

ADAP Advocacy Association Newsletter – November 2008

ADAP Advocacy Association Offers New Online Resource
to Highlight Ongoing Access to Care Crisis in Puerto Rico



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ADAPs in Crisis: Puerto Rico

By Brent B. Shimmin

Puerto Rico, an island that is only 35 miles wide by 100 miles long, is home to nearly four million people, making it far more densely populated than any of the fifty states. The prevalence of HIV/AIDS in Puerto Rico is estimated to be 2.3% (second only to Sub-Saharan Africa), which means that there could be as many as 92,000 Puerto Ricans living with the virus (although the Kaiser Foundation, in 2005, estimated the figure to be closer to 30,000). Though mostly concentrated in the urban areas of San Juan, Ponce and Bayamon, there are nevertheless significant populations of people living with HIV/AIDS in the rural areas as well.

The demographics of the pandemic in Puerto Rico are very different from those of the rest of the US (among Latinos). According to the [Centers for Disease Control & Prevention](#) (CDC), the transmission modes are as follows:

Behind The Numbers			
Latinos	U.S.	Mexico	Puerto Rico
MSM	30%	44%	14%
IVDU	24%	9%	48%
MSW	11%	14%	25%

This means that those affected by HIV/AIDS in Puerto Rico are much more likely to be heterosexual, indigent, have multiple health issues, and are much more balanced by gender than in the US proper.

The infrastructure of care in Puerto Rico is different as well. From the establishment of commonwealth status in 1952 until 1994, all health care was administered through state-owned hospitals, emergency centers and free clinics. In an effort to bring down costs, and in response to criticisms of a slow and unprofessional bureaucracy, then-Governor Pedro Rosselló proposed and implemented the privatization of the public health system under the name "Health Reform" (Reforma de Salud de Puerto Rico in Spanish, or simply La Reforma). This privatization plan included selling the government-owned hospitals and medical centers (except the Rio Piedras Medical Center in San Juan which still is run by the commonwealth government) to local and American investors and then implementing a universal free and/or low-cost health insurance plan for poor and needy citizens. The Reform is administered by the Puerto Rico Health Insurance Administration and, as of December 31, 2005, provides healthcare coverage to over 1.5 million Puerto Ricans, or 37.5% of the island population.

This has led to three competing systems of care for those on the island living with HIV/AIDS: one in San Juan serving greater than 10% of the island's total population, the second being Rio Piedras Medical Center and yet another for the rest of the island. Because of the lack of a centralized reporting system in Puerto Rico, knowing the true number of yearly infections is impossible, and this lack of centralized authority accounts for many of the subsequent troubles administering Ryan White/ADAP funds. In December 2006, the FBI raided four San Juan Health Department offices, confiscating 400 boxes of documents in a criminal investigation into possible misuse of Ryan White grants and, most recently, a demand from HHS that \$24,000,000 be returned to the US Government.

In July 2007 Puerto Rico's Governor, Anibal Acevedo Vila, appointed Jorge Delgado Rivas as an assistant to Puerto Rico's Secretary of Health becoming the first Puerto Rican government official expressly charged with overseeing the commonwealth's response to HIV/AIDS. Despite much initial goodwill and hope that Mr Rivas's appointment might bring the urgent change required (he came with an excellent résumé and is, himself, HIV positive), he has accomplished little of substance in eighteen months.

Puerto Rico Resident Commissioner (Puerto Rico's representative in Congress) Luis G. Fortuño issued a scathing press release on October 7, 2008:

U.S DEPARTMENT OF HEALTH ASKS FOR RETURN OF \$24 MILLION DUE TO MISMANAGEMENT OF PUBLIC FUNDS

Fortuño denounces negligent management of HIV/AIDS funds

The U.S. Department of Health and Human Services (HHS) disclosed mismanagement of Ryan White federal funds destined to HIV/AIDS patients by the Commonwealth Government in a report made public today by the Resident Commissioner, Luis Fortuño. The report by HHS's Inspector General recommends the return by the Commonwealth Government of \$24 million in Ryan White funds and concluded that the Commonwealth Government does not have systems in place to ensure that recipients comply with the program's eligibility requirements.

"For some time I have been expressing concern and dismay as to the irresponsibility of this administration with respect to HIV/AIDS patients in Puerto Rico, many of whom are homeless; today's report confirms my previous expressions on the matter," said the Resident Commissioner. According to the 28-page report, the Commonwealth Government must reimburse the federal government over \$24 million in overcharges made between 2002 and 2004, while Sila María Calderón was governor and Aníbal Acevedo Vilá was the resident commissioner in Washington.

"The negligence and ineptitude in managing these funds during the last eight years has put at risk the health and quality of life of HIV/AIDS patients in Puerto Rico, many of whom depend on Ryan White funds for much needed medicines and services," said Fortuño. After an exhaustive investigation, HHS's Inspector General determined that the Government of Puerto Rico overcharged the federal government \$24 million in medicines not eligible for coverage under the Ryan White program.

Under Title II of the Ryan White program, Puerto Rico receives an annual grant to fund the purchase of life-extending medicines for HIV/AIDS patients who lack health insurance or who are underinsured. The law states clearly that these funds cannot be used to buy medicines for patients that have private or public health insurance, such as Medicaid, that cover these drugs. This is known as the "payer of last resort" requirement.

"The Commonwealth Government was not only negligent in managing these funds, but when the federal government gave the Acevedo Vilá administration the opportunity to explain how it was planning to correct the situation, the federal government did not receive an answer," the Resident Commissioner observed. Fortuño explained that, as indicated in the report, the current government did not address the Inspector General's recommendations when the Inspector General provided the current government a draft of the report and allowed for comments.

On various earlier occasions, Fortuño has denounced the Commonwealth Government and Acevedo Vilá's administration for its mismanagement of federal funds that the Island receives, especially under the Ryan White program. In May of this year, the Resident Commissioner sent a letter to the Secretary of HHS, Michael O. Leavitt, describing the magnitude of the problem as it pertained to Ryan White funds: "Despite the significant federal funding allocated to Puerto Rico, too many of my constituents living with HIV/AIDS find it terribly difficult to obtain – and, in some cases, cannot obtain at all – the services they need to stay healthy and enjoy life. This state of affairs is the direct result of chronic mismanagement of federal funds on the part of the government of Puerto Rico." In February, Fortuño introduced legislation, co-sponsored by Congressman José Serrano, that would empower HHS to directly administer federal grants if HHS determines that a state or territory "substantially failed" to make appropriate use of previous federal grants. This legislation aims to ensure that Ryan White funds actually reach those who need it: HIV/AIDS patients on the Island.

In his report, the Inspector General recommends that the Commonwealth Government develop procedures to bill HIV/AIDS drugs to the Federal, State, or private health insurance plans with primary payment responsibility.

What is left obvious but unstated is that, through such vast institutional incompetence, the health of tens of thousands of Puerto Ricans living with the virus has suffered and many unnecessary deaths have occurred. Any research of the HIV crisis on the island will quickly uncover the name of Jose Colon. A long-term survivor, Colon has been on the front lines of AIDS activism and advocacy in Puerto Rico since 1991, when his partner of seventeen years died "not of AIDS, but of neglect" in the federally-funded San Juan AIDS Institute in the capitol. His testimony in federal court helped to assure a conviction on corruption charges for his partner's attending physician, Dr Jorge Garib, in 2000.

That same year, Colon testified before Congress in a 10-minute address to the U.S. House of Representatives Commerce Subcommittee on Health and Environment, shouting: "You must help us against these...these thieves!" and detailed the systemic neglect, corruption and apathy that led to his partner's death. His testimony elicited much sympathy, but little direct action, and in the end, the crisis only deepened.

Following the FBI raid, but elucidating long-standing sentiments, Colon sent an impassioned e-mail to HHS Secretary Michael O Leavitt dated February 23, 2008. In it Colon pleaded for federal intervention in the health care mess on Puerto Rico as it relates to those living with HIV/AIDS:

Dear Secretary Leavitt:

It has taken a lot of thought and almost three years for me to finally sit down and write down details of what has been occurring in Puerto Rico, the administration of RWCA funds for parts A and B.

Nevertheless, acknowledging that my health is downhill I believe the time has come for you to understand the matters that have made me finally decide to inform you of certain patterns regarding the relationship of HRSA's [Health Resources and Services Administration] HIV/AIDS Bureau, and patients, like me, who try to defend our rights and the absolute compliance of a law that was done to protect HIV/AIDS patients from stigma, discrimination, prejudice and possible, bigotry.

I have to go back to year 1999, when the AIDS Institute scandal trial proved that approximately fourteen administrators, lawyers, politicians, doctors and high ranking officials from the Municipality of San Juan were tried and jailed for the embezzlement of \$2.2 million dollars of funds destined to the care and treatment of PLWHIV/AIDS. See *United States vs. Kouri, Sotomayor and Borel*, the first of the three trials in which all the accused were convicted for using money for personal use, political campaigns and kickbacks in a period that ran from 1988 to 1994. During this period HRSA's HIV/AIDS Bureau was silent, and incredibly did not investigate the issue in depth, even though when they never received or asked for audits, reports on the way the money was spent. A gentleman named Mr. Lawrence Poole, who I recently found out, already retired from HRSA.

The record of the trial states, when he was being interrogated that HRSA was very bureaucratic and that documents got lost from office to office and building to building. I recently visited the HIV/AIDS and saw with my own eyes, and was told by Ms. Laura Cheever that what Mr. Toole said was not true; she said that "this is not a big building."

As you may know there are two measures which have restricted HIV/AIDS funds both to the Part A Grantee, Mayor Jorge Santini, and part B, the Governor of Puerto Rico, Honorable Anibal Acevedo Vilá. An intervention by the Federal Bureau of Investigations took an extensive amount of documents of four municipal offices: the San Juan AIDS Task Force, the Office of Federal Affairs of the Municipality, the Municipal Tower and, once again, nine years later what today is called "Programa SIDA Más Salud con Salud", which was called nine years before the San Juan AIDS Institute, where the scandal occurred.

These measures were taken after numerous grievance letters and communications from Executive Directors who provide services with these funds, and participants of the San Juan EMA Planning Council who asked questions regarding late payments, problems with their contracts, and the rhythm of expenditures of the AIDS Task Force of the Municipality of San Juan. which turned into demoralizing employees of such dependencies, and of course the quality of treatments given to patients who received them either at the CBO's [Community-Based Organizations] or through governmental health facilities.

It is to me like a "déjà vu" in which personnel like Mr. Douglas Morgan of the HIV/AIDS Bureau were working there then, and are working with them still...

About approximately four weeks ago a group of CBO's Executive Directors and some patients decided to visit the Bureau and met with Ms. Cheever and surprisingly, with Mr. Douglas Morgan. During the conversation I asked Mr. Morgan if he remembered a conference call that we had with other members of HRSA's staff, whose names I can not remember. He smiled, put his hand in his chin, sank a bit in the chair, and that was it. I, seeing that he seemed not to remember refreshed his memory about the conversation, specifically when I asked him for he to tell me what had happened and he answered that "some mistakes were committed", to which I questioned "what mistakes, and by whom" and all I got was silence as an answer.

Exactly the same silence which has permeated for quite a long time now, leaving PLWHIV/AIDS with no one to talk to, frankly without a Project Officer to go to and claim for our rights. And there, in that same office is still working Mr. Douglas Morgan, which in my opinion does not care about the problem, or has been brainwashed by some local politicians, wearing health professional hats, when they are running to the post of Resident Commissioner these next elections. All of this has truncated, and I hope that you do not blame me, because all I am doing is struggling for quality and continuum of care not only to myself but also for the approximate persons living with HIV or AIDS in Puerto Rico, mostly of whom are American citizens.

This does not seem to keep up with the standards of a Federal Government Office. (It is incredible that we get responses from HRSA through a Communications Officer, and not from what the CARE Act and Congress detail and perceive should be done by a Project Officer. When will we have one, and when will this veil of distrust disappear, so we can have a legally constituted Planning Council, (which is working now with an Executive Committee delineating the rules and regulations of a PC which in my humble opinion has been created as a rubber stamp for San Juan's Grantee).

TA has been given, visits have happened, telephone calls, e-mails and the process of going through all the appropriate channels have been complied with. May it be that Puerto Rico is being treated differently than other EMA's [eligible metropolitan areas]?

In regards to Part B of Puerto Rico's DOH, a very understaffed office, which quarters now are unsafe and clustered with whatever equipment and/or employees they have been able to contract, discriminately declared a waiting list, denied its existence and sent letters of it only to CBO's that offered primary care, not including their eight Immunological Centers around the island. In other words, some patients were on a waiting list and other not, depending where they were treated...

I am dying with cancer, diabetes, chronic pulmonary obstruction, osteoporosis, chronic asymptomatic dermatitis, and in November of 2006, had a heart attack. It is quite a endemic complicated health, but, nonetheless, I still have the strength to write this letter on my behalf and all other HIV/AIDS patients in Puerto Rico, which affects not only the island, but many of the states in which patients have had to migrate looking for a better quality of life...

I need for you to read this letter intensively. I have no doubt that it entails details which I do not know, and probably you neither. I strongly believe that an internal evaluation and/or investigation should be carried ASAP because we have already lost 63% of the almost 30,000 cases documented by the Health Department's Statistics Office.

I am quite aware of what some health officials involved in the administration of funds, quality and continuum of care might say about me. This is because I have not stopped for one second to try to get justice for all that died during the San Juan AIDS Institute Case scandal, and those whose lives are in jeopardy now.

I wish you can answer this letter soon. Time is precious...

Thank you.

Mr. José F. Colón

Colón's e-mail was answered, not by Secretary Leavitt, but instead by Assistant Surgeon General Deborah Parham Hopson in April, 2008. In following a familiar pattern regarding response to his activism, Ms Hopson sympathized, saying that HRSA "understands and shares your deep concern and frustration with the challenges of the care and treatment systems" in Puerto Rico, she remained silent regarding the appointment of a central third-party intermediary to administer the \$53million in federal HIV/AIDS funds, something Colón and other advocates familiar with the crisis in Puerto Rico have demanded.

Amid much confusion and obscurity regarding the ADAP crisis in Puerto Rico, one thing is very clear: the residents of the island are not benefitting from federal funds proportionally to the amount being expended. The system isn't failing, it has failed. The cost of this failure isn't counted in dollars or in the public humiliation of local officials seemingly impotent in solving this crisis; it's counted in the needless and uncounted deaths of thousands of people.



ACROSS THE NATION

CDC Report on New HIV Infections in U.S. Did Not Include Data From Puerto Rico; Omission Has Widespread Consequences, Advocates Say [Sep 2, 2008]

A [CDC report](#) released last month about new annual HIV infections in the U.S. did not include data from Puerto Rico, an omission that Hispanic HIV/AIDS advocates say could have widespread consequences nationwide, the [Orlando Sentinel](#) reports..

According to the advocates, CDC ignored the seriousness of HIV/AIDS in Puerto Rico, which has the fifth-largest concentration of HIV cases nationwide, by not including data in the report. In addition, the omission significantly lowers estimates on the number of Hispanics nationwide affected by HIV/AIDS. According to Guillermo Chacon, vice president of the [Latino Commission on AIDS](#), the share of new HIV infections represented by Hispanics increases from the 17.3% reflected in the CDC report to 22% when data on Puerto Rico are included.

Accurate new infection estimates also help gauge how quickly HIV is spreading, which groups are at high risk and which areas have higher rates of HIV, all of which are necessary to develop effective prevention and treatment strategies, according to advocates. Chacon said that the report is "not acceptable," adding that the "number the CDC came up with doesn't fully reflect the severity of this epidemic among Latinos." Chacon added that "[n]ew policies" that address HIV/AIDS "are being formulated based, precisely, on the numbers" in the CDC report.

National HIV/AIDS estimates that do not accurately reflect HIV incidence among Hispanics could result in fewer resources allocated for prevention and treatment targeting Hispanics. "Excluding Puerto Rico, which has such a high incidence [of HIV], implies a reduction of funds for everybody," Rosaura Lopez, director of an HIV clinic in the San Juan suburb of Rio Piedras, said.

CDC said it did not include data on Puerto Rico in the report because it uses census population data for the report, and population is estimated differently in Puerto Rico than in the rest of the country. Kevin Fenton -- director of [CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention](#) -- said the agency is working with health officials in Puerto Rico to estimate HIV incidence. According to the Sentinel, CDC "further complicated" the issue last month when officials announced that eight states and Puerto Rico would not receive federal funding for an advanced HIV monitoring system (Rivera-Lyles, Orlando Sentinel, 8/30).

Related Editorial

CDC's new estimate of HIV incidence "has critical implications for the nation," David Holtgrave -- chair of the [Department of Health, Behavior and Society](#) at Johns Hopkins Bloomberg School of Public Health -- and Julie Scofield, executive director of the [National Alliance of State and Territorial AIDS Directors](#), write in a [Baltimore Sun](#) opinion piece, adding that the U.S. "has much work to do."

Holtgrave and Scofield outline "seven things the U.S. can do now to get smarter and better at fighting the [HIV] epidemic," including increasing funding for HIV prevention services and funding a "new testing technology that enables better HIV incidence estimates" in additional states. In addition, CDC should aim to reduce new HIV cases by 50% in five years and increase efforts to fight HIV among minority communities and men who have sex with men, the authors write.

The authors add that the "next president must go further and once again make HIV in the U.S. a priority," concluding that the current "national path of apathy is not only ill-advised and expensive but also unethical and a public health error of the greatest magnitude" (Holtgrave/Scofield, Baltimore Sun, 8/31)