

# Guatemala: An analysis of Obstacles to Universal Access

Hundreds of PLWHA Fall Between the Cracks Each Month

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The response to the HIV epidemic in Guatemala has grown considerably over the past five years. This is not just due to national efforts, but also to international assistance, particularly that of The Global Fund to Fight AIDS, Tuberculosis and Malaria. The response during this period has increased both prevention efforts and medical attention to PLWHA. Nonetheless, current data shows that this response has yet to reach the level required to halt the spread of the epidemic, particularly in terms of delivering antiretrovirals (ARV) and comprehensive health care.

The latest UNGASS (UN General Assembly Special Session) country progress report found that in December 2009 10,362 PLWHA (768 children and 9594 adults) were receiving ARVs in Guatemala.<sup>1</sup>

During the past two years, Guatemala has increased decentralization in its HIV health network to include hospitals located in the cities of Peten, Zacapa, Escuintla, Santa Rosa Sacatepequez, Quetzaltenango, and Huehuetenango as well as in existing health centers in Guatemala City, Coatepeque, and Izabal. While this is encouraging, the UNGASS report estimates that these 10,362 patients represent only 58% of those with advanced infections. In other words, *42% of PLWHA who need antiretroviral treatment (some 7,500 people) are not receiving them.* Other sources estimate the total number who require antiretrovirals at 21,000. If this is true, the percentage of patients receiving treatment would drop below 50%.

So, where are the 7,500 people who aren't getting treatment? Why are they unable to access treatment in spite of increased investment in the HIV response? What are the gaps to achieving universal access?

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<sup>1</sup> Available at:  
[http://data.unaids.org/pub/report/2010/guatemala\\_2010\\_country\\_progress\\_report\\_es.pdf](http://data.unaids.org/pub/report/2010/guatemala_2010_country_progress_report_es.pdf)

One of the primary barriers to antiretroviral treatment access and comprehensive health care is the *limited availability of free HIV testing*. Testing is available to pregnant women and other specific populations (MSM and female sex workers) but it is only performed at level III health centers. Throughout the majority of the country, men and women in the "general population" do not benefit from free HIV tests.

If one wants the test performed at a private lab, the cost may run as high as 175 Quetzales (US\$ 22). When the individual voluntarily chooses to have the test, he or she must cover the cost.

The lack of centralized health care with *personnel trained* in identifying HIV associated infections is another significant barrier. Generally speaking, PLWHA who present with opportunistic infections are incorrectly diagnosed; they are told they have a cold or transient diarrhea and sent home without further lab tests. This has been reported by key Guatemalan stake-holders, among them Mrs. Guadalupe Deras, Director of Amistad Positiva, an organization in the city of Peten (north of Guatemala City). First line health workers and those who mainly work far from the capital are not sufficiently trained in identifying HIV related infections.

After a few months, these same patients return to seek medical attention, but this time in a different health center where the doctor will recommend they take an HIV test. Unfortunately, by this time they often have developed opportunistic infections (OI) that are seriously advanced.

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## Barriers to ARV access in Guatemala

Barriers	Description	Consequences
Limited access to HIV diagnostic testing.	Testing is unavailable in rural areas or limited to certain populations. Private labs charge \$22.00 for the test.	Delayed diagnosis; PLWHA arrive at hospitals with late stage opportunistic infections (OI).
Lack of trained personnel in rural areas.	Rural health center personnel have not received training or been sensitized to identify and to treat OIs.	PLWHA do not receive proper medical care during their first visit. Many develop serious infections that place their lives in jeopardy.
Centralized health care	The only level III health centers are in Guatemala City, Puerto Barrios, Coatepeque, and Quetzaltenango	Impoverished PLWHA lack funds for travel and hence die because they fail to get treatment.
Treatment abandonment	Roughly 10% of PLWHA abandon treatment.	They will develop resistance to the drugs and/or die.
Inadequate information system	Guatemala does not possess a national system for identifying deaths or cases of treatment abandonment.	Lack of information results in the country failing to perform strategic interventions that would lead to universal access to ARVs
Personnel hiring ceilings	In two years, the number of ARV recipients has doubled, yet the number of health workers in that area has remained the same.	Health workers are exhausted because of a work load that exceeds their response capacity, resulting in decreased quality of care.
Lack of third line drugs	Some newly developed drugs are not available in Guatemala or are so expensive that the Health Ministry cannot afford them.	Once people become resistant to ARV's available in the country, there are no other treatment options for them, so they die.
Limited genotype testing	Difficulties identifying specific resistance.	Medication regimens are chosen without taking into consideration issues related to resistance
Drug procurement problems	Ministry of Finance has restricted certain possibilities for using cost effective procurement methods. Temporary fixes have been used to deal with this barrier.	High medicine costs lead to difficulties in preparing long term national procurement plans.
Extremely weak PLWHA activism and advocacy	Organizations are seeking funds to sustain themselves rather than to monitor barriers to universal access.	Fragmented and disorganized activism. Unnecessary deaths.

This situation is borne out in the records of the Asociacion de Salud Integral (ASI) clinic, which found that 20% of people diagnosed with an OI die before being able to begin ARV treatment. The most common presenting OI's in Guatemala are tuberculosis, cryptococcosis, histoplasmosis, and HIV wasting syndrome. If patients do not receive timely care, they may die. Sadly, these deaths would normally be avoidable if interventions were

provided early in the course of the disease.

There are some strategies already in place to get ARV's to more people who require them. IDEI is an NGO that has been working on HIV in Quetzaltenango for years and is searching actively for PLWHA who need treatment. It is partnering with the tuberculosis hospital to assure that patients with TB are offered HIV diagnostic tests and get timely access to ARVs. The initiative needs to be

replicated in more health centers regardless of level in order for diagnostic testing to be carried out and ARV's provided to people at a much earlier stage. Moreover, IDEI is monitoring ARV treatments, stressing to PLWHA that they need to be available for diagnostic testing when it is needed.

As cited above, there are few health care centers for PLWHA. Most are located in department capitals, known locally as "*cabeceras departamentales*." According to Dr. Carlos Mejia, Head of the Comprehensive Care Unit of the Roosevelt Hospital in Guatemala City, if a person wishes to set up a doctor's appointment at one of these centers, they may need to invest a large portion of their income in travel expenses.

The Roosevelt Hospital treats close to 3000 PLWHA from all over the country, yet it is known that many stop treatment or miss appointments because they cannot pay travel expenses to get to the capital. In some cases these costs run as high as 400 Quetzales (approximately US\$50.00). Hence, a logical solution to this barrier would be *decentralizing health services*.

When someone interrupts treatment, they are classified as non-compliant. Once classified as non-compliant, PLWHA are denied medical services, as illustrated below in the case of David Efen Lopez.

Dr. Mejia cites that roughly 10% of patients in the Roosevelt Hospital abandon their treatment, yet this figure increases whenever the hospital experiences treatment interruptions. Such interruptions occurred several times in 2010 and forced PLWHA to return to the hospital up to twice a month to receive their ARVs.

In a country such as Guatemala, where 50% of the population lives below the poverty line, treatment-related out-of-pocket expenses are a huge barrier. This reality is also described by the organization Gente Positiva in their 2009 document, "Results Report: Home Visits to People Who Abandoned Treatment at the Roosevelt Hospital: Clinic 17." They found that nearly 50% of people missed their appointments because they lacked funds for travel.

Gente Positiva also reports that roughly 30% of these people *end up dying*. Coordinated actions by PLWHA and other grassroots organizations become vitally important in overcoming this type of ARV access barrier. NGO's and health care centers need to coordinate efforts in order to reestablish contact with people who have abandoned their treatment.

It is clear that Guatemala has made significant

progress on its HIV response since 2007 when only 4500 people were receiving treatment; that number increased to more than 10,000 in the span of just two years. Such rapid growth in terms of care and treatment delivery has brought about new challenges for PLWHA and health providers.

Health care facilities are now treating two to three times as many people as before, and this has a negative impact on the quality of care. "We have to treat more people with the same number of staff workers, and so attention is not going to be the same," says Dr. Mejia. Given the diversity of the Guatemalan population, the people who need more personalized and culturally adapted attention will be the ones most impacted by the shortage of health care workers.

*The health worker situation has worsened over the past few months.* Transitioning from the second to the third phase of the Global Fund project has meant the Fund no longer pays the salaries of health workers; these costs should have been picked up by the Guatemalan Ministry of Public Health and Welfare (MSPAS) towards the end of the second phase. Instead of hiring more workers (given the increase in the number of patients), the Ministry has dismissed some workers while offering others jobs in specialized HIV care. New employees, however, are offered much lower salaries than would be appropriate given their level of experience.

No impact study has been performed on the results of these decisions, but one anticipated consequence of personnel dismissal is that health centers will be forced to reduce their working hours. In the eyes of Dr. Mejia, this would leave many people without care since they would not be able to go to appointments during working hours.

*Real and efficient decentralization* would be a significant step toward universal access to health care. Nevertheless, it should be provided comprehensively, accompanied by health workforce training, and in coordination with grassroots organizations that understand the relationship between the PLWHA experience and poverty. This was suggested by Guadalupe Deras, whose Peten-based group searches for people who have abandoned their treatment and assists them to get back on track. "This is a job for everyone. Comprehensive service has to be increased, and we are here to help the Comprehensive Care Unit and to save the lives of people who have abandoned treatment," she says.

This opinion is shared by another HIV activist, Iris Lopez, who argued, "We should not leave each

other alone, each on his own, but help one another out, especially those people who just started treatment and are not receiving all the social support required to guarantee their adherence.” She feels that support group strategies need to be reinitiated since they were very effective at providing emotional support to people who had recently learned about their diagnosis or who had just started treatment. It is also important to try to raise money for meet the adherence challenges that PLWHA face (for example, fund raising activities to cover transportation or testing costs).

The decentralization process has not responded to the needs of the population, even though the government has built new comprehensive care units across the country (it is expected that the number will reach 17 by year’s end).

Unfortunately, PLWHA still *do not trust their local health professionals*, which forces them to seek treatment in a hospital far from home in spite of the additional cost.

Some facilities have limited hours; this has been an issue for PLWHA at the Quetzaltenango Regional Hospital. Patients complain: “The doctor only sees three to four patients from 7 A.M. to 11 A.M. each day. That’s not enough to cover the needs of the population.”

Recently, a PLWHA from a town far from Quetzaltenango arrived at the hospital two days before her scheduled appointment, apparently having misunderstood the date written on her last appointment card. When she inquired about seeing the doctor that day, she was told it was not possible; instead she was given a new date, three months later.

One PLWHA said, “Sometimes, [health workers] tell us we should be happy because they are doing us a favor by caring for us.”

A local self-help group in Quetzaltenango offers treatment adherence workshops for 60 PLWHA. In light of deficiencies in health care, this is a key element, yet it is not normally found in all urban or rural areas because clinics do not provide adherence counseling and support groups are weak or nonexistent.

Lastly, one more consequence of the lack of decentralization is *drug availability*. Hospitals that recently launched ARV programs do not have all of the nationally available drugs. “Generally, what they have on hand are first line regimens, the basics, but if you need second-line drugs, you will have to go to Guatemala City,” says Guadalupe Deras. She places

responsibility for this squarely on the Ministry of Health which is responsible for supplying the drugs and for all health services offering ARVs.

### **Other aspects jeopardizing ARV access and sustainability**

#### *Stigma and discrimination*

Guatemala is a poor country with low levels of formal education and a concentrated HIV epidemic. HIV prevention strategies and response are focused on people living in the largest cities; rural populations are left far behind. Another disturbing aspect is that information on the infection and prevention is not being disseminated throughout the country. When we add stigma and discrimination to this lack of information, we see how people who suspect they are HIV positive are afraid of visiting a health care facility. Fear of being reprimanded or criticized may also increase treatment abandonment.

The following are extracts from a letter summarizing abuses at the Quetzaltenango Clinic One, published by Jessica Lasaga Aviles, a psychologist doing her internship at that hospital:

*“Some patients say that when the doctor sees you, she just asks ‘How are you?’ If you reply ‘I’m fine,’ she sends you to the hospital pharmacy to pick up your medicine and makes the next 3-month appointment. Even when someone complains they are not well, she does not check them out, she just sends them on to the pharmacy.”*

*“Several patients arrive late to their appointments and are only allowed to pick up their medicines... [O]ne patient arrived late with a serious infection. The doctor had him undergo tests, telling him she would go over the results with him and give him something to treat the infection at his next appointment which was given for two months later. I’m no doctor, but I think that an infection untreated for 2 months might cause serious harm to a patient and that the tests would be of no use at that time.”*

*“It’s a pity to see patients coming here for treatment and having to endure treatment like that. We know from health psychology that support is one of the most important things for patients suffering from chronic diseases, and support from your doctor is vitally important. This is not just about providing medicine, but it also means a doctor has to care about the patients and treat them correctly.”*

#### *Unavailable drugs and tests*

An ongoing worry for caregivers of PLWHA and

ARV receivers is the difficulty of obtaining *recently developed drugs*.

Darunavir, Raltegravir, Atazanavir, and Efavirenz are some of the drugs that are neither sold in Guatemala nor have national marketing authorization. They are needed by some people who have undergone multiple treatment regimens and are resistant to commonly used drugs.

While the plan is to purchase these drugs with monies from the third phase of the Global Fund project, treatment programs will have to overcome two great challenges over the next two years if they wish to become sustainable: 1) lack of authorization to sell them and 2) high costs. We have yet to gather updated information on their prices, but annual treatment costs in other countries using these drugs exceed US\$ 5,000.00. One drug costs more than US\$ 15,000.00.

Having access to newly developed drugs is linked directly to the availability of resistance testing. Right now, there is just one entity in all of Guatemala performs this test: the Asociación de Salud Integral clinic in Guatemala City. The cost of supplies for this test varies between US\$ 300 and 400.

Lastly, *drug procurement processes* are another barrier to access. Since 2009, when Ministry of Finance regulations were amended, government funds have not been used to purchase drugs through low cost procurement mechanisms like the PAHO strategic fund. This is limiting MSPAS's ability to ARV purchases at competitive prices.

Because of these limitations, the MSPAS had to buy a first round of ARV's from the local market for more than US\$ 5 million (close to 40 million Quetzals). The costs were as much as 10 times the going rate in the Latin American market.

In June of 2010, the country entered into an agreement whereby it was able to claim exception to Ministry of Finance regulations. This allowed the procurement of a second round of ARV's at a cost of US\$ 1.76 million. Although we do not know which drugs were purchased at what prices, we know a comparison of the time framework covered by both rounds are similar. This would suggest the government "wasted" more than USD 3 million in the first round.

This new contract might be a demonstration of interest on the part of the MSPAS to procure drugs using cost effective mechanisms, although the laws need to be changed substantially to permit using PAHO or other organizations without running into

roadblocks.

Now that the country is on the cusp of beginning the Global Fund project's third phase, it should align its policies with those of the Fund. According to some HIV stakeholders, the Global Fund should condition further funding on the purchase of drugs and supplies through PAHO, other international providers, or a GF procurement mechanism.

Both *civil society incidence and activism* have lost strength in Guatemala. "The primary goal should be universal access to comprehensive health care for all Guatemalan PLWHA," say Alma de Leon, Coordinator of the International Treatment Preparedness Coalition (CIAT) and advisor to Guatemala's Alliance of PLWHA Groups and REDCA+. "Activism in Guatemala needs to continue growing and to be proactive; that way, we will guarantee a permanent Civil Society voice so that laws will be enforced and strategic plans followed."

Locally generated divisions and other conflicts between groups could explain why Civil Society influence has weakened. Nonetheless, Alma de Leon asserts that those conflicts must be overcome and the movement should be directed to guaranteeing that no Guatemalan citizen is without care or treatment. A sensible way to achieve this would be to train a group of activists to monitor HIV response actions strategically anywhere in the country and to guarantee that all PLWHA receive medical attention.

Guatemala is making advances on its HIV response, yet the situation seems to indicate that the speed or intensity is not where it needs to be to stop the spread of the epidemic. We must be clear that barriers leading to lost lives must be overcome. Civil society and affected populations must reenergize actions so as to increase access to comprehensive care.

### **A Case Study: Saving People who fall between the cracks in Guatemala: is it "cost effective"?**

(by Richard Stern)<sup>2</sup>

On March 19<sup>th</sup> 2010, I was contacted by Mathew Kavanaugh, an activist based in the U.S., in reference to David Efrén López, a 23-year-old Guatemalan PLWHA who was having trouble getting treatment at the Roosevelt Hospital in Guatemala City. Eight months earlier, David had

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<sup>2</sup> David Efrén López gave permission to tell his story and use his name

decided not to take Kaletra when it was offered to him as a substitute treatment for a cocktail to which he was apparently developing resistance. At that time, David did not have the necessary information to realize this was a dangerous decision. He felt that, because of his extensive work-related travel to hot climates, he would be unable to maintain the drug refrigerated, and it would be useless. Due to his refusal, it was noted in his file that he was a “non-compliant” patient.

When he returned to the hospital eight months later, he presented with weight loss and night sweats. However, the hospital refused to treat him because he had been labeled non-compliant. At this point, I intervened. David declared his willingness to take whatever treatment was assigned to him (by this time, the version of Kaletra that did not require refrigeration had become available).

After talking with Mr. Kavanaugh, I contacted a supervising physician, Dr. Carlos Mejia, who agreed the hospital would reopen David’s file and allow him to be treated. However, in his first few visits, nothing was done except some diagnostic evaluations, which revealed, among other things, that his CD4 count was dangerously low.

A few days later, Dr. Mejia told me David could not start on a Kaletra-based cocktail because it would have to include Abacavir, of which there was none in Guatemala at that time. In the mean time, he would receive prophylactic medication for prevention of opportunistic infections.

Time passed – too much time. David began to deteriorate, and weeks later there was still no Abacavir in the public health care system. He now had constant fevers and was losing more weight. The hospital simply performed more diagnostic tests and sent him home with no antiretrovirals.

On May 25<sup>th</sup>, more than two months after my initial contact, the Roosevelt Hospital was still out of Abacavir. I saw Dr. Mejia in a meeting in the Dominican Republic, and he explained to me that the only treatment regimen available to David would have to include Tenofovir, Abacavir, and Kaletra (Aluvia).

Finally, around June 20<sup>th</sup>, David’s former employers, who had been sympathetic throughout the entire process, realized how ill he had become. He could no longer work due to his rapidly deteriorating state. After considerable effort, he was declared eligible to go to the semi-private Infectious Diseases Hospital (“Hospital de Infectologia”). Guatemala has a divided health care system, and the

Guatemalan Social Security Institute (IGSS) is available only to those people whose employers make monthly contributions; only about 20% of the population are members of the IGSS system. There, David was finally given a cocktail of DDI, Kaletra, and Tenofovir.

He spent two weeks in the hospital and was discharged, apparently improved. But when I spoke to him on Saturday, July 10<sup>th</sup>, he was home in great pain and unable to walk. I notified Rudy Felipe of the NGO where David works, and he helped David get to the emergency room of an IGSS hospital, and shortly thereafter, he was readmitted to the Infectious Diseases Hospital, where he has been ever since. I then began calling David on a daily basis. He complained of severe pain and said the dose of Tramal (tramadol) was not helping with the pain.

His physician promised him a lumbar puncture for July 12<sup>th</sup> to try to investigate the cause of his severe back pain and walking difficulty. I was concerned that he might have a serious opportunistic infection that had spread to his spinal cord.

On the day of the procedure, David awoke to the news that his physician had left for two weeks and that there would be no lumbar puncture. I decided to call the office of the hospital director to complain about the situation and to press for reasons why the promised procedure was not taking place, yet the only person who would take my calls was his secretary. She suggested I email my request, which I did. No one replied. Finally, I faxed a formal letter, figuring that sending it that way would make it impossible for the assistants and secretaries to ignore it. (see page 176)

On July 23<sup>rd</sup>, I called Dr. Cambranes’ secretary. The same afternoon, I finally received a reply from Dr. Cambranes’ secretary, indicating that she was trying to contact me by telephone. Meanwhile, David was taken the same day to a neurologist and given a series of tests. His pain medication was increased. When I returned the call to Dr. Cambranes’ secretary July 27<sup>th</sup>, she told me David’s doctor had returned from vacation and he would order physical therapy and further testing. She also said that the entire hospital staff had denied harassing David because he sought outside support from our organization, but at the same time, that they had been ordered to stop any such harassment if it had indeed occurred.

All this begs the question: *Has it been cost effective to spend the amount of time I did following*



*up on David Efren Lopez's case?*

I don't know. In total, there have been over 100 e-mails exchanged and roughly an equal number of phone calls made to Guatemala. Is this a viable, reproducible approach for intervening on behalf of a PLWHA who has fallen between the cracks and for reducing the mortality rate? Probably. Yet, if there were well organized, civil society activists in Guatemala who had easier access to decision makers, then the effort would be much less. A dedicated "coalition" of perhaps 100 well trained PLWHA activists, linked by e-mail and telephone throughout Guatemala and following up on these kinds of cases, would be an ideal solution.

There are two things I know for sure: 1) over \$10 million of foreign aid for HIV/AIDS now flows into Guatemala each year, the majority of which comes from USAID and the Global Fund, and 2) 42% of all PLWHA who need treatment continue to die without it. Some, but not all, members of civil society NGO's are now focused on Round 10 Global Fund projects. Will their focus be on projects

that will have an impact on the mortality rate? Where is the civil society effort centered on the more than 100 Guatemalans who die *each week* for lack of access, in spite of all the money that is available, and how do we create an effective activist coalition dedicated to strategically intervening on these unnecessary deaths?

The Guatemalan health care system cannot justify labeling a PLWHA as "non-compliant" and then refuse to provide that individual service as was David's case. They need to provide better treatment literacy programs and to recognize basic human rights. The fact that David made a mistake in refusing his Kaletra in 2009 should not translate into a death sentence issued from the Health Ministry as a consequence. I doubt strongly whether anyone knows the actual number of people labeled "non-compliant" for similar reasons who have died as a result. Who knows how many will arrive at a hospital today and be refused services for being "non-compliant."

**Post-script:** Since this article was written, David was taken off anti-retroviral treatment because of a severe case of pneumocystis pneumonia combined with pancreatitis, severe liver dysfunction and anemia. It was felt that the cocktail he had been placed on was causing liver toxicity. He was bedridden and received oxygen and blood transfusions, and was being treated with medications for the conditions listed above. Through a donation, a genotype test was recently done at the cost of over \$400, in hopes that his physician would be able to find an appropriate anti-retroviral cocktail. David was up beat and his companion Efrian was given permission to remain with him in the hospital 24 hours a day.

Unfortunately, David passed away August 20<sup>th</sup>, 2010. The cause of death was complications due to AIDS, but mostly bureaucracy and negligence. Activist Matthew Kavanaugh of Health Gap in the US said it best:

"This is immensely sad to hear and outrageous. Having followed David's struggle from afar, his story is an indictment of both the medical system's failure to respond as well as the global system of drug distribution... in a wealthy Northern country David would have had access to regimens that worked and he would be alive today. But instead, even those doctors who were trying to right the wrongs done to David previously couldn't actually even get the drugs many in the North take for granted."

*21 de July, 2010*

*Dr. Edwin Cambranes  
Director, Department of Infectology*

*Dr. Juan Roberto Morales  
Director General de Medicina, IGGS Guatemala*

*Dear Dr. Edwin Cambranes and Dr. Juan Roberto Morales.*

*I am writing to you today to request a telephone conference in which we can talk about the case of David Efren Lopez, a PLWHA at the Infectious Diseases Hospital. He was admitted four weeks ago, and yet during the past three weeks he has shown no sign of improvement.*

*I am not looking for medical information about David since I am not a relative. What I want is for you to assure me that you will take appropriate actions in order to monitor David's case since he has been seriously ill for some time.*

*I was informed today by one of David's visitors of a disturbing situation: some of the nurses and hospital staff have complained to directly to David about having sought our organization's support. I feel that he has every right to seek out help in his extremely fragile condition.*

*Once again, I wish to express my willingness to collaborate in supporting David, a young 23 year old who is fighting for his life.*

*Sincerely, Richard Stern, Ph.D*