



Independent observer
of the Global Fund

David and Goliath - PWAs and the Global Fund CCM in Bolivia

[Adapted by the author from a presentation she gave on July 14 at the Bangkok International AIDS Conference, at a satellite session entitled, “The Global Fund: How CCMs Can Be More Effective,” organized by Aidspan and other NGOs. A translation of this article into Spanish will shortly be posted at www.aidspan.org/gfo/docs/gfo62.pdf.]

I was once invited as a community representative to attend a meeting at the Global Fund (GF) headquarters in Geneva. I entered the building and saw many people working hard. I felt I was looking at a machine with human parts. While in that big building, I felt so small, so insignificant, so lacking in information and skills – I felt hardly qualified to speak to the GF staff person who deals with my country.

Yet I speak English; I was able to attend university; I am middle class, single, without children, and able to travel. Imagine then how people feel if they have HIV and are already sick, if they do not have basic English language skills or basic education, if they have never been in an airplane or been to Europe, if they are poor and isolated. I am sure that when they want to deal with the Global Fund, they feel like David facing Goliath. Yet isn't it the goal of the Global Fund to save the lives of precisely these people?

My aim in using this metaphor is not to highlight a tense relationship with the GF, but to illustrate the conditions faced by PWAs (People Living with HIV/AIDS) who want to get involved in the GF process. Unfortunately, the Global Fund has become a bureaucratic Goliath. And unfortunately, PWAs are still Davids. The happy ending for this story is not the death of the giant, which we certainly do not want. It is that sometimes PWAs do succeed in dealing with the GF giant.

A Weak Start

When the Global Fund began to accept Round 1 proposals, few people in Bolivia had heard of the Fund.

Many PWAs, even PWA leaders, knew nothing about what was being done in Bolivia about the GF. One reason may be that most of the information was only available in English.

Proposals were written to the Fund almost in secrecy. During Round 1, for example, a Bolivian network of NGOs presented its own proposal to the GF without telling anyone else about the initiative. We only learned about their proposal much later – when this network asked for a seat on the CCM – and fortunately, their proposal was rejected.

As for the CCM, PWAs were only invited to join after we applied pressure.

During the second round, a Bolivian CCM as a national mechanism was created for the first time. Unfortunately, most of its members were from La Paz, the capital.

The GF guidelines suggested that CCM members should belong to already existing networks. But we at the grassroots level suspected that some of the networks claiming to have worked on AIDS were coming only for the money. We said to them, “If you were already working on AIDS, why did we feel lonely for so long?”

At this stage we formed REDBOL, the Bolivian Network of PWAs, but our new network lacked formal legal status as an NGO. This was the principal argument people used to block our participation on the CCM. We were seen as beneficiaries but not as legitimate voices to design and implement the proposal.

Much of Bolivia’s Round 2 proposal was written at the last moment; certainly PWA leaders were consulted only at the very end. This situation produced a very weak proposal, which was rejected.

Strategies for Pressing the CCM and the Government

After the Round 2 failure, before the buildup to the third round, the Bolivian CCM was open to becoming more inclusive, and invited membership from TB and Malaria organizations, organizations of indigenous people, traditional healers, members of the army, and others.

REDBOL decided at this point to develop a serious advocacy strategy for effective PWA membership of the CCM. And since a principal objective of the Global Fund grants was to save the lives of PWAs, we believed our inclusion was mandatory. This is how we set about achieving our goal:

- Our first task was to learn about the Global Fund. Most of the available information was in English. We turned for help to REDLA, the Latin America Network of PWAs, and ICASO, the International Council of AIDS Service Organizations. (The inputs of Rodrigo Pascal, a member of the “Communities” delegation to the GF board, were especially important for us.) These friends provided us with information in Spanish. They taught us it was our right to be involved. They helped us understand the GF and its principles and goals. They provided technical and practical tools to help us advocate for our participation and to play an active role.
- We then started advocating with the government. We started to put this issue on the national AIDS agenda.
- We wrote a position paper calling for the inclusion of PWAs in the CCM. By this time, our knowledge about the GF was quite good. PWAs across the country developed a unified position related to the GF, and we did not fight each other for access to the funds.
- We were persistent in sending letters denouncing the fact that PWAs were not involved in the CCM and the whole GF process. We kept emailing these letters to national and international networks, even to the GF. These letters were intended to embarrass the CCM and the Bolivian government. They were very effective.
- At that point, the CCM not only excluded PWAs, it excluded most cities and regions outside La Paz, the political capital. We networked across the nation. We had leaders in the three principal cities of

Bolivia who were open about their HIV status, and ready to go to the media. We agreed on the key issues and then publicly said, “We demand to be included in the CCM as the national network of PWAs; we demand this, that, etc.”

- We also started a personal skills-building process. Using materials from REDLA, we learned how to negotiate, come to a consensus and maintain the dialogue, all critical skills that allowed our leaders to become active CCM members. It was especially important for us to learn how to put a firm line around our “not negotiable issues” for the GF proposal (e.g. access to treatment, support for REDBOL, etc.)
- REDBOL took on the constant role of watchdog. We encouraged all PWAs to read the failed Round 2 proposal which was to be the basis for the Round 3 proposal, and to give their opinions.
- Our strategy was completed by setting up strategic alliances with the government’s National Program on STDs and HIV/AIDS, with NGOs, and with key officers of some UN agencies. All of these actors supported our demand to be included more seriously in proposal development.
- At the GF regional meeting in Panama last November, Julio César Aguilera, a PLWA from Bolivia, commented “I am grateful that almost all of the agencies who are here [USAID, PAHO, GTZ, UNAIDS, the World Bank, etc.] are working to help us in Bolivia. But I wonder how it is possible that as yet not even one PLWA in my country has received ARV treatment?”

A Summary of Victories

The above actions were very effective.

- Since the time of development of the Round 3 proposal, we have had three national representatives of PWAs on the CCM, one from each of the main cities, up from zero before.
- The REDBOL coordinator is not only a CCM member but also a member of the CCM’s executive committee. Even though he lives in Santa Cruz, we successfully negotiated with the CCM to cover his travel expenses to La Paz.
- PWAs in Bolivia are now among the experts on the GF. And it is generally accepted that whenever something is being done related to the GF, PWA representatives must be consulted.
- The Bolivian CCM now uses an election process for choosing members, whereas members were originally appointed.
- The reconstituted Bolivian CCM developed a spirit of unity and harmony, focusing on the fight to develop a successful Round 3 proposal.
- The GF accepted all three proposals (HIV/AIDS, TB and malaria) that Bolivia submitted in Round 3. The GF’s Technical Review Panel wrote, “Good Government/NGO partnership. Defense of human rights of PLWHA is a priority.”
- Sixty percent of the Bolivian proposal on HIV/AIDS is destined to purchase ARV medication. This was one of the “not negotiable” items of REDBOL. Part of the grant will also support existing networks of PWAs.
- The CCM has become a place where PWAs can sit at the same table with policy makers and other national leaders, talking and negotiating.
- The CCM has become a more transparent mechanism. It has developed a constitution with agreed goals, structure, and responsibilities.
- During a recent political crisis, in which there was an unexpected change of political leaders within Bolivia, the Bolivian CCM managed to keep working with unity and harmony, despite having a new chair.

Challenges Ahead

We have had many successes, but we still have a long way to go. We have to analyze how the approved

grants will function at the grass roots level. The CCM doesn't yet cover the transportation costs of most of those members who have to travel from around the country to meetings in the capital city. REDBOL still lacks offices of its own and has only a small group of leaders. The CCM has grown too large, including many representatives of organizations with no background in AIDS, TB or malaria. The CCM has yet to fully implement the GIPA principles (Greater Involvement of People Living with HIV/AIDS), and must improve its dissemination of key information to PWAs across the country. The CCM does not have currently any female PWA members. We face political instability in Bolivia, which means the government representatives to the CCM often change, disrupting the CCM's functionality. Lastly, CCM members still sometimes think of the CCM as a governmental institution, and view the desires of the government representative as requirements. We must not forget that the CCM is a mechanism of the country, which includes civil society, not just government.

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