legal on how to help. Click here to read how you can donate to HIV-related needs. For an update on Puerto Ricans living with HIV on the island, click here.

Demonstrations and strikes have become almost standard operating procedure across Puerto Rico since the beginning of the year. That’s when a controversial financial oversight board and the incoming governor began to impose increasingly harsh austerity measures to address an economic crisis. For decades, the government operated under deficit spending and borrowed to close the gaps. Billions more are owed in pensions to retired civil servants. Exacerbated by a soaring cost of living and a public debt of over $72 billion, the financial situation has devastated this unincorporated territory of the United States.

The strikes and demonstrations of May 1 brought global news coverage and awareness to the crisis. Thousands of people across the island shut down offices, protested on university campuses and blocked traffic. The actions were largely peaceful, but police reportedly used tear gas, pepper spray and violent tactics to disperse some protesters.

Twenty-nine-year-old L’Orangelis Thomas Negrón, who was born with HIV, experienced the brutality firsthand during a demonstration outside La Fortaleza, the governor’s mansion, built in 1533 to defend the harbor of San Juan, the island’s capital and largest city. She was protesting with other members of Colectiva Feminista en Construcción, a coalition of feminist, social justice and human rights groups.

“I don’t have enough food in my refrigerator right now. We were banging pots, pans and kitchen utensils as a symbol that our plates are empty,” recalls the San Juan–based health and human rights advocate. “Four officers approached me. I tried to run away, but they dragged me by my neck and hair. My clothes were torn. It was so painful. I was so scared because I thought that I was dying.”

Thomas Negrón sighs before explaining further.

“This is a very scary time. Police powers are increasing. People cannot afford food or electricity. Millions of dollars are being cut from health care. How will that impact care and treatment for HIV and other conditions?”

An exploration of the unique characteristics of the HIV epidemic on the island—who tests positive for the virus and what care and treatment they receive—must be preceded by a broader look at the fallout from Puerto Rico’s dire economic situation.

A wave of extreme austerity measures is aggravating Puerto Rico’s already significant public health challenges, such as higher rates of diabetes, asthma, cancers, infant mortality, HIV and, now, Zika virus. Residents also face intersecting socioeconomic inequities that are fueled by the island’s political and economic dependence on the United States, which many analysts have described as “colonial.” The financial crisis has also triggered violence, stress and mental health challenges.

Puerto Rico has been contending with a severe recession since 2006. That’s when the U.S. Congress closed loopholes that had drawn many companies to the island by allowing them to avoid paying income tax. As a result, Puerto Rico underwent rapid deindustrialization. The official unemployment rate of about 12 percent is almost three times that of the United States. About half of residents live in poverty.

Dwindling job prospects have launched a mass migration from Puerto Rico. In 2014, for example, about 7,000 people left the island for the mainland every month. The exodus continues, leaving a net population loss.

Meanwhile, the cost of living is stratospheric. Compared with more than 325 urban areas in the United States, utilities on the island ranked fourth highest (behind cities in Alaska and Hawaii). Supermarket items are over 20 percent more expensive than in the states. And more than 80 percent of the island’s food is imported—and by law, everything imported into Puerto Rico must arrive on an American-made ship with an American crew, further raising costs.

“People see me sometimes traveling to other countries or speaking at the United Nations [as part] of my advocacy,” says Thomas Negrón, a peer educator at Taller Salud, a community-based feminist group that focuses on reproductive justice, violence prevention and women’s health; she’s also on the advisory boards of several AIDS groups. “But I don’t get paid to do that,” Thomas Negrón points out. “I have only $20 to last me two weeks until we get paid.”

The day after the nationwide protests, Governor Ricardo Antonio Rosselló Nevares announced that a federal oversight board would initiate a process similar to bankruptcy. The restructuring of Puerto Rico’s debt—$72 billion—is the largest in the history of the U.S. municipal bond market. The seven-member board, known locally as “La Junta,” controls all fiscal decisions on the island. Appointed by President Obama and unaccountable to the island’s 3.5 million residents, the board is majority Republican and viewed as friendly to the hedge funds that hold half of the island’s debt.

The Puerto Rico Health Insurance Administration—the country's version of Medicaid, which manages care for about 2 million people—is insolvent and recently received a bailout of almost $300 million from Congress. The debt crisis and mass migration have consequences across health care settings.

"The debt has [created] longer wait times for clinical and therapeutic procedures, overcrowded emergency rooms, attempts to directly charge patients for services and an increasing exodus of physicians from Puerto Rico," reported El Nuevo Día, Puerto Rico's largest newspaper, adding that nearly 364 and 500 physicians left the island in 2014 and 2015, respectively.

"Puerto Rico has long experienced a shortage of specialists, and the migration of doctors, nurses and health care professionals is affecting HIV care and treatment," says Arecibo-based health educator and advocate Ángel Luis Hernández, who has more than 20 years' experience in health care administration and finance and serves as the community representative on several HIV planning and prevention boards. (Hernández, who found out that he had HIV in 2003 when he received an AIDS diagnosis, was named to the POZ 100 in 2014.)

"We don't have many infectious disease specialists or virologists. Many of those are retiring or leaving due to the economic crisis," he says, adding that appointments for these specialists are often booked up to a year in advance.

Ángel HernándezAngel Valentín

Public health officials, academics, policy analysts and human rights advocates have joined people living with HIV in expressing heightened concerns about the effects of austerity. How will the cuts affect a territory that already has, in the words of advocacy group AIDS United, "some of the most concerning HIV/AIDS statistics in the United States"?

Puerto Rico ranks in the top 10 of states and territories in total number of HIV cases. Almost half of these—some 44 percent—are in metropolitan San Juan. Similarly, the island's HIV mortality rate is nearly four times the national rate. In fact, with the exception of the District of Columbia and Guam, Puerto Rico's HIV mortality rate is higher than any other U.S. state or territory.

As of December 31, 2015, about 48,500 people have been diagnosed with HIV since 1981, according to new data that the Puerto Rico Department of Health (PRDH) extrapolated for POZ. Today, about 19,000 people are living with the virus in Puerto Rico.

"There were 529 new cases on the island in 2015," says Sandra Miranda, MPH, an HIV surveillance manager. "It's a huge decrease since 1993, when there were 2,000 new cases. This is because of the introduction of antiretroviral therapy."

When taken daily, antiretroviral therapy can slow down the replication of the virus and suppress the viral load (the amount of virus in the body) until it becomes undetectable. Maintaining an undetectable viral load not only improves the health of people with HIV but also lowers their chance of transmitting the virus during sex to virtually zero. This phenomenon is known as "treatment as prevention" (TasP) and has become one of the cornerstones of global prevention programs. (Click here for the latest research findings about TasP.)

But this impressive decrease in the rate of new HIV cases since the 1990s doesn't mean that the epidemic has been under control all this time. When POZ visited San Juan in 2008 to report on HIV in Puerto Rico, the activist Anselmo Fonseca, who has been HIV positive for nearly two decades, described Puerto Rico's epidemic as a public health tragedy. Years of neglect—worsened by corruption, stigma, homophobia and a lack of funding—contributed to substandard quality of care.

"Back then [in 2008], we were having so many problems with rationing medications and very long waiting lists, and the quality of care was not very good," Fonseca says today. "Fortunately, most of that has changed." Fonseca, who in 1999 cofounded Pacientes de Sida Pro Política Sana (AIDS Patients for Sane Policies), enumerates several improvements: "People are being linked to care and treatment as soon as they test positive. There are no longer any waiting lists for medications, which is fantastic. Quality of care has improved. Many clinics are moving toward certification as federally qualified heath centers, which will greatly improve services and access to HIV care."

As Puerto Rico's response to the epidemic has escalated during the past decade, the results have become visible in its HIV-related statistics. For example, the overall HIV diagnosis rate decreased by almost 30 percent between 2007 and 2013, according to the PRDH. The mortality rate also dropped—by almost one third—during this period.

Anselmo FonsecaAngel Valentín

Fonseca also mentions a pilot program for HIV and hepatitis C virus (HCV) coinfection. The program offers free access to the new direct-acting antiviral therapies, such as Sovaldi and Harvoni, which have revolutionized HCV treatment. Robust data on the extent of HIV/HCV coinfection is lacking—such gaps in data and research are another reflection of the economic crisis—but studies indicate that Puerto Rico is burdened with a much greater prevalence of HCV, especially among people who inject drugs.

“José and I worked on this for years,” adds Fonseca, referencing the late José F. Colón López, his partner of nearly two decades. “I lost him four years ago but feel his influence every day.”

Puerto Rico has also made significant progress in the prevention of mother-to-child transmission. “Since 2011, we have not seen one infant born HIV positive, and we hope to maintain this,” says PRDH’s Miranda. “It’s a huge success. Cuba may have been the first country to reach this milestone, but Puerto Rico was not far behind.”

“Many gains have been made,” Fonseca says. “Our main concern is that those gains [should] not be lost.”

The principal mode of HIV transmission has also changed since the epidemic’s beginnings. For the past five years, condomless sex between men who have sex with men has been reported as the most frequent route of transmission. Currently, it makes up 45 percent of new HIV cases, followed by condomless heterosexual sex, at about 33 percent. But historically, since the early 1980s, HIV

incidence was highest among people who injected drugs. Puerto Rico has been challenged for decades by a significant epidemic of people who use opioids and other injectable drugs; unfortunately, a corresponding public health response—syringe exchange, treatment and harm reduction, for example—has been lacking.

But public health analysts and advocates have long called these rates into question. “Stigma likely played a key role in how people self-identified. In the 1980s, it was less stigmatizing to be someone who used drugs than a man who had sex with men,” says Carlos E. Rodríguez-Díaz, PhD, a public health scientist and an associate professor at the University of Puerto Rico–Medical Sciences.

“Stigma is very prevalent among health care workers,” Rodríguez-Díaz adds. “We know that stigma has a negative impact on retention in care and access to preventive services. My hypothesis—and we’re trying to evidence this—is that a complex series of stigmas have challenged men who have sex with men in accessing HIV services and care in Puerto Rico.”

Rodríguez-Díaz factors in another missing variable in the HIV equation: “We also don’t have enough information on the transgender population here because transgender men and women are not made visible,” he says. “It’s a barrier for them to access care and services as far as documentation around their gender and names.”

Compared with a few decades ago, “there is probably more openness toward the LGBT community,” adds Hernández, who started coming to terms with his sexuality in the 1990s. “But I don’t think stigma against living with HIV has lowered here in Puerto Rico.”

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Now would be an appropriate time to discuss the political relationship of Puerto Rico to the United States, says Rodríguez-Díaz. “The funding crisis to [treat] people living with HIV is due to our political relationship with the United States.”

In other words, Puerto Rico’s current HIV epidemic is linked to a generalized lack of funding and the island’s structural dependence on the United States. Thanks to the contentious Jones Act of 1917, Puerto Ricans are U.S. citizens by birth, but they do not have voting representation in Congress and cannot vote for president. What’s more, Puerto Ricans also do not pay federal income tax, which means that everything—parks, power grids, public schools, infrastructure, public health, funding for HIV treatment—is dramatically underfunded.

“Funding for health care is structurally very different from the states,” Rodríguez-Díaz explains. “There is a block grant that Puerto Rico gets to spend on health care and services. No matter how bad things are here, we always get the same amount.”

Puerto Rico’s Medicaid funding is subject to an annual ceiling—in 2015, the cap was $329 million, which covered 14 percent of the more than $2.35 billion in costs—although the Affordable Care Act (ACA, or Obamacare) provides billions more in funding to states. “If there were no funding cap

and Puerto Rico's [matching rate] were based on per capita income," reports the Center on Budget and Policy Priorities (CBPP), "the federal government would pick up approximately 83 percent of [Puerto Rico's] total Medicaid costs."

Health care reform provided a one-time Medicaid grant "of about $6.4 billion available to be spent through 2019," reports CBPP. "But Puerto Rico is expected to exhaust those funds by the end of calendar year 2017."

The structural inequities and funding disparities are made even worse by the conservative politics of President Donald Trump and the Republican leadership in the House and Senate. "Public health does not seem to be a priority of the Trump administration," adds Melissa Marzán-Rodríguez, an assistant professor of public health at Ponce Health Sciences University and a colleague of Rodríguez-Díaz. "Any cuts in the Ryan White CARE Act [which provides HIV-related funding] or Medicaid will hurt Puerto Rico because we have no other funding," she explains. "What if the Department of Health doesn't have enough funding to run offices? That means that people with HIV may [have to wait] longer for their medication."

Community-based organizations are already reeling from the austerity measures.

"We just learned that our [Ryan White] funding has been cut by 20 percent. Our funding from the [U.S. Centers for Disease Control and Prevention] is also cut," says José Joaquín Mulinelli Rodríguez, who has been the executive director of Coaí, the island's oldest AIDS service organization, since 2013. "We are awaiting to hear from SAMHSA [the federal Substance Abuse and Mental Health Services Administration] and our department of health. We are expecting cuts from the government here. The irony is that the ruling party just held a plebiscite on statehood in June that cost $8 million." (That month, 97 percent of voters in the territory voiced support for becoming a state, though the odds are slim that Congress will support the effort.)

Mulinelli Rodríguez sighs. "We haven't cut any services—yet—but anticipate that this very likely could happen by November. We also know that housing and nutrition support are facing cuts."

San Juan–based Thomas Negrón, who protested in May over food shortages, confirms this. "I'm not getting nutrition assistance because my clinic froze that service."

She applied to the Puerto Rican version of the Supplemental Nutrition Assistance Program—which offers an electronic benefit transfer to low-income people and people living with disabilities—which is administered by the Department of Family Affairs. "I waited three months, and I was eventually disqualified over $11. Eleven dollars!" She laughs. "Can you believe that? I don't know if I will reapply, because the office near me closed for [budget] reasons."

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"The stress is affecting my mental health," Thomas Negrón continues. "Every day on Facebook [I see that] something new has happened here. Sometimes I just want to sit down and cry."

The decade-long economic crisis has created an “environment of tension, volatility, violence and conflict,” and many people in Puerto Rico are suffering from “anxiety disorders, panic [and] depression,” reported El Nuevo Diá in January, in its coverage of the first epidemiological study since 1985 on the state of mental health in Puerto Rico. The study found that 10 percent of adults are experiencing severe depression.

This is concerning news for people with HIV, a population already disproportionately at risk for stress and depression, especially those individuals facing socioeconomic barriers.

“I’m practicing the best self-care that I can while making my voice heard,” says Hernández, the Arecibo-based health educator. “We need more creative ways to enhance the quality of life for people living with HIV and for the rest of the population.” He believes that change is possible only if people with HIV are included in efforts to find solutions.

Despite the challenges, Thomas Negrón has noticed small improvements. “Some people are talking about politics and social justice who never discussed it before,” she says. “It’s going to get worse before it gets better. But it will only get better if more people take to the streets.”

For a related POZ article concerning Puerto Rico and HIV, read “Discovering That Your Uncle, Who Died in 1987, Had AIDS, Not Cancer,” in which documentary filmmaker Cecilia Aldarondo talks about the secrets and generational rifts of her Latino family.

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