Government and Civil Society in the Fight Against HIV and AIDS in Brazil[1]

Introduction

Paulo Teixeira, the current National Coordinator of the AIDS/HIV and STDs Control Project, inherited a project considered an international reference point not only due to the quality but also the innovation and institutional framework for AIDS/HIV and STDs control which is strongly supported by partnerships with state and local governments and numerous Civil Society Organizations (CSOs).

He can look with satisfaction at the results obtained, but simultaneously he cannot avoid the concern for assuring sustainability of the CSOs' intervention's after the World Bank project ends. The challenge is multiple:

- Who will fund the CSO projects?
- Who will manage the allocation of resources among CSOs to ensure appropriate and effective targeting of high risk populations?
- Who will provide the sophisticated technical guidance necessary for the design of effective messages and behavioral interventions?
- Who will monitor CSO activities and assume responsibility for avoiding inefficiency and duplication of activities and products?
- Who will measure the impact of CSO activities?

Background: AIDS and AIDS Control in Brazil

The first case of AIDS in Brazil was diagnosed in 1980. Since then, changes have been documented in the geographic distribution of the disease and in the profile of the affected population groups. Between 1980 and 1986, 85% of reported cases were primarily concentrated in cities of the Southeast (Rio de Janeiro and Sao Paulo). Today, all 27 Brazilian States have reported AIDS cases and 3,000 (out of 5,500) municipalities have registered at least one case of AIDS.

Initially (from 1982 to1986), the epidemic was concentrated among men who have sex with men, generally, men of a higher educational level. Later (1987 to 1992), the epidemic began to appear among intravenous drug users and heterosexuals. Since 1993, the trend has been towards greater heterosexual transmission, especially among lower income populations and women. After 1992, 65% of the reported AIDS cases were

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[1] This case was prepared by John Garrison and Anabela Abreu (World Bank) with the collaboration of Julio Sanchez Loppacher, IAE, as the basis for class discussion rather than to illustrate either effective or ineffective handling of an administrative situation. The elaboration of this case has been sponsored by the World Bank.

AIDS - Acquired Immune-deficiency Syndrome

HIV - Human Immune-deficiency Virus

persons with no literacy or who had completed at most, elementary school. While in 1985 the gender ratio was 28 men / 1 woman, in 1997/98 this ratio had climbed to 2 men / 1 woman, and as high as 1 / 1 in the 15 to 24 age group.

The age group most affected by HIV/AIDS has been the 20-39 age group, accounting for 70.6% of the total of cases reported to the Ministry of Health as of May 1998. Transmission from intravenous drug use is the principal cause for incidence of the disease among the 15-24 age group. Out of the total number of notified cases within this age group, 36% are intravenous drug users (IDU).

Today, the population groups identified as most likely to acquire and/or transmit the HIV virus ("high risk groups") are intravenous drug-users, men who have sex with men, and commercial sex workers. Other populations that appear to be at greater risk and vulnerability include persons of low income, adolescents and women.

Since its inception in 1987, the HIV/AIDS and STD Control Program has been targeting all of the above groups in its own HIV/AIDS prevention and treatment activities, and has also supported numerous CSO subprojects which also target these specific high risk and vulnerable populations. Since 1993, these efforts have been supported by two World Bank loans (US$325 million total) for projects that aim to reduce HIV/AIDS by investing in prevention, treatment and institutional development (see Annex 2, for more detail).

The Second AIDS and STD Control Project basically kept the same goals as the first project, but has a greater focus on decentralization as well as on the sustainability of the activities and results toward the HIV/AIDS and STD control.

Both World Bank financed projects support activities at the federal, state and municipal levels, as well as CSO subprojects and research. The National Coordination (NC) also collaborates with multi-lateral agencies including the World Health Organization, UNDCP, UNICEF, and UNESCO, as well as bilateral and non-governmental donors.

The overall Program supports health education, media campaigns, and behavior change programs, focused on raising awareness and/or modifying attitudes and behaviors that place people at risk of acquiring AIDS and STDs. In 1996, the Ministry of Health created a national telephone hotline for health that has logged over 2 million calls throughout Brazil. The NC also maintains an extensive and informative homepage on the internet. The NC has built a nationwide network of 133 Testing and Counseling Centers (CTA) to provide greater access to HIV testing; to date they have carried out over 400,000 HIV tests. Also, there are 159 maternity hospitals that offer HIV tests and which are specialized in treating HIV-positive pregnant women. Brazil was one of the first countries to guarantee universal and cost-free treatment of HIV/AIDS patients. Over 70,000 patients now benefit from this policy. The program also supports the National Human Rights AIDS Network (RDH) which combats AIDS discrimination by providing legal aid to civil society organizations and human rights groups throughout Brazil.

In partnership with the private sector, the Program and the National Business AIDS Council have involved over 3,000 companies in prevention initiatives, reaching an estimated 3.5 million workers. Also, in a partnership with the Brazilian Army, over 700,000 conscripts who appear annually before local draft boards receive condoms and information on prevention. The NC is also working through several hundred civil society organizations that target their efforts to high risk and vulnerable groups mentioned above.

The NC has also worked to strengthen the country's public laboratories through training of technicians; quality control of serological diagnoses; and increasing capacity to carry out HIV testing and treatment related laboratory analysis, including acquisition of equipment and installation of new laboratories.

HIV/AIDS and STD related training has been supported by the NC, for health professionals, teachers, and others. Approximately 3,800 teachers and 32,500 student trainees received training in l,375 schools utilized for AIDS and drug prevention instruction. The "Health in School" project trained about 144,000 public school teachers and 4.5 million children in sexuality, drugs, self-esteem, and AIDS.

Civil Society and HIV/AIDS Control in Brazil

A Brief History

The term civil society has emerged in Latin America in the last two decades. Its meaning varies greatly depending on who is utilizing it. In Brazil, the term civil society has a political connotation and refers to the vast non-governmental sector composed of community organizations, social movements, NGOs, charitable organizations, professional associations, churches and corporate foundations. The emergence of strong social movements is a recent phenomena in Brazil tied to the redemocratization of the country.

CSOs have played a significant role in the evolution of the fight against AIDS in Brazil. The Government's response to the AIDS crisis was partly fueled by pressure from CSOs in several state capitals that formed to support people with AIDS. These included the *GAPAs* or *Grupos de Apoio a Pessoas com AIDS*. Also, the *Associacão Brasileira Interdisciplinar de AIDS* (ABIA) brought together doctors, lawyers, sociologists, church leaders, and journalists to carry out independent research on the growing epidemic and to monitor government action. It was headed by two capable and charismatic leaders, Herbert “Betinho” de Souza and Herbert Daniel[2]. ABIA assumed a leadership role within the AIDS civil society community.

[2] Herbert "Betinho" de Souza and Herbert Daniel are two well-known anti-governmental leaders from the time of the dictatorship in Brazil. Both were in exile for several years and came back to Brazil when the military regime fall. Betinho was a hemophilic and discovered he had been contracted the HIV virus and Daniel was one of the leaders of the gay movement in Brazil and also HIV+. Their militant past and their

In light of the alarming number of hemophiliacs infected through tainted blood, (85% in the city of Rio de Janeiro) ABIA mounted a successful campaign for more stringent standards in blood banks throughout the country. The lobbying campaign consisted of demonstrations in front of blood banks, letter signing campaigns, visits to the Congress, and assisting in the drafting of legislation. In 1989, an offshoot of ABIA was established in Rio de Janeiro called *Grupo Pela Vidda*. The *Pela Vidda* was comprised of HIV-positive persons and was geared toward providing care and support services to people with AIDS including legal aid, counseling, and support groups. Today these patients groups have evolved into a large national network, *Rede Nacional de Pessoas Vivendo com AIDS* (RNP+) comprised of about 400 care and support organizations.

In the late 1980s, these various organizations began to pressure the Brazilian government to take action against the epidemic. Their tactics included street demonstrations, distribution of condoms, letter writing campaigns, delegations to Brasilia to meet with the Minister of Health and the President, and distribution of flyers and other materials urging the Government to provide funding and develop AIDS prevention programs.

With time, many of the CSOs began to establish local, regional, and national AIDS/CSO networks in order to exchange information and more effectively influence public policy. Several state capital cities and regions such as Sao Paulo, Rio de Janeiro, Northeast, Centerwest, have active AIDS/CSO networks. The first national AIDS/CSO conference was held in 1989. One of the leaders of this nascent movement, Jane Galvao of ABIA, was recently appointed the head of the NC's CSO Liaison Office.

In the 1990s, the number of CSOs involved in HIV/AIDS control and prevention proliferated. Many of them were able to form as the direct result of funding made available by the Ministry of Health under a special component of the World Bank financed AIDS and STD Control Project. The 120 CSOs registered with the NC in 1992 grew over 600 today. Between 1994 and 1997, the Ministry of Health (with World Bank financing) supported 427 CSO projects costing US$ 18.1 million and involving 175 implementing organizations. The Second World Bank Aids and STD Control Project, which has been effective for about 18 months has already implemented 350 CSOs subprojects.

To date, CSO activities funded by the Ministry of Health have included research centers, social movements such as the association of transvestites, and informal community or single-constituency groups. The make-up of the organizations funded and/or their target groups have included homosexual men, feminists, transvestites, pregnant women, truck drivers, children, commercial sex workers, drug users, prisoners, hemophiliacs, and the general public.

The breadth of activities funded has included research, public education, condom distribution, patient care, policy analysis and advocacy, counseling, patient family

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health conditions gave them the motivation to actively fight and lobby the Government in initiating HIV/AIDS control measures. Both died in the 1990s as a result of AIDS.

support, organizational networking, materials production and distribution, teacher training, and networking events. CSO activities focused on behavior intervention (34%), followed by information, education and communication initiatives (31%), support to persons living with AIDS (29%), and a small number of institutional strengthening efforts (6%).

These organizations demonstrated their ability to reach groups of individuals at-risk whose needs the government was either unable or unwilling to address. The CSO projects funded over the past 8 years have distributed over a million condoms, disseminated educational materials to over half a million persons, provided specialized orientation to over 200,000 persons, and have trained over 2,000 trainers. While the impact and cost-effectiveness of CSO activities in changing high risk behaviors has yet to be quantified, CSO participation has clearly broadened the reach of control efforts into a number of key high risk, marginal and hard to reach populations.

Forging a Government - Civil Society Partnership

What is most remarkable about the collaboration which has been forged between the Government and the civil society sector is that it began to become solidified at a time when overall government/CSO relations were still quite tense due to a long history of suspicion and animosity framed by the period of the military regime from 1964 to 1985. On the other hand, there were apparently several underlying reasons which led the Government to attempt an operational partnership with AIDS/CSOs.

First, the very multi-faceted and social nature of the epidemic itself. It was clear from the onset that government alone would not be able to reach the most high risk populations (IV drug users, commercial sex workers, men who have sex with other men) and undertake the needed grassroots prevention and treatment work. CSOs complement government action by their flexible, innovative, and generally more cost-effective approach. Further, CSOs could reach and work effectively with people at the community level, especially with marginalized segments of society.

Second, actions which are politically difficult for the Government to undertake sometimes can be done by CSOs (harm reduction programs, for example)

Third, International development agencies such as the World Health Organization (WHO) and the World Bank clearly encouraged the NC to pursue a collaborative approach to civil society.

In addition to the Government interest in involving the Civil Society, the latter were ready and keen in fighting the epidemic which was affecting their friends and family.

The CSO Comparative Advantage: Examples from Aracaju and Porto Alegre

The AIDS CSOs contribute in important and unique ways to the fight against AIDS. These civil groups have greater access than government agencies to specific groups at risk such as men who have sex with men, commercial sex workers, street children, drug users, low-income women, indigenous peoples, and truck drivers. Often, these risk groups comprised of sex workers, transvestites, homosexuals, and street children have established their own CSOs to carry out support and prevention activities. These beneficiary groups often have a better understanding of the target population and a better sense of what methods may or may not work to modify high-risk behaviors. They also have the trust needed to work and be heard on such sensitive issues such as sexual and drug habits. Being closer to the ground allows these CSOs to interact on a daily basis with a sometimes transient population that may be suspicious of governmental authority.

A good case in point is the commercial sex worker population of the state capital, Aracaju, of the Northeastern state of Sergipe. In 1990 an association of commercial sex workers was established in response to the growing level of violence being perpetrated against them. In 1993, the *Associacao Sergipana de Prostitutas* leaded by Maria Nizina best known as Cambelária, launched an AIDS prevention program targeted to the 2.800 sex workers of the capital, who were beginning to show alarming rates of HIV infection. They organized a multi-faceted program which included training of health agents, condom distribution, psychological counseling, referral to city medical centers, and support groups. The results have been impressive. Over half of the sex workers reached through the program, 400 women and youth, were trained as health agents, and there have been no new reported cases of HIV infection among the beneficiary population.

As could be expected, there have also been difficulties in carrying out the prevention work and forging a relationship between the Association and the local government. These include: lack of medication in the government health clinics; insensitivity and discrimination among some health professionals towards the commercial sex workers; the transient nature of commercial sex workers which made follow-up on behavior change approaches difficult; and the lack of government funds to sustain the various HIV/AIDS initiatives.

A second example involves the drug user population in a completely different regional setting of Brazil, the southernmost state of Rio Grande do Sul. The state capital of Porto Alegre has one of the highest rates of intravenous HIV infection caused by indiscriminate drug use. There, a small NGO composed of a largely volunteer staff called the *Associacao Brasileira de Redutores de Danos (ABORDA)*[3] decided to address the problem by establishing a limited needle exchange program geared to intravenous drug

[3] Domiciano, the leader of this association is a former IV drug user, who currently dedicates his entire time to preventing HIV transmission though IV drug use. It is interesting to note that most of the volunteers are IV drug users who quit or are in the process of quitting it, and IV drug users family members. This subproject has a double advantage not only for the implementation of harm reduction activities, but also a means to help IV drug users to quit.

users located in low-income neighborhoods. While the project began modestly in several low-income neighborhoods, it has evolved into a much larger program with greater social impacts than envisioned. *ABORDA* has been able to more than double the number of drug users reached, increase the drug-prone areas serviced, and substantially increase the number of needles exchanged on a monthly basis (10,000). Further, ABORDA has been able to establish effective working relations with key medical care facilities and professionals, train university students and local "neighborhood agents" to undertake the needle exchange activities, launch an educational and counseling program geared to children of drug users, and, perhaps more importantly, bring back some dignity and purpose to one of the most discriminated and vulnerable groups in society.

Managing the CSO Contribution to HIV and AIDS Control

Selection of CSOs. The selection criteria for CSO projects were developed and adapted over a period of years and reflect the intent to support the most qualified, targeted, and strategic AIDS initiatives in the country. These criteria are posted on the NC's Web page and sent out with the *edital* which is sent to a mailing list of some 800 CSOs. The selection criteria include: institutional capability; financial soundness; programmatic consistency; technical competency; geographic coverage; and methodological replication.

The selection committee is composed of medical professionals and health researchers, and meets for an entire week to carefully select the hundreds of proposals received each year. Through the selection criteria, the selection committee attempts to ensure a balanced selection. This includes: ensuring that each one of the five regions of the country is contemplated (proportionate to the incidence of HIV/AIDS): that all major populations-at-risk groups in society are covered; and that new populations-at-risk groups also be funded.

Institutional Framework . The Government, particularly at the federal level, provided a variety of support to AIDS/CSOs geared to institutional capacity-building and improving their delivery of services. This support included: providing training in project design and program implementation; grant monies for AIDS prevention/treatment projects; technical assistance in such areas as financial management, fund raising, and materials production; and even financing of national CSO network meetings.

The Government has also provided support to AIDS/CSOs through hiring their services and providing them a seat at the AIDS policy formulation table. These activities have allowed CSOs to grow professionally, feel more empowered, and take on greater ownership for the AIDS work in Brazil. CSO staff have been hired to design AIDS education and prevention programs, provide technical assistance to other CSOs, and monitor CSO projects. A case in point was the hiring of a leading AIDS/CSO activist and researcher by the World Bank to carry out the social analysis of the AIDS II project as a way of ensuring that the Government took into account the concerns of the AIDS/CSO community.

A key element in this partnership has been the Government commitment in transparency by sharing all documentation and pertinent information related to its decision-making process.

This relationship and the availability of Bank funds have a tremendous impact on the rapid growth of the CSOs. This rapid growth and high diversity among CSOs (from commercial sex workers, to churches, and heath professionals, etc) naturally overwhelmed a process which at that time was exclusively centralized, from selection, and implementation, to monitoring and evaluation. The PCU was challenged in maintaining transparency, efficiency and quality control, with a large numbers of CSO subprojects. Even with different level of state capacity, the PCU decided to focus on decentralizing CSO activity management. This decentralization process has been implemented cautiously with technical assistance to the state project coordination units. The central level still has the big portion of the burden. However, the tendency is to progress to the full decentralization.

Challenges for the Future: Financing and Quality Control

In order for CSOs to continue making their unique contributions to the fight against HIVAIDS in Brazil, two great challenges will have to be met: where will the money come from and how will the technical quality of HIV/AIDS interventions be directed and maintained. In other words: Who will pay and who will provide critical technical guidance (strategic and tactical) ?

Financial Sustainability Issues. CSO leaders are concerned about the sustainability of the State-CSO partnership in the absence of World Bank financing. At present, many CSOs are fully dependent on World Bank funds and have not developed plans for alternative financial support. These leaders warn that if an adequate transition strategy to alternative sources of external funding or self-generated funding is not implemented, there could be a serious and dramatic collapse of services as many CSOs may have to close their doors.

Several alternatives to federal support exist: (i) State and Municipal governments could assume responsibility for financing CSO projects; (ii) private sector corporate entities could do the same; and/or (iii) CSOs could pursue new fund raising strategies ranging from selling goods and services to leveraging resources from local communities.

Technical Sustainability Issues. At present, the federal Ministry of Health, through the NC, is responsible for technical oversight of all HIV and AIDS prevention and treatment activities in Brazil. These responsibilities can only be carried out effectively with a high level of technical expertise and with a sophisticated, nationwide infrastructure for HIV/AIDS and STD surveillance. Coordination of complex inputs from all parts of the country is required to determine where best to allocate resources for disease control. In light of these needs and the importance CSO involvement, in the future:

- Who will manage the allocation of resources among CSOs to ensure appropriate and effective targeting of high risk populations?

- Who will provide the sophisticated technical guidance necessary for the design of effective messages and behavioral interventions?

- Who will monitor CSO activities and assume responsibility for avoiding inefficient duplication of activities and products?

- Who will measure the impact of CSO activities?