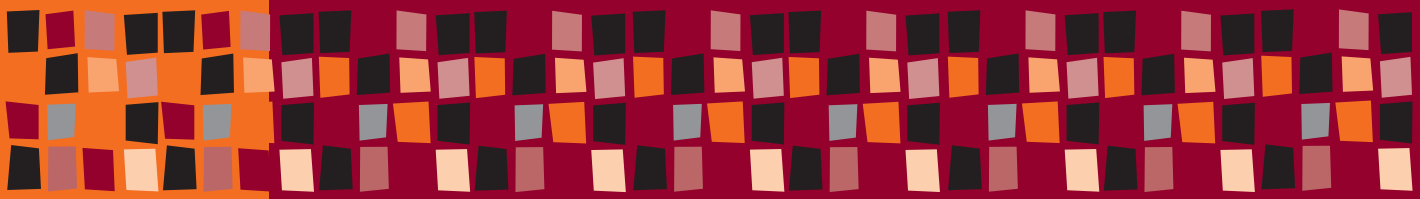
Access to AIDS treatment in Bolivia and Paraguay

international cooperation and social mobilization



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ABIA
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Rio de Janeiro/RJ - Brasil
2006

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Electronic Editing: A4 Mãos Comunicação e Design

Support: DST-AIDS FORD FOUNDATION
Printing: Reproarte
Edition: 500 copies
Printed in Brazil

This publication is the english version from the original: Pimenta, Cristina et al (Org.). Acesso a Tratamento de AIDS na Bolívia e Paraguai – cooperação internacional e mobilização social. *Coleção ABIA, Políticas Públicas N. 6*. Rio de Janeiro/RJ - Brasil: ABIA, 2006.

CIP-Brasil. Catalogação-na-Fonte. Sindicato Nacional dos Editores de Livros, RJ.

A158

Access to AIDS treatment in Bolivia and Paraguay : international cooperation and social mobilization / organizers Cristina Pimenta... [et al.]; [translater James Mulholland]. - Rio de Janeiro, Brasil : ABIA, 2006
55p. : il.
Translation of: Acesso a tratamento de AIDS na Bolívia e Paraguai : cooperação internacional e mobilização social
Includes bibliographical references
ISBN 85-88684-29-2

1. AIDS (Doença) - Pacientes - Bolívia - Cuidado e tratamento. 2. AIDS (Doença) - Pacientes - Paraguai - Cuidado e tratamento. 3. AIDS (Doença) - Pacientes - Serviços para - Bolívia. 4. AIDS (Doença) - Serviços para - Paraguai. 5. Acesso aos serviços de saúde. 6. Políticas de saúde - Bolívia - Cooperação internacional. 7. Políticas de saúde - Paraguai - Cooperação internacional. 8. Políticas de saúde - Bolívia - Participação do cidadão. 9. Políticas de saúde - Paraguai - Participação do cidadão. I. Pimenta, Cristina. II. Associação Brasileira Interdisciplinar de AIDS.

06-2262. CDD 362.196978
CDU 364.2:626.98

Summary

PRESENTATION

The Brazilian Interdisciplinary AIDS Association (ABIA), founded in 1986, has been active in the fight against the HIV/AIDS epidemic in Brazil through actions involving prevention, awareness-raising and social mobilization in defense of the rights of those living with HIV and AIDS, as well as producing and disseminating information and knowledge, and, monitoring public policies related to the epidemic over the last twenty years. Especially as of 2002, ABIA has been strengthening its actions within the Latin-American sphere in order to contribute its participation and interchange with countries in the region, focusing on the importance of developing South-South cooperation strategies that enhance national and international responses to the epidemic.

This publication (Number 6) is a continuation of the Public Policies Series and presents two texts on *Cooperation, social mobilization and access to AIDS medication in Latin America: Case Studies on Bolivia and Paraguay*, resulting from the project Cooperation, Social Mobilization and Decentralization of Public Policies on HIV/AIDS in Latin America, developed with the support of the Ford Foundation, and from internal cooperation actions with civil society in this region of Latin America, in partnership with the Brazilian National STD and AIDS Programme of the Ministry of Health.

The purpose of the case studies was to gather information on access and integral care for people living with HIV/AIDS and on social responses to control the epidemic in a country in the Andean area of Latin America – Bolivia – and another from Mercosul – Paraguay – with which the Brazilian government has a cooperation agreement for donating medication and providing technical support for AIDS treatment. One of the relevant aspects of the work was to find out the impact of Brazilian donations to other developing countries and what this represents in the field of production of generics and external cooperation programs in an attempt to enhance understanding of the inter-relation between national production, protection of patents, and forms of access to treatment. In this respect, the purpose of the study also included a diagnosis of the local response, including the social-movement component and the nature of the participation of civil society in these countries, as well as the challenges to be faced in order to ensure the political and financial sustainability of national and international responses to the AIDS epidemic.

Some of the basic questions in the studies were: Does Brazil cover 100% of Bolivia's and Paraguay's needs for anti-retrovirals? What can civil-society organizations from these countries do in partnership to continue guaranteeing access to current and new medicines for AIDS treatment, from the perspective of an effective regional integration that is not restricted to trade agreements on access to markets? Another question that drew our attention refers to how the topics related to protecting intellectual property (IP) and their impact on the production and access to medication for HIV/AIDS have been treated in the sphere of trade agreements that involve the countries of the region, such as the Free Trade Area of the Americas (FTAA), and between the European Union (EU)

and Mercosul, and which might bear consequences for the whole developing world inasmuch as they strengthen the mechanisms that protect intellectual property to the detriment of access to medicine and local production of pharmaceuticals.

This being so, attempts were made to strengthen the instances of the local social movement, to promote a process of awareness-raising of Non-Government Organizations (NGOs) to work on the issues of access to treatment, intellectual property and production and purchase of generics, and to sensitize local governments. This was done through seminars and workshops held in Bolivia and Brazil for the purpose of mobilizing public opinion to guarantee that the interests of public health and the welfare of citizens are not neglected because of the economic interests of private sectors, by promoting multiple strategies such as disseminating information, debating, denouncing, researching, in other words, marking social participation in these matters.

The texts presented were prepared based on information gathered by means of interviews held in Bolivia (in the provinces – *departamentos* – of Cochabamba, La Paz and Santa Cruz) and Paraguay (Asunción) with representatives of civil society and the government in September 2005, and also based on data obtained through reports and documents provided by governmental institutions, civil society and international agencies that work in these countries.

In February 2006, ABIA also held the seminar on *Cooperation, social mobilization and decentralization of public policies on HIV/AIDS in Latin America,* with representatives of Brazilian and Paraguayan civil society, staff from the Brazilian National STD/AIDS Program, from the Mercosur Forum of AIDS NGOs, and international agencies. There were two days of rich debate on the theme of universal access to treatment and prevention of HIV and AIDS, the processes of developing projects and establishing international cooperation agreements between Brazil and the countries that receive donations of AIDS medication. In March, ABIA received a delegation of Bolivian activists to discuss a first draft of the text of the case study on Bolivia. A summary of the discussions and considerations made during the seminar also appear in the texts presented herein.

We believe that disseminating the results of this interesting process in Brazil and other countries can be a unique contribution to the sustainability and enhancement of the programs involved, both the Brazilian program and those of the partner countries in question, as well as to strengthening mobilization of the political and technical capacities related to access to treatment and prevention in the region.

The preparation of this study had the collaboration of the International Center for Technical Cooperation on HIV/AIDS – National STD and AIDS Program/Ministry of Health (CICT - PN DST/AIDS - MS), the Advisory Division of External Cooperation (COOPEX), the coordinators of the International Cooperation Program (PCI) for Bolivia and Paraguay, the German technical cooperation for development *Deutsche Gesellschaft für Technische Zusammenarbeit GmbH* (GTZ) in Bolivia, Paraguay and Brazil, the ONUSIDA/Paraguay Working Group, the coordinators of the National AIDS Programs in Bolivia and Paraguay, and the activists and representatives of the Bolivian and Paraguayan civil-society organizations who were interviewed. We are also thankful to consultant Marcos Benedetti for conducting interviews in the initial phase of the study.

CASE STUDY: BOLIVIA

INTRODUCTION

Bolivia, a country situated in the center of South America, has an area of 1,098,581 km² and a variety of geographical and cultural characteristics. Its population of 8.15 million lives in conditions of extreme poverty. Much of this population has no access to basic services such as drinking water, electricity and primary health care (Carrizo, 2006). In the 2004 Index of Human Development (HDI), Bolivia appears with 0.681, an improvement on the 2003 figure of 0.672. Along with Peru, Ecuador, Venezuela and Colombia, Bolivia forms a political and geographical region called the Andean Community of Nations. Politically, it constitutes a Unitarian Republic with a presidential regime. Most of the Bolivian territory (62%) corresponds to the area of the Amazon and Chaco, and 32% to the high Andean area.

From the geographical point of view, Bolivia is divided into three large regions. The *Altiplano* high plateau, despite being an area not propitious to agriculture, is known for its production of a large variety of vegetables and cereals. In this region are located the cities of La Paz, Potosi and Oruro. The *Vales* lowlands, a region occupied by 30% of the total population, are characterized by their dry climate, the most densely populated provinces being Cochabamba, Chuquisaca and Tarija. The third region, the *Llanos* plains, covers the largest part of the Bolivian territory and is characterized by its high income compared

with the other regions, which provokes migration of people from other regions. This region is subdivided into two distinct zones: to the North lie the plains of Mojos or Del Beni, and to the South lie the dry plains of Chaco, which stretches from Santa Cruz as far as the borders with Brazil, Paraguay and Argentina (Silva, 2005).

Bolivia is administratively subdivided into nine provinces: La Paz, Oruro, Potosí, Cochabamba, Chuquisaca, Tarija, Santa Cruz, Beni and Pando. The country's economy is based on mineral exploration – such as tin, petrol and natural gas; extraction of wood and rubber; agriculture, especially soy - and animal-raising, especially cattle and camels (*alpaca* and *vicunha*, used to make wool). The industrial complex – food, textiles and metallurgy - is still modest

Bolivia is a multi-ethnical and pluricultural country, with 60% of the population being indigenous and 25% *mestizos* (racial and cultural miscegenation between Spaniards and Indians). The main ethnic groups are the Aymaras and Quechuas in the Andean part and the Guaranis in the Amazon region. The dominant class is historically the white population of European descent, which corresponds to 15% of the entire population (Carrizo, 2006).

The indigenous population is socially excluded, suffers discrimination on the part of whites and *mestizos*, and sometimes even from within the indigenous community itself, especially when members of the community achieve success in the social scale or professional training. Poverty is a factor that exacerbates even more the discrimination against the indigenous population. Indigenous women are among the most discriminated against, frequently identified as poor women and potential bearers of sexually transmitted diseases, even among health professionals (Ibid, 2006).

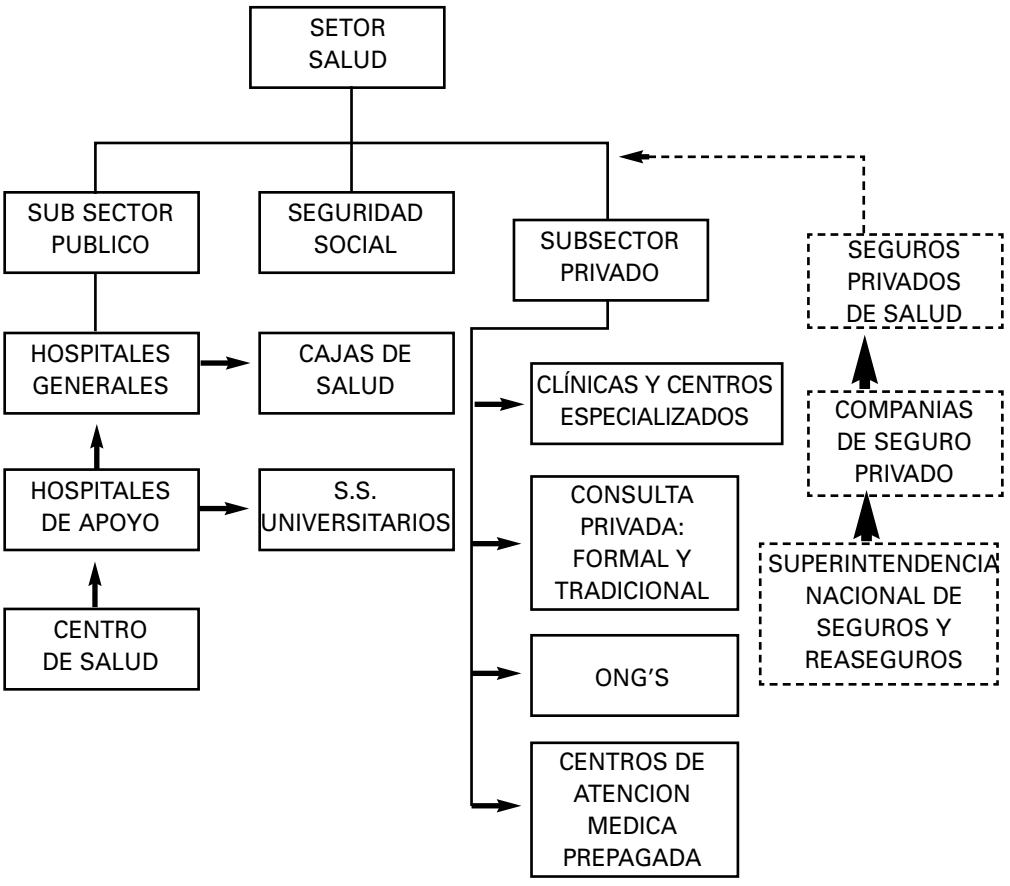
The principal language spoken is Spanish, but Quechua is spoken by over 2.5 million people and Aymara by two million. This ethnic plurality found in Bolivia demands looking more closely at the complexity of the relations that are established among the different groups. The ethnic question in Bolivia, characterized by miscegenation and diversity, has provoked a tense climate among different population groups. Even today, conflicts between the indigenous and the white population of European descent are quite common. One perceives a frontier separating the white, wealthier minority and the indigenous, poorer majority.

In the early nineties, the Bolivian health authorities pushed forward a set of political and social reforms that resulted in the constitutional reform of the State. The process of political-administrative decentralization included investing in primary education, developing policies of gender equality, preventing and eradicating domestic violence, and other policies geared towards ethnic groups and infancy. In the specific area of health, special mention should be made of social policies such as the National Insurance for Maternity and Infancy and Health Insurance for those over 60 years old. The Bolivian health legislation includes many norms related to infections of epidemiological importance, such as the sexually transmitted infections (STI).

1. The Bolivian Health System

The Bolivian Health System is made up of the public health service, social insurance

Bolivia's Health System



Source: Informe Cuentas Nacionales de Salud: Bolivia, 1998.

(Health Banks), and private and traditional medicine. According to the 2004 report of the Pan-American Health Organization, fragmentation of the system, especially public service and social insurance, is one of the biggest and most complex problems. Fragmentation and segmentation of the system reproduce the inequalities of access to health services. Information on health coverage in Bolivia is still very deficient; in 1997, a not very accurate estimate showed that 66.3% of the population was covered, distributed in the following way: 30% by the public service, 25.8% by social insurance and 10.5% by private insurance (10% by NGOs and 0.5% by private insurance). We see from these figures that 33.7% of the population has no access to any type of health service, except traditional medicine. In 1984, through the Law of Public Participation, the public health infrastructure was transferred to the municipal governments, leaving the management of human resources to the central administration of the Ministry of Health.

The Ministry of Health is the leading actor in implementing special health-promoting and prevention programs, which are national and free of charge. In practice, however, public health care is not totally free, since in order to obtain complete assistance, patients pay (very low prices) for medicine, consultations and/or hospitalization. Nevertheless, those interviewed also report

that the quality of these services is low and that they are used by people of very low income and people who live in the streets.

The public health system, which is partially subsidized by the Ministry of Health, is only fully free of charge for pregnant women and their children up to five years old, through Maternal and Infant Universal Insurance (SUMI), which is maintained through the national budget and international cooperation.[1] All other patients are attended in the public health network, but they also need to pay a portion of the costs, with the other part being subsidized by government funds.

In addition to the public health system, there is the health system maintained by the National Health Bank, the principal and most popular system that is sustained by the monthly contributions of formal workers (such as industrial workers, teachers, employees of small firms and other public functionaries) to guarantee exclusive attendance for workers and their dependents, who amount to about 20% of the population. There are other health insurance schemes, such as COSSMIL (military insurance), SSU (social insurance for university employees), Caixa Bancária, Caixa Petroleira (for workers in the oil and aviation sectors). In these cases there are differences in the quality of care, and the worker's contribution is 10% of the insurance. Nonetheless, it is reported that saturation of services and the low quality of care lead people who can afford to pay for better assistance to resort to the private healthcare system.

Although a number of private clinics offer services of better quality than the public system, these are not accessible to the poorer segments that make up the vast majority of the population. Those who can afford a consultation prefer the quality and efficiency of private services, which include some non-governmental organization (NGOs), non-profit institutions and churches. The NGOs that provide health-care services act both as administrators and providers of services. These institutions have their own centers and hospitals and work predominantly in the peripheral areas of big cities.

Traditional medicine is also considered an important alternative in the country, especially in the rural and peri-urban areas. Traditional medicine and cures are resorted to as the first option in cases of disease or suffering, for reasons of cultural identity, geographical proximity and low cost. There is also a society comprised of traditional doctors, SOBOMETRA, which includes professionals with or without university qualifications. About 40% of the rural population is attended by traditional medicine and by doctors of the obligatory rural service (composed basically of newly-graduated doctors).

Health services are divided into a network comprised of four levels of management and three levels of assistance. The levels of management correspond to the national, provincial, municipal and local dimensions. The levels of assistance are structured according to the capacity of the services to resolve the cases. The first level of care corresponds to out-patient attendance, the second level to hospitals that have up to four basic specializations (pediatrics, gynecology, internal medicine and

[1] The purpose of SUMI is to promote free assistance to pregnant women and their children up to the age of five. It also attends to the elderly (60 and over). However, it does not include procedures related to HIV/AIDS care.

general surgery), while the third level involves specialized and micro-specialized hospitals. Traditional (or informal) medicine becomes a reality that co-exists with Western medicine.

2. National Response to the AIDS Epidemic in Bolivia

2.1. Epidemiological Data

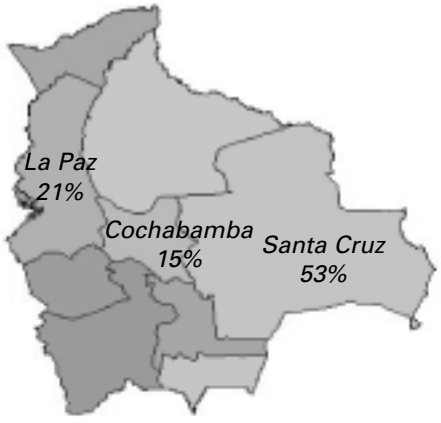
According to records from the Ministry of Health, the first AIDS case notified in the country occurred in 1984, in the city of Santa Cruz, and the second in Cochabamba in 1985. The first notifications were of cases found among the male population. Up to November 2005, the number of officially registered cases was 1,800 people infected. The estimate being that 522 people are living with HIV and 378 with AIDS and, that approximately 900 cases have already died since the beginning of the epidemic.

According to data from the National STD/AIDS Program, until 2003 the epidemic in Bolivia was considered incipient.[2] According to current data from UNAIDS (2005), Bolivia presents an HIV infection rate of 0.1% among the adult population, which is quite low in comparison with the 0.6% indicated as the average prevalence for Latin America.

As observed during this study, activists and representatives of civil society organizations in the country question these numbers, indicating several problems regarding sub-notification as well as a possible bias in the methodology used in data collecting which are generally obtained through sentinel studies only among pregnant women. Some activists say that Bolivia may experience a concentrated epidemic among some sub-populational groups such as men who have sex with men (MSM) and sex workers, for example.

Studies carried out by the Ministry of Health (2003) pointed to a current tendency toward a concentrated epidemic, and some regions in the country present indications of a growth tendency among men, with a verified prevalence of 14.5% among the MSM population in the city of La Paz and 21% in the city of Santa Cruz. According to the 2004 data from the country's National STD/AIDS Program, a prevalence of 1.02%

Distribution of cases of AIDS



Source: National Program for STI/HIV/AIDS - Ministry of Health and Sports. Bolívia, 1984-2004.

[2] According to the definition given by UNAIDS and WHO, epidemics can be characterized in three states:
a) Incipient: prevalence of 5% in the population groups with high-risk behavior (for example, prostitutes, homosexuals with multiple partners, people who inject drugs), but the prevalence of HIV among the general population, measured among women who receive prenatal care in urban areas, is practically zero.
b) Concentrated: prevalence of HIV above 5% in one or more high-risk groups. Nevertheless, the prevalence among the general population (evaluated among pregnant women) is below 5%.
c) Generalized: prevalence of HIV among pregnant women is above 5%.

was registered in pregnant women in the Galindo de Pando Hospital in the North of the country (Carizo, 2005). With regard to the level of education of the cases registered, 54% of the infections correspond to people with intermediate schooling.

According to the UNAIDS document on the "AIDS epidemic situation in Latin America" (2005), the growth of the epidemic in this country seems largely driven by sexual commerce and sexual relations among men (MSM). Recent studies on sex workers show an increase in the adoption of safe sexual practices, which may indicate that today this population is more aware of the risks of infection by HIV/AIDS (UNAIDS, 2005). The age range of the most affected population is from 25 to 34 years old, corresponding to 64% of the total number of cases.

In accordance with data provided by the Bolivian National STD/AIDS Program, the proportion of cases among men and women infected in the period from 1984 to 1990 was 7:1. As of 1991, this proportion narrows and the ratio between sexes dropped to 2.5 men to each woman infected. In relation to marital status, the vast majority of notifications involves single persons (51%), followed by married persons (37%); and, 12% are distributed among those who declare themselves divorced, widowed or in a relationship classified as "free".

The most common means of transmission is sexual (97%), followed by perinatal transmission (from mother to baby) with 1%, and 2% of cases are under the ignored category. Of the total of cases of sexual transmission, 78% are reported among heterosexuals, 11% among the homosexual population and 6% among bisexuals. In the year 2004, the age brackets most affected by the epidemic were those between 25 and 34 years old (41%) and between 15 and 24 years old (23%).

The provinces most affected by the epidemic are those located in the Santa Cruz, La Paz and the Cochabamba corridor. The province of Santa Cruz, characterized by its great commercial activity and internal and external migration flow, accounts for 53% of the total number of cases notified in Bolivia. 21% of the cases are concentrated in La Paz, followed by Cochabamba with 15%. The total sum of cases in these provinces corresponds to 89% of the AIDS case notifications in the entire country. Across all the states, the epidemic is concentrated in the urban areas, with few cases scattered among the rural areas.

The mortality rate for AIDs patients registered in the period from 1991 to 1995 was 46%. In 2004, this rate fell to 9.9%, a reduction that the Bolivian National AIDS Program considers to be a possible consequence of flaws in the monitoring of notifications of AIDS cases, together with the inadequate notification of causes of death.

2.2. National AIDS Program of Bolivia

The National AIDS Program in Bolivia is based in La Paz, and its strategic plan for prevention and control of STD/HIV/AIDS for the period of 2006 to 2010 receives financial resources directly from the National Treasure earmarked to pay for infrastructure and human resources; from the cooperation of the United States Agency for International Development (USAID), administered by the Integral Health Project (PROSIN); from the Department for International Development – United Kingdom (DFID) via OPAS; from the Brazil-Bolivia International Cooperation

Financing Flow Sheet

Management	International Financing	%	National Financing	%	TOTAL
2003	1.281.221,00	71,03	522.576,58	28,97	1.803.797,58
2004	1.525.171,00	73,94	537.634,94	26,06	2.062.805,94
2005	2.149.533,47	83,37	428.923,79	16,63	2.578.457,26
TOTAL	**4.955.925,47**	**76,89**	**1.489.135,32**	**23,11**	**6.445.060,78**

Source: OMS/OPS-USAID/BOLIVIA-UNICEF-FONDO GLOBAL – Ministry of Health and Ministry of Finance, 2006.

Project (PCI); and, starting in 2005, from the Global Fund (Bolivia, 2005).

Prior to the creation of the National STD/AIDS Program, State control of the epidemic was based on an administrative structure of the Ministry of Health, through a component of sexually transmitted infections (STI) together with the Maternal-Infant Health Program. In 1986, the National Program was set up as a Ministry of Health program, and in 1990 strategic planning was drawn up and actions formalized on a national scale.

Since 1992, Bolivia's Ministry of Health and Sports, with the financial support of USAID and the United States Centers for Disease Control (CDC), implemented a prevention strategy geared towards the vulnerable segments of the population, with the opening of the Provincial Centers for Surveillance and Reference (CDVIR) for STI/HIV/AIDS.

The first stage of the project was in the city of La Paz, and later it expanded to another nine provincial capitals across the national territory, with the following objectives: a) to improve follow-up on sexually transmitted infections (STI); b) to improve the capacity of diagnosing STI; and c) to promote the use of condoms. In that same year, an agreement was signed with the Ministry of Health and Social Planning - later called the Ministry of Health and Sports – to develop the Project Against AIDS (PCS) with the following guidelines[3]: a) strengthening the STI control services; b) offering counseling; c) skill-building for personnel; d) information, education and communication (IEC); e) donations of drugs and laboratory reactives; f) epidemiological surveillance; g) systematized control of STI in vulnerable groups; and h) promoting the use of condoms.

These centers were expanded and established through PROSIN, which played a fundamental role in developing the National STI-HIV/AIDS Program of the Ministry of Health and Sports, as well as in implementing the Provincial Centers of epidemiological surveillance of STI-HIV/AIDS in the nine provinces.

Through this mechanism, it was possible to pay for the salaries of technical staff who work in the National AIDS Program, in addition to also receiving supplies and commodities, medication and materials necessary to carry out their activities.

In general, the Ministry of Health tends to be quite dependent on funds from external cooperation to implement their public policies and actions. The Union budget allocates about 4% for the health area as a whole, these funds being used to pay for

[3] OPS/OMS/Bolivia News Center, 2005.

human resources and infrastructure rather than for supplies and commodities and direct actions for prevention, assistance and treatment of HIV/AIDS.

As of 2000, seven centers of sentinel surveillance began to function in the subpopulations selected, based on epidemiological and demographic criteria. These centers were set up in La Paz, Cochabamba, Santa Cruz, Tarija, Beni and Pando. In the same year, 101 persons living with HIV/AIDS were notified in the country. In 2001 this number doubled to reach 210 cases notified. In 2002, 195 cases were notified, rising to 225 in 2003 and to 244 in 2004.

At first, carrying out HIV tests was quite irregular, because it was difficult to perform the Elisa test and the confirmatory test by Western Blot. Nowadays there are voluntary HIV testing services in most large cities, but these are paid for(the test costs between two and five dollars, or seventeen Bolivian pesos).

At present, there are provincial level AIDS programs in each of the nine provinces. In each local provincial program there is a coordinator and a health-care facility with specific services for people living with HIV/AIDS, sex workers and men who have sex with men. These centers offer medical care, gynecology assistance, pre- and post-anti-HIV counseling and psychological support. They also have a laboratory where both the HIV test and for other sexually transmitted infections are held. However, since these centers attend to socially marginalized segments of the population, such as sex workers, the general population does not use them for fear of stigmatization.

With regard to prevention activities, informative campaigns are produced (such as the 1st December commemorations), besides radio programs in local languages (Quechua and Aymara) to promote HIV prevention, which shows a concern on the part of those in charge to expand access to information for the most excluded segments of the population. Some informative materials, especially meant for youth, are also produced for distribution in schools. According to civil society, this informational material does not always arrive and is mostly distributed only in the health services. On the other hand, reports indicate that the National Program has done little in terms of prevention aimed at men who have sex with men (MSM), even though a recent and still unpublished study indicates a high rate of prevalence of HIV in this segment of the population (varying between 14% and 20%, according to the region).

Some of the major obstacles to access HIV diagnosis and adherance to AIDS treatment are directly related to both the difficulties of making services, supplies and commodities available (since the diagnosis test is not free and access to medication is still not universal), and, to the persistent presence of very high levels of stigma and discrimination suffered by people living with HIV/AIDS. During the interviews held in Bolivia there were reports that in the city of Tarija, for example, the name and photograph of people who test positive for HIV would be published in the local newspapers (even under the protests of activists), thus worsening the stigma and social exclusion associated with the disease and in this way leading to increasingly less people seeking the test services for HIV serology.

Summing up, the main actors who organize and support the Bolivian response to the AIDS epidemic are:

a) the governmental level, represented principally by the Ministry of Health and

Sports, especially through its National STI/AIDS Program, the National Board for Medication, the Laboratories Sector – INLASA, and the sector for storing and distributing supplies and commodities;

b) the international level, with the global initiatives of financing and technical cooperation such as the Pan-American Health Organization, UNICEF, bilateral agencies for cooperation, such as the specific case of the Department for International Development, from the United Kingdom (DFID), the *Deutsche Gesellschaft für Technische Zusammenarbeit*, from Germany (GTZ), the United States Agency for International Development (USAID), the Brazilian Agency for Cooperation (ABC), and, on a smaller scale, Swiss Cooperation and the Global Fund for Tuberculosis, AIDS and Malaria, since 2005;

c) civil-society organizations, including associations of people living with HIV/AIDS, and national networks (*Redbol* and *Unibol*) that represent a recent movement that is very well organized and active on all fronts (prevention, assistance and promotion of human rights), especially concerning questions of access to treatment and ARV (antiretroviral)drugs.

2.3. Civil-Society Organizations

One important observation regarding policies to control the epidemic in Bolivia was the absence of AIDS NGOs exercising the fundamental role of "social control" at the outbreak of the epidemic in the early 80's. Apparently, even with the historical mobilization of Bolivia's civil society to claim labor and political rights, in the 90s there was a notable absence of an organized, cohesive social movement to fight for the rights of people living with HIV/AIDS and against social and sexual discrimination practiced against them.

Treatment therapies including ARV, antibiotics and antifungals for the treatment of AIDS in Bolivia only arrived in December 2003, which represented a significant landmark in the struggle against the epidemic in the country, soon after the mobilization of people living with HIV and AIDS in a forum held in the city of Cochabamba in September 2003 to stress the need for medications. People were dying because they had no access to treatment for opportunistic infections (OI) or to ARV for treating AIDS. So, it was decided at this forum to make a denunciation against the Bolivian government through the Inter-American Committee on Human Rights in Washington. The denunciation contained 52 signatures of people living with HIV/AIDS. The Committee stood in defence of HIV-positive people and demanded that the government buy medicine. Even so, the government took no systematic measures for access to AIDS treatment and patients went on dying. According to data collected in interviews, four or five people died on average each month. And, as the deaths continued, the HIV-positive denounced the government and demanded treatment. Faced with the pressure orchestrated by the social movement with repercussions also in the international sphere, the Ministry of Health and the Bolivian National AIDS Program then found themselves obliged to create a strategy to reduce the number of deaths.

As of 2003, the first community based work with the participation of people living with HIV in the country begin. In the

provinces where there are no NGOs, the only instance for control of the epidemic ends up being governmental, which is reported to be quite deficient. Most of the epidemic–control actions are concentrated in the La Paz/ Cochabamba/Santa Cruz corridor.

Bolivia's organized civil society today plays an important role in controlling the epidemic, since its organizations drove forward the mobilization and coordination process involving the AIDS challenges, in contrast with the still sparse efforts promoted by the State. At the moment, different groups from many cities across the country are integrated with the National Network of People living with HIV/AIDS (*RedBol*). *RedBol* appeared in 2002 at a meeting held in Cochabamba with the main leaders of people living with HIV/AIDS in Bolivia. This network now has groups affiliated throughout the country and acts mainly in the area of advocacy and monitoring of public policies and of cooperation agreements, occupying prominent spaces of political representation in the interests of those living with HIV/AIDS.

When this paper was being prepared, *RedBol* had six organizations and five focal points with representatives in nine provinces: the *Fundación Red Cruceña* lends full support to people living with HIV and AIDS (Santa Cruz), *RedVihda*, *Asociación Más Vida* (La Paz), *Asociación Wasynancywa* (La Paz), *Grupo Esperanza Positiva* (Cochabamba), *Grupo Vivo en Positivo* (Cochabamba), *Grupo VIHoruro* (Oruro) and focal points in Sucre, Potosí, Tarija, Beni and Pando (Aguilera, J., 2005). In addition to *RedBol*, there is another national network of different representations, *UniBol*, which strengthens the groups of people living with HIV/AIDS and people living with HIV/AIDS affiliated to AIDS organizations, namely: *Asociación Más Vida* (Paz and Potosi), *Juntos por la VIHda* (Cochabamba), and *Más Vida* (Oruro).

Both the NGOs that work with people living with HIV/AIDS and other civil-society organizations managed to participate in carrying out the projects financed by the Global Fund, in spite of resistance from the Country Coordination Mechanism (MCP), the body responsible for drafting the Global Fund's proposal for HIV/AIDS, Tuberculosis and Malaria. Approval was given to 11 projects for NGOs that work with HIV/AIDS, representing 8% of the total financing for HIV/AIDS from Global Fund resources.

From the point of view of civil society, in Bolivia there are only two legally established non-governmental organizations that work with HIV/AIDS (AIDS NGOs): the Institute of Human Development (IDH) and *RedVida*, located respectively in Cochabamba and Santa Cruz, with two committees identified as "Committees for the struggle against HIV/AIDS". However, there are other associations and about five groups of people living with HIV, all of them affiliated with *RedBol*. Organizations and member groups of *RedBol* engage themselves in setting up programs on "safe sex for people living with HIV/AIDS" and "human rights for seropositives", and make important contributions to the National Plan for Prevention and Assistance. The principal strategy of the activists, however, has always been focused on universal access.

In November 2004, during the Workshop "Networking between Civil Society, Government and Cooperation Agencies" in Bolivia (which members of the ABIA staff attended), the "Forum for Life" was founded for the purpose of organizing

and following up on the process of networking between Bolivian civil-society organizations. The objective of the Forum for Life was to hold in 2005 the First National Encounter of Bolivian NGOs involved in Civil-Society Organizations. Four organizations were in charge of organizing this national encounter: PROSALUD (Santa Cruz), IDH (Cochabamba), PROCOSI (La Paz) and *RedBol* (represented by *RedVida* from Santa Cruz). The meeting could not take place due to lack of funds. Even so, it remains the objective of civil society to strengthen and lend continuity to the Forum for Life as a mechanism of networking among the NGOs and strengthening civil society.

The interviews point to the lack of efforts towards multi-sectorial integration and support, both on the part of governmental and international agencies, and the mechanism of national coordination of the Global Fund in Bolivia. The donor institutions and bilateral programs for cooperation that exist in the country need to engage in an effort to harmonize their policies to support civil society in an effective manner through financing and technical support for development of actions geared not only towards specific target populations, but also actions that strengthen political networking, interchange between NGOs, and development of the institutional capacity of organizations and civil-society groups that constitute part of the response to the epidemic. The existing networks require strengthening in order to enable them to continue to contribute to the process of informing and educating the population regarding treatment and supporting people living with HIV, both in the areas of treatment and primary and secondary prevention.

Paradoxically, although the value of the contribution made by civil society is recognized by governmental and international cooperation agencies that operate in the country, it is underused and underestimated. Nevertheless, in the last few years civil society proved to be an essential partner not only as possible providers of services and distributors of information, but also as defenders of integral care to patients, principally in combating the high level of stigma and discrimination that prevail in the country, especially related to homophobia and HIV-positive persons.

3. The Brazil-Bolivia International Cooperation Program (PCI)

Implementing the International Cooperation Program (PCI) between the governments of Brazil and Bolivia began in 2003 with the objective of strengthening the national response of the Bolivian program for control of the HIV/AIDS epidemic. This technical-cooperation program proposed strengthening a plan of integral care for people living with HIV/AIDS, improving the network of services for diagnosis and treatment, developing a system of epidemiological surveillance to monitor and evaluate the epidemic by the Bolivian National Program, and supporting the formation of strategic alliances between the government and civil-society organizations.

The Brazil-Bolivia PCI initially projected strengthening AIDS treatment for 100 patients, which was later expanded to 400 patients. Up to the end of 2004, three shipments of medication were made to attend to 300 patients. Accordingly, since February 2005 the Brazilian Program meets the target of 400 treatments with top-line medication.

According to data from the Bolivian National STI/HIV/AIDS Program, 256 people are under treatment.

Prior to the PCI, people living with HIV and AIDS in Bolivia had no access to treatment, nor were any public laboratories available to carry out CD4 counts and viral-load tests. The existing programs and services only attended to sex workers, who were charged a sum sent to a PROSIN/USAID account.

According to the 2003 report of the Latin-American and Caribbean Council of AIDS Services Organizations (LACCASO) on the Situation of HIV/AIDS and Human Rights in the Andean Community, people living with HIV had no type of support from the State for the treatment of opportunistic infections, nor did they receive anti-retroviral medicine (ARV) in the region for adequate treatment. With regard to ARV medications, the report pointed out that there is still no political will to promote universal and sustainable access to treatment in the region.

Several efforts were made to obtain the medications. At first, through the PCI, a Bolivian proposal was presented to Brazil, which declined because of the priority criteria established for the countries with the highest incidence of AIDS, such as the Portuguese-speaking countries in Africa. Following numerous meetings with the Brazilian National AIDS Program, a joint program was developed among the countries within the scope of the PCI, and then Bolivia began to receive donations of ARV from Brazil. The first Brazilian donations of ARV arrived in December 2003, which coincided with the time when the government began to distribute drugs related to the provisional legal measures won by patients and implemented in consequence to the support of the Inter-American Committee on Human Rights.

The medications donated by the Brazilian National AIDS Program are sent to the national supply center - the CEAS - and then to the regional supply centers. Requests for treatment therapies are made according to the needs of each province. In the initial project the agreement only provided for La Paz and Santa Cruz, half and half. Now ARV drugs are distributed in all nine provinces.

One important result of the cooperation between the two countries was the technical capacity achieved with the training of 70 health professionals in the areas of diagnosis, treatment and monitoring of patients in the cities of La Paz, Santa Cruz and Cochabamba. The cooperation also resulted in the possibility of offering CD4 tests which previously were only carried out in private clinics, as well as reviewing the therapeutic consensus for treatment initiation. In 2004, when the National Institute of Health Laboratories (INLASA) purchased the flow cytometer[4], CD4 and viral-load tests began to be carried out. Also, the agreement signed with the Pan-American Health Organization (OPAS) and resources donated by the United Kingdom Agency for International Cooperation (DFID) allowed for reactives to be purchased. In this way, four months after implementation of the PCI, it was already possible to perform free laboratory tests with a regular periodicity of six months.

[4] Apparatus that evaluates the patient's immunity and enables constant monitoring of the stage of evolution of the disease, and consequently the patient's state of health.

Estimates for universal coverage of anti-retroviral medicine for countries with a cooperation agreement with the Brazilian Government

Latin America	Estimated number of people living with HIV/AIDS (PVHA)* 2003	Estimated number of people living with HIV/AIDS who need ARV treatment**	PVHA identified by PNLS for immediate ARV treatment	the People in ARV treatment	
				PNLS	PCI
Bolivia	4.900	980	400	0	100 (400)
Colombia	190.000	38.000	4.000		100
El Salvador	29.000	5.800	-		
Paraguay	15.000	3.000	700	300	100 (400)
Dominican Republic	88.000	17.600	5.000	40	100

Source: Report on the Global AIDS Epidemic - UNAIDS, 2004 (4º Global Report) <www.aids.gov.br>. Accessed in April 2006.
** This calculation was made on the basis of 20% of the estimated number of people living with HIV/AIDS in the respective countries. WHO uses as a standard the variant percentage between 20 and 30%.*
*** This calculation was made on the basis of 5 to 7% of the estimated number of people living with HIV/AIDS in the respective countries.*

Number of people under treatment and the estimate of those who need treatment per region

Region	Number of perople in ARV treatment	Number of perople who need ARV treatment	Coverage
Americas	220.00	410.000	54%

Source: Report 3 by 5 - WHO, June 2004 <www.aids.gov.br>. Accessed in April 2006.

At present there are three reference laboratories in Bolivia, located in La Paz (INLASA), Santa Cruz (CENETROP) and Cochabamba (LABIMED). They all perform CD4 tests, but only INLASA performs viral-load tests. The criteria adopted to indicate treatment are those of OPAS,[5] Caracas and the CDC.There is also a therapeutic consensus committee to orient therapeutic medical conduct in relation to HIV and AIDS, which prepared the guidelines for access to medicine for the Bolivian population, based on the national consensus recommendations for anti-retroviral therapy for Brazilian adults and adolescents infected by HIV.

The great majority of AIDS treatment drugs distributed in Bolivia come from Brazilian cooperation through the PCI. However, some of the drugs used are not included in the Brazilian donation, such as Efavirenz and other second-line medication needed by people attended by virtue of the provisional measure, so these are purchased by the Bolivian government.These purchas-

[5] For the developing countries, one positive Elisa and the presence of an opportunistic infection is sufficient to start treatment with anti-retrovirals, provided the person is not already being treated with medication for opportunistic infections.

es, although small and also mostly of therapeutic schemes of first-line medications, are made with CIPLA, the Indian generics industry. Now, with the PCI and the Global Fund, all treatment is free; the PCI has to cover the first-line medication produced in Brazil, the Global Fund being responsible for purchasing second-line medication[6] imported from the international pharmaceutical industry. Nevertheless, managing the source of funds from the Global Fund has proved difficult.

According to declarations made by those interviewed, the government reveals a lack of political will to invest own resources in the purchase of medicine, which up to the present moment in time has only been possible under specific conditions. Since Bolivia does not produce anti-retroviral medication for the treatment of opportunistic infections, if the national government shows no medium- and long-term interest in developing this area, the situation could come to represent a barrier regarding universal access to treatment and integral care for patients.

Health professionals and activists interviewed indicate that the only medicine that patients are guaranteed to continue are those donated by Brazil. This adds a further concern with regard to maintaining and expanding the production of these medications in Brazil, should local and sustainable alternatives to purchasing and producing in the region fail to be developed.

With the intention of promoting guaranteed universal access to medication, Ministerial Resolution number 0711[7] was signed in 2002 for the prevention and surveillance of HIV/AIDS and serves as a juridical reference to regulate the actions of medical care, prevention, promotion and epidemiological surveillance. Even though articles 158 and 164 of the Bolivian Constitution establish the obligatory nature of defending the population by protecting health with all available means, nevertheless, in reality these constitutional principles are not always observed, since the Ministerial Resolution is not a law. The application of the Ministerial Resolution lies within the competence of the Ministry of Health and Sports, responsible for implementing it through the Provincial Health Services (SEDES). The Ministerial Resolution also provides for developing a partnership with the Ministry of Education and Labor, but in practice, inter-sectoriality is still to be effectively implemented.

4. Access to Medication and the Intellectual Property Law

Distribution of ARV medication in Bolivia is characterized by three phases. In the first phase, people had access to medication donated by different countries and institutions in specific and sporadic fashion - which included adult and pediatric AZT and DDC. The second phase was around 2002, when Delavirdina was added to these medications.[8] At that time Bolivian customs bureaucracy, unaware of the procedure,

[6] First-line medicines (AZT, 3TC, AZT + 3TC, DdI, D4T, Indinavir and Nevirapina) are generic medicines produced in Brazil. Second-line medicines (such as Efavirenz and Kaletra) are imported.

[7] Ministerial Resolution number 0711 for prevention and surveillance of HIV/AIDS in Bolivia; Ministry of Health and Sports/ Pan-American Health Organization and World Health Organization, November 2002. This document is included in the agenda established by the declaration and commitment approved in June 2001 at the General Assembly of the United Nations to face the stigma and discrimination caused by HIV/AIDS.

[8] Medication already out of use, including in Brazil.

delayed the release of the medications and entry of these commodities into the country, causing negative consequences for the population. Few people then had access to the therapy. A third moment was in late 2003, with the agreements signed for continued donations of ARV and the Brazilian government donating the complete treatment schemes (AZT, 3TC, AZT + 3TC, DDI, D4T, Indinavir and Nevirapina).

Prior to the first donation of ARV by Brazil, there was also the possibility of purchasing medications at very high costs through a local import firm. Besides this, purchases could be made in the informal market. Some people began their mono- and bi-therapy with the medication available up to then. In some cases they began treatment with ARV obtained through donation and bought what was lacking. At this moment, according to data from the interviews, patients who took medicine presented two profiles: those unafraid of exposing themselves sought treatment in the Provincial HIV/AIDS Programs, in general people of low income, while others who were afraid to expose themselves went on buying medication on the informal market through their private doctors, this second group being in general people of high income who worried about keeping their HIV-positive status a secret.

An important fact related to AIDS treatment in Bolivia has to do with the law of patents dating from 1918, linked to a supranational norm to which Bolivia is signatory: decision number 486 of the Andean Community of Nations for the drafting of national norms, after approval by all the member countries. The Andean Community has been important on the issue of access to medicine, for it established a strategic plan through which it makes joint purchases of anti-retrovirals and medication for opportunistic infections. The objective of this committee is to seek means of consolidating an Andean agency for medications that could make universal access in the region feasible. According to the Director of the National Board of Medication (DINAMED), Bolivia is interested in carrying out research on medications by addressing the clinical, political, economic and social aspects related to policies concerning production and access to medications. There is no formal investigation in Bolivia on medications, only a pilot project on a pharmaceutical watch containing 1,800 indicators divided into four thematic blocs covering: a) policy; b) regulations; c) access; and d) market. This study represents a first investigation of impact on access to medication and intellectual property, and also includes products used in traditional medicine.

5. The Global Fund

The Global Fund for Combating AIDS, Tuberculosis and Malaria was set up in January 2002 with the mission of supporting expansion of coverage of prevention, assistance and treatment activities for these three epidemics. Being an international cooperation agreement between governments, civil society, the private sector and affected communities, the Global Fund constituted a fresh focus for international financing for health. It is an independent organization ruled by a board of directors made up of representatives of donor and beneficiary governments, non-governmental organizations (NGOs), the private sector and affected communities, as well as representatives of the World Health Organization

(WHO), UNAIDS and the World Bank. Its organizational structure can create opportunities for work by creating important partnerships among different actors involved in controlling the epidemic in the country and the world, using for this purpose the Mechanism of Country Coordination (MCP).[9]

The proposal for Global Fund financing for actions in the combat against AIDS, tuberculosis and malaria in Bolivia was presented and approved in 2003, but the resources only arrived in July 2004, when the first agreement was signed. Six million dollars were approved for HIV/AIDS, for a period of two years, with US$ 800,000 earmarked each year for the purchase of medication.

The first call for presentation of proposals for support through Global Fund resources generated a demand for inter-institutional coordination on the local and national level which unfortunately the Ministry of Health authorities did not manage to conduct in a participative fashion, according to the interviewees. The meetings held in the city of La Paz to discuss the Fund were only informative, complying with a United Nations requirement for obtaining funds (Carrizo, 2006).

As occurred in many other countries, since the existence of Global Fund and the announcement of resource availability, numerous organizations that had never worked with AIDS in Bolivia (or had done so as a complement to their main activities) began to present work proposals in the area of HIV/AIDS.

The project presented by the MCP of Bolivia to the Global Fund contains the following core proposals: a) to reduce the occurrence of new transmissions of HIV/AIDS; b) to reduce the morbidity and mortality of people living with HIV/AIDS; c) to extend access to treatment of opportunistic infections and AIDS, and in special cases, other sexually transmitted infections; and d) to make feasible the purchase of supplies and commodities for viral load, CD4 and routine examinations.

According to the members of the Bolivian National Network of People Living with HIV/AIDS (*RedBol*), the entry of the Global Fund into the country was quite strategic for the control of the AIDS epidemic, at the same time as it constituted a challenge, since many community based institutions had to present proposals to the Fund while also implementing, monitoring and evaluating them. On the other hand, a resource that would help public policies for HIV/AIDS prevention, care and assistance became a substitute for the Bolivian government's investment in strengthening epidemic-control actions.

Nevertheless, members of civil society who were interviewed emphasized that the introduction of the Fund's resources enabled expanding access to treatment and improving the quality of life of people living with HIV and AIDS in Bolivia. In this sense, the proposal of the Global Fund began to be seen as a priority for the leaders of *RedBol*.

In practice, however, the Fund, designed to complement the purchase of medication not included in the technical cooperation agreement with Brazil, suffered many setbacks involving bidding, purchasing and dis-

[9] The Bolivian MCP is made up of 29 institutions considered as founder members. Cochabamba has four and Santa Cruz two. The regulation of the Global Fund to organize the MCP and establish equal participation of different regions and actors has never been put into effect.

tribution, meaning that, at the moment the medication donated by Brazil is still the chief source of ARVs for Bolivia.

It should be underscored that the Global Fund was introduced to Bolivia, and to many other developing countries, with the mission of enhancing the public policies of these countries for the control of the epidemic. However, the governmental structures of these countries suffer from great deficiencies not only concerning the organization of the whole health system (prevention, health promotion, medical care and assistance), but also from lack of political interest in this theme, which makes it difficult to obtain and manage the resources channeled by the Fund.

On the other hand, another important aspect which also has a direct effect on the national capacity for implementing, networking and coordinating (in this case the AIDS program of Bolivia's Ministry of Health), is the creation of "parallel systems" of national authorities and AIDS policies based on the setting up of the MCP of the Global Fund in the country, which leads to a confusion of roles. In practice there are situations where the MCP holds the actual "power" or "authority" in decision-making regarding investing in one area rather than another, or what policies and actors will be financed, and in such situations the capacity of the national program is corroded, thereby reducing the capacity to retain competent personnel and involve civil society correctly in the process.

6. Final Considerations

This study was set out to contribute to the interchange among countries in the Andean region with which Brazil has agreements for external cooperation involving the donation of generic ARV medications. The central focus was to know the impact of Brazilian donations of ARV medication on the reality of these countries, and, what they represent in the sphere of South-South cooperation and in the sustainability of national and international access policies to AIDS treatment. Through the cases in question, the study seeks further to point to the inter-relation between intellectual property and access and, to know the involvement of Latin-American civil society in this process.

As a result of this study, we can say that the main actors in Bolivia's response to the AIDS epidemic are present in the governmental sphere, in organized civil society and in the international scope of agencies and programs for cooperation. These actors are organized on different hierarchical levels according to the specific strategies, programs and resources that are available. In general the donor agencies exert more influence in implementing AIDS strategies and programs in the country, seeing that over 70% of the average resources for implementing the actions of the Bolivian AIDS Program come from outside sources. Nevertheless, the government is sovereign and sets the guidelines to be adopted in the country by implementing public policies, as shown in the Strategic Plan for Control and Prevention of STI/HIV/AIDS of the Bolivian Ministry of Health and Sports for the 2006-2008 period.

The Bolivian social movements, in turn, through different strategies of political pressure in national and international spheres, have been trying to influence the government to satisfy their demands in the political domains of actions to control the epidemic, especially questions concerning human rights,

access to treatment and to methods of prevention and technologies to control the disease. Through the relationships it holds with networks of Latin-American organizations or even networking of local networks, the country's organized civil society endeavors to mark its positions and whenever possible to negotiate, either with the government or with the international agencies and programs.

Among the advances observed, we should mention in particular that over the last three years this process of South-South cooperation between Bolivia and Brazil has allowed for an interchange of technical and social knowledge and a real exchange of experiences among the governmental and non-governmental spheres of these two countries. As a result of this exchange and interchange, in addition to expanding access to AIDS treatment by means of the Brazilian donations, projects implemented have made it possible to build on professional capacity in health care, treatment support and adherance of patients, and in adjusting treatment to less sophisticated (but of good quality) infrastructures. All these factors are viewed by the local actors as being important for the success of the implementation process of achieving universal access to treatment.

Nevertheless, the Bolivian social movement reveals a context of uncertainty and concern in relation to the continuity of the policy towards the universal right to services and medication for AIDS treatment. It also remains to be seen how long the guarantee of this right will last and the conquests already obtained for AIDS patients preserved. Another doubt arises as to whether Brazil will continue to honor its commitments in the face of its own national difficulties and internal obstacles. In this sense the case study may interest both the countries studied and Brazil, as a reflection of its reality and the sustainability of its own cooperation programs, and more specifically the matter of donating medications. Should there be any interruption, flaws or collapse of the Brazilian system, or any incapacity of national production, not only will the lives of Brazilians be in jeopardy, but also those of Bolivians, Paraguayans and all those who depend on donations of Brazilian medications.

With a view to sustaining and expanding the programs in Bolivia and Brazil, it is of utmost importance to lend technical and financial support to the institutional participation of civil society, on all levels of strategic preparation and decision-making. That is why it is so necessary to create a harmonious engagement of the international community in order to keep pledges of medium- and long-term technical and financial cooperation in order to face the challenges described herein (intellectual property, access to generics), as well as to maintain the fight against AIDS as a policy priority in the international cooperation agreements.

7. Bibliographical References

AGUILERA, J. C. Lecciones aprendidas en VIH y Sida: con una mirada desde la salud pública y el activismo comunitario, PubliMarcas Santa Cruz, Bolivia, 2005.

BOLIVIA. Plan estratégico del Programa Nacional de ITS/VIH/Sida para la prevención y control del ITS/VIH-Sida (2006-2010), Ministerio de Salud y Deportes, Programa Nacional de ITS/VIH/Sida, 2005.

_____ Resolución ministerial nº 0711 para la prevención y vigilancia del VIH/Sida en Bolivia, Ministerio de Salud y Deportes Programa Nacional ITS/Sida, Programa Nacional de ITS/Sida-Bolivia, 2002.

BRASIL. Ministério da Saúde - Programa de Cooperación Técnica Brasil-Bolivia, Proyecto Prevención y Control de ITS/VIH/Sida en Bolivia. Brasilia – DF: Programa Nacional de DST/AIDS, Ministério da Saúde, 2002.

CARRIZO, E. V. El Sida en el reino de la impunidad: hasta las últimas consecuencias. Asamblea permanente de los derechos humanos. Cochabamba, Bolivia & CAFOD, Inglaterra, 2006.

Compilación Bibliográfica relacionada con el VIH/Sida en Bolivia 1985-2000. Apoyo: OPS/OMS/USAID/MSH. Programa Nacional de VIH/Sida. Ministerio de Salud y Deportes.

Informe comparado sobre la situación del VIH/Sida y los derechos humanos en la Comunidad Andina de Naciones; seguimiento al cumplimento de las obligaciones emanadas de la declaración de compromiso en la lucha contra el VIH/Sida, Comunidade Andina de Naciones, Laccaso, ONUSIDA, dezembro de 2003.

MANTILLA, M. D. C. y MULDER, S. S. Avances y retrocesos en un escenario cambiante: reforma en salud, mortalidad materna y aborto en Bolivia, Centro de Información y desarrollo de la mujer- CIDEM, Development Alternatives with women for new era DAWN, Red de educación popular entre mujeres de América Latina y el Caribe- REPEM, La Paz, Bolivia, 2004.

ONUSIDA. Situación de la epidemia de Sida. América Latina, 2005.

OPAS. Centro de noticias OPS/OMS Bolivia, comportamiento del VIH y SIDA en Bolivia de 1984 al tercer trimestre de 2005. Disponível em <www.ops.org.bo/servicios>. Acessado em 1/2/2006.

_____. Legislaciones e hitos sobre acceso a tratamientos en Latinoamérica y el caribe, agosto de 2003. Disponible em <www.paho.org/spanish/AD/FHC/AL/acceso-arv-06.pdf>. Acessado em 7/2/2006.

SILVA, S.A. Bolivianos, a presença da cultura andina. Série Lazuli, imigrantes no Brasil. São Paulo: Companhia Editora Nacional, 2005.

THE GLOBAL FUND TO FIGHT AIDS, TB AND MALARIA. Propuestas de Bolivia. Formulario de Solicitud para propuestas al Fondo Mundial, 126 pp, 2004.

Case Study: Paraguay

Introduction

For the Paraguay case study, representatives from civil society and government were interviewed in the capital city of Asunción, in September 2005. As in the Bolivia study, the outline of the field work was designed by ABIA and field data were collected by a consultant. The document in question was drafted from reviews of documents and reports provided by different stakeholders, in addition to the information collected from the field through interviews with health professionals and civil society representatives in Paraguay and during a seminar held in Rio de Janeiro in February 2006.[10]

Paraguay underwent the longest dictatorship in South America: 35 years under the command of General Alfredo Stroessner. The end of the Stroessner dictatorship in 1989 did not bring political stability to the country. Although elections were held in 1993 and 1998, the army still has strong influence in Paraguayan public affairs and the former dictator's Colorado (Red) party is still in power. Struggles among its various factions led to a uncessesful military coup in 1996 and the assassination of Vice President Luis Maria Argaña in 1999, as a result of which President Raul Cubas resigned.

Administratively Paraguay is divided into 17 provinces – *Departamentos* - and its largest cities are the capital Asunción, followed by Ciudad Del Este (on the border with Brazil) and Encarnación (on the border with Argentina). The north and northeast of Paraguay are taken up by the very sparsely populated Chaco plains.

Paraguay's 2002 national census reported a population of 5,163,158, of whom 50.4% are men and 49.6% women. Paraguayan society is multiethnic – there are 17 indigenous ethnic groups and about 95%

[10] *Seminar Cooperação, Mobilização Social e Descentralização das Políticas Públicas em HIV/AIDS na América Latina*.

of Paraguayans are *mestizos* of mixed Spanish and indigenous descent. There are marked differences among the various groups' access to wealth, cultural development and power[11], and a diversity of ethnicities, social situations, religious beliefs and political ideas.

The intense process of miscegenation in Paraguay began with the Spanish conquest and resulted in the phenomenon known as bilingualism. The Guarani language is both a decisive dimension in the rural-urban contrast and a strong source of socio-cultural ties and integration. Bilingualism is greater in urban than in rural areas, because Guarani is spoken more in the rural areas, while its use is declining in the urban areas. Official use of Spanish, despite the use by the media, increasing urbanization and expanding formal education, involves only 6% of the population. There is also a kind of dialect, a mixture of Guarani and Spanish, used in everyday dealings. Because of its proximity to the Brazilian border, Ciudad del Este is trilingual: Spanish (the dominant language) is spoken along with Guarani and Portuguese, in a situation that has impacts in terms of the process of economic integration among Brazil, Argentina and Uruguay.[12]

Since the early 90s Paraguay's economic growth has been minor but steady. In human development terms, Paraguay ranks 88 out of 177 countries (more or less in the middle), with rates that are improving year by year, accompanying the evolution of social indicators and social policies adopted to make up the index. However, about 8.5% of the adult population is illiterate, 17% have no access to treated water and 21.8% live below the poverty line. Paraguay has no significant natural resources and depends basically on agriculture.

1. Indigenous and Peasant Populations

The indigenous population – 85,674 in 2003 – is almost exclusively rural and lives in areas where access is difficult. The lack of clear policies for the sector means that most of this population lives in extreme poverty.[13] The fertility rate among indigenous women is high (6.3), almost double the rate (3.9) among other Paraguayan women. Access to health is precarious,[14] as can be seen from this Health Ministry document:

> *"regarding health care, health systems do not meet the indigenous population's needs, in terms of either quality, quantity or distribution. The indigenous minorities are the victims of longstanding discriminatory relations and still number among those excluded from the health system. Systematic care focused on these populations, where the children die from respiratory infections and the adults from tuberculosis and Chagas disease, not to mention the other ills they are prey to because of malnutrition. Neither are drugs provided to combat the many diseases that affect them. There is a health law exempting them from payment at any of Paraguay's care institutions, but the authorities do not always comply with it" (Rojas, 2006:89).*

[11] Rojas, MER. Situación en Salud. Ch. III. Características socioculturales. www.mspbs.gov.py. Accessed 17 Mar. 2006.

[12] Ibid.

[13] Rojas, MER. Situación en Salud. Ch. III. Características socioculturales. www.mspbs.gov.py. Accessed 17 Mar. 2006.

[14] Of Paraguay's 496 indigenous communities, only 129 have some kind of health service. Idem.

The peasant organizations, grassroots groupings represented by the *Movimiento Campesino Paraguayo* (MCP), *Organización Nacional Campesina* (ONAC), *Coordinación Nacional de Productores Agrícolas* (CONAPA), *Unión Nacional Campesina Oñondivepa* and *Central Unitaria de Trabajadores* (CUT), work to combat the lack of land and work, the scanty coverage and extremely poor quality of education in rural areas, the intense process of degradation and depletion of natural resources, rural-urban migration, the lack of rural development policies, lack of peasant participation and so on. Regarding health care, primary care centers have been built with labor and materials provided by local peasant organizations, but there too, access is precarious.

2. Health System

In many Latin American countries, health reforms came as part of an overall reform process designed to modernize the State or to respond to the influence of international financial organizations. Latin America introduced its social security programs many years before other developing countries in Africa, Asia and the Middle East. According to ECLAC (Economic Commission for Latin America and the Caribbean), by the end of the 70s all the countries in the region had such programs in place, although there were substantial differences among them.

In 1980, the countries of Latin America were categorized and arranged into three groups, on the basis of the date they introduced their first social security programs and the degree of development attained in such programs: pioneer-high, intermediate, late-low.

The pioneer-high group, comprising Uruguay, Argentina, Chile, Cuba, Brazil and Costa Rica, was the first in the region to set up social security systems (in the 20s and 30s). Their systems attained high levels of coverage and development, their populations relatively aged and life expectancies increased, though the systems lacked stratification, incurred high costs, and suffered from growing deficits and financial and fiscal imbalances.

The intermediate group (Panama, Mexico, Peru, Colombia, Bolivia, Ecuador and Venezuela) implemented its programs in the 40s and 50s, influenced by international policies and agreements, and their systems attained average coverage and development, were less stratified, incurred lower costs and enjoyed a better financial situation than those in the first group, although certain countries suffered some imbalance.

The late-low group, which includes Paraguay, Dominican Republic, Guatemala, El Salvador, Nicaragua, Honduras and Haiti, was the last to introduce its programs (in the 60s and 70s). Its populations were younger and life expectancies lower, and its systems relatively more unified and with fewer financial difficulties, although attaining lower levels of coverage and development. The differences among these three groups are reflected in how current their social security principles are (Mesa-Lago, 2005:14-15, 29).

In absolute terms, there are estimated to be 2.3 million poor people in Paraguay (41.4% of the population), half of whom live in extreme poverty.[15] The health reform

[15] *Objetivos de desarrollo del milenio. Informe alternativo de la sociedad civil – Paraguay. 2000/2005.* Plataforma Paraguay Sin Excusas contra la Pobreza. Paraguay, September 2005.

dates from the years 1996-1998. The health system is divided into the public, social security (various regimes) and private subsystems, together with some separate programs (for the armed forces, police, public employees, and other groups). In the years 2003-2005, when ECLAC produced a document on health reform in the region, the proposal in Paraguay was to extend coverage and separate the functions.

In the public sector, it is the public health and social welfare ministry (*Ministerio de Salud Pública y Benestar Social*, MSPBS) that plans health policies, regulates public and private health actions and administers the public system via a process of fund transfers to the 18 health regions. The governors of the 17 provinces are responsible for the regional health councils and coordinate the local councils at the municipal level. The health reform set up a National Health Council (*Consejo Nacional de Salud*), which is chaired by the health minister and includes representatives of all the units in the system. Its function is to restructure and coordinate the national health superintendency (*Superintendencia Nacional de Salud*), which supervises the public and private health insurance institutions.[16] The social security authority (*Instituto de Previdencia Social*, IPS) runs the disease and maternity program and has its own facilities for workers employed in private enterprise, decentralized institutions and public or mixed enterprises. Within the IPS there are special regimes for domestic servants in the capital, teachers in public and private schools, one decentralized institution (ANDE) and a contributory regime for veterans of the Chaco War. Public employees have a tax-subsidized medical insurance and there are other programs in the quasi-independent government agencies and in two decentralized state enterprises.

The private sector is divided into a nonprofit sector, comprising foundations, NGOs, churches, the Red Cross and two aid institutions in Mennonite communities in the Chaco; and, into a private sector, for-profit, and subdivided into three areas: a) 33 prepaid medical care companies (concentrated in the capital and the central province); b) 30 private establishments, most of which have prepaid care as a secondary activity and are either closed (offering their own services), open (members are free to choose among services) or mixed; and c) extensive traditional or popular medicine.

In the process of decentralizing the public sector, management agreements were signed between the central authorities and the intermediate or local units. However, studies have identified a large number of problems in terms of: a) coordination (lack of prior planning of mechanisms for coordination among the various levels and of precise definition of responsibilities; fragmentation of responsibilities among the various levels of government); b) standards (lack of a coherent national regulatory framework and lack of clarity in the standards); c) financing (not defined previously or precisely); d) personnel (lack of capacity-building for complex, new functions, use of temporary staff); e) local autonomy (decisions on financing and human resources continue to be subordinated to the central level, strict central regulations limit adaptation to local needs, and responsibilities and funds are transferred without

[16] It is unclear whether it also regulates or whether this is done directly by the Ministry.

Table 1. Health System in Paraguay

Reform Istarted	Model	Separate programs	Degree of decentralization	Decentralization from central government to intermediate and local geographical units
1996-1998	Public, social security and private	Armed forces, police, public employees and other groups	Very low, with problems	From the central government to 18 regions, 17 departments and 221 municipalities, to but only operating in 17 (8%) of them

Source: ECLAC, 2005.

any appropriate managerial capacity-building); f) commitments (little progress without setting up results-based indicators, while at the same time there is an increasingly complex array of indicators for evaluating results); g) hospitals do not function as a network, nor do they share resources, and there are no proper referral and counter-referral mechanisms (Mesa-Lago, 2005:170-171).

Studies estimate the proportion of the total population with social security or private health insurance at 13.4% in 1999 and 19.9% in 2002. In both periods, such coverage corresponds to 31.2% in urban areas and 6.7% in rural areas. Coverage by social security and prepaid medical care companies is concentrated in the capital and the metropolitan zone. No information is available on coverage among the indigenous population.[17]

In terms of social oversight, according to ECLAC, there was no workers' participation in the reform process, one of whose purposes was to promote social and community participation by setting up regional and local health councils. However, in 2001, the councils were working in only 17 of the 221 municipalities. It is the local councils' task to put together a health plan in discussion with neighborhood committees, representatives of the health and education sectors, in order to determine priority needs and groups, and at times, they are responsible for administering physical and financial resources transferred to them by the ministry of health. The social security council of administration (*Conselho de Administração do Seguro Social*) includes representatives of workers (a minority), pensioners, employers and the State (Mesa-Lago, 2005: 226).

3. Epidemiological Panorama of HIV/AIDS[18]

The first official estimates of people living with HIV/AIDS made by the National Program for Control of AIDS and Sexually Transmitted Diseases (PRONASIDA) date from 2002 and 2003. At present it is estimat-

[17] Ibidem, p. 70.

[18] See ONUSIDA. *El SIDA em Paraguay. Situação Epidemiológica*. June 2005. www.onusida.org.ar/paraguay/docs/EpidemiologiaParaguay.doc. Accessedon 25January 2006. See also: Plataforma Paraguay Sin Excusas contra la Pobreza. *ODM. Objetivos de desarrollo del milenio. Informe alternativo de la sociedad civil – Paraguay. 2000/2005*. Plataforma Paraguay Sin Excusas contra la Pobreza. Paraguay, September 2005.

ed that there are 20,000 people living with HIV/AIDS in Paraguay.[19] The program used for the calculations was developed by a WHO/ONUSIDA working group for global surveillance of HIV/AIDS and STDs, for which PRONASIDA was qualified in a workshop held for Latin America and Caribbean countries in June 2003.

From 1986 until April 20051,036 AIDS cases were notified in Paraguay. At the moment there are 1,036 cases of AIDS and 3,974 persons living with HIV. The rate of annual incidence was 2.35 per 100,000 inhabitants in late 2004, and the rate of prevalence of HIV in the 15 to 49 age range was 0.5% in 2003. The growth of the epidemic is considered to be constant.

Chart. 1
Epidemiological data on Paraguay

Number of notifications of HIV infections	3.974
Number of cases of AIDS	1.036
Number of deaths according to the notification	371
People living with HIV/AIDS	3.603
Estimated percentage sub-registered	80%
Estimated number of people living with HIV/AIDS (2002-2003)	18 mil people
Estimated number of people living with HIV/AIDS (2004)	20 mil people
Estimated number of women (15-49 years old) living with HIV/AIDS (2004)	6.600
% of adult women (15-49 years old) living with HIV/AIDS	33%

Source: Data from the Department of Epidemiology of PRONASIDA, extracted from Fundación Vencer (2004b).

[19] Department of Epidemiology, PRONASIDA in Fundación Vencer (2004).

The largest number of people living with HIV/AIDS live in Asunción and Central (with an internal migrant population) and the provinces that border with Brazil and Argentina, Upper Paraná, Amambay and Itapuã (with an intense flow of people for commercial reasons). These provinces account for 80% of all notifications. With the passage of time, notifications have spread from the big cities like Asunción and Central and reached the border towns. At present there are records of people with HIV/AIDS across the whole national territory, but the profile of the epidemic continues to be concentrated and mostly urban.

Through April 2005, official data show that 74.4% of AIDS cases were concentrated among men, whereas women represented 25.6% of the cases, with 0.7% of ignored categories. The ratio between men and women is 2.9, but there exists a constant growth of infected women since the 1996-1997 period. The largest proportion of infected people are in the 25-49 age range (81.1%). The age group with least frequency of cases is 30-34 years old, followed by the 20-24 bracket. The tendency is for the number of cases to increase between the younger age groups (32.2% of the cases between 15 and 24). Those under 15 correspond to 14.65% of the cases, for both sexes.

The most common form of transmission is sexual, with most notifications being of men who have sex with other men (HSH), when the accumulated cases are analyzed. But at the present moment, heterosexual transmission is registered more frequently. Transmission by blood accounts for 8%, two thirds of this figure being due to infections among users of injectable drugs (UDI). Among these, 80% are men and 70% admit

to having multiple partners. Vertical transmission contributes 5% of notifications, the highest frequency being between 0 and 4 years of age. Among the accumulated cases, 37.8% died.

According to national reports, the epidemic is concentrated in the group represented by sexual workers and HSH, and there is a tendency towards feminization and ruralization. Studies carried out between 2002 and 2003 show that the rates of prevalence are 0.8% for pregnant women from pre-natal clinics, 12% for MSM and 2.6% for sexual workers. Results of surveys on knowledge, attitudes and practices of vulnerable population segments (pregnant women, HSH and sexual workers) show that 62% of pregnant women do not use condoms in their habitual relations and 82% of sexual workers declared that they used a condom in their last meeting with a commercial partner.

4. The AIDS Program: principal guidelines for prevention and assistance

The National Program for Control of AIDS and Sexually Transmitted Infections (PRONASIDA) was set up in 1991, five years after the first case of AIDS was detected in the country. The general objective of the Program is to intensify the national response to the HIV/AIDS epidemic in a intersectorial, participative and decentralized manner, the intention being to lower the incidence of the epidemic and promote better quality of life for those who live with HIV and AIDS. The Program's aims include reducing the present deficiencies in the supply of antiretroviral therapy in an endeavor to obtain and sustain universal access to therapy across the country.[20] PRONASIDA is responsible for expanding the activities involved in prevention and increasing the level of awareness on the problematics of HIV/AIDS on the national level by consolidating alliances between the public and private sectors, non-governmental organizations (NGOs) and people who live with HIV and AIDS (PVHA).

As seen earlier, public health in Paraguay is not totally free. The health sector absorbs 16% of general State spending, 0.5% of which is allocated to PRONASIDA and distributed as follows: 80% is earmarked for purchasing ARV (second-line), 10% for reactives (laboratory exams), and 10% for prevention. There are alliances with international organizations that help prevention activities. PRONASIDA makes available, at no charge, HIV testing, diagnosis, medical consultations, follow-up examinations, antiretroviral medication, psychological care, assistance and counseling.

A 2004 report of the Vencer Foundation, a Paraguayan AIDS/NGO, describes the two profiles of PRONASIDA: an assistential profile whose function is to provide free medical and specialized outpatient, pediatric and adult care, ARV medication and laboratory follow-up studies; and a normative profile that provides for preparing, validating, assigning and qualifying health professionals from different sanitary regions in standards of prevention and inte-

[20] Holst, J. (org.) *Proteção Social Universal e Resposta Integral ao HIV/AIDS. Atuais desafios e perspectivas dos sistemas de saúde na América Latina e no Caribe*. Rede Setorial de Saúde e Proteção Social da GTZ na América Latina e no Caribe. PAHO, WHO, WTO, Brazilian Ministry of Health, September 2005.

gral laboratory assistance through programs on STI/HIV/AIDS with a regional manager and coordinator. It also provides IEC campaigns directed at the general public and specific groups, and prepares material on prevention.[21]

The Program is structured into departments (the Department of Epidemiology/ Epidemiological Surveillance, responsible for carrying out sentinel studies; the Department of Integral Hygiene, responsible for the national guidelines of free, integral and quality care for patients in the sphere of the services; and the Department of Education, responsible for reducing the prevalence of the HIV infection by means of skill-building and prevention campaigns), all submitted to a general committee that coordinates projects.[22]

Assistance to patients with HIV/AIDS is provided by PRONASIDA and the Institute of Social Welfare (IPS). The latter covers approximately 20% of the patients and offers consultations; it does not provide antiretroviral medications, but rather refers patients to the Program. There is a ministerial resolution that establishes the gratuity of VDRL and Elisa tests.[23] Consultations, CD4 and viral-load exams are free. For inpatient care there is a somewhat inefficient security system of the social service that on the average attends to two seropositive persons per month. The other patients requiring assistance have to cover the corresponding costs.

The health system is divided into 18 sanitary regions, each one with a regional director and centers of varying complexity: regional hospitals, district hospitals, health centers and stations (in decreasing order of complexity). The stations only provide vaccines, and in some cases, accompaniment of pregnant women. The hospitals offer full assistance, except for CD4 and viral-load exams, which are only made in PRONASIDA.

There are eight infectologists in the country (all in the private sector), a number that does not guarantee assistance to patients. According to statements from those interviewed, clinical doctors are being trained to provide the necessary care. This training is conducted by doctors from the programs in different clinical areas and in decentralized ways. For example, in vertical transmission for doctors, in management of prevention of vertical transmission for laboratory technicians, in skill-building and counseling for nurses and social workers. According to information provided by activists, up till recently there were few doctors qualified in HIV/AIDS, and the health professionals in general did not even know how to begin the treatment. According to information gathered in the work field, there is little clarity as to which specialists can lend assistance.

In general, the National AIDS Program does not offer consultation services, being a normative and regulatory body. However, this was not the case of PRONASIDA, which was not limited to being a directing body.

[21] Fundación Vencer e BASE Investigaciones Sociales. Relevamiento de las principales debilidades en los Derechos de las Personas que viven con VIH/SIDA en el Paraguay. Documento de Trabajo nº 111. Asunción: Fundación Vencer e BASE Investigaciones Sociales, November 2004.

[22] Coordinator of Projects at the time of the study: Dr. Alma Garnoso. The Program has a staff of 22 permanent employees and 40 under contract, counting administrative technicians and health professionals.

[23] Prior to this resolution, these were paid tests, costing about US$ 7.

Although the program is slowly leaving aside this area of activity, it was compelled to have an assistential profile because there was no other way to provide care for people living with HIV/AIDS. At present, assistance is being transferred to the Institute of Tropical Medicine (IMT), a center of reference for seropositive people that functions together with PRONASIDA and used to receive patients only for inpatient care but has now absorbed patients also for outpatient care. This transition is seen as beneficial, because the patients reported deficiencies in the previous form of assistance.

4.1. Pregnant Women and HIV/AIDS

Data on Paraguay provided by the External Cooperation Unit (Coopex) of the Brazilian AIDS Program report an average of 150,000 pregnant women per year, and the coverage of both prenatal care and hospital child delivery is 60%.The estimated number of seropositive pregnant women per year is 1,200-1,500 (a prevalence of 0.8% according to a sentinel study).There are three hospitals in the country that attend to seropositive gestants (two in Asunción and one in the Central province),but no confirmatory tests are available for the children born of seropositive mothers.There are no available supplies and commodities to substitute maternal milk, and the estimated cost of benefiting an infant with industrialized milk for six months is approximately US$ 152. According to one interviewee, UNICEF is helping maternal-infant prevention and the country wants to implement the rapid test for prevention of maternal-infant transmission. However, in order to for the test to be offered, ARV medication has to be available for the treatment of seropositive mothers and their babies after childbirth.

4.2. Comments on prevention actions

Those interviewed mentioned a lack of resources to develop and implement the prevention component, and warned of the need to intensify campaigns. According to reports from PRONASIDA, at the moment of the field work the program had three ongoing projects investigating HIV/AIDS.

4.3. Evaluation of services and planning for skill-building

In March 2005, an assessment of the services in Ciudad del Este and the Hospital Nacional was carried out by external evaluators with a national counterpart. Some recommendations resulting from this process were: 1) promoting decentralization to ensure medical care and provide ARV for the inhabitants of the interior of the country (at the moment both diagnosis and treatment are concentrated in the capital); 2) assuring the Program's infrastructure; and 3) qualifying health professionals.[24]

The interviews held with civil society mentioned that people, no matter where they lived, need to go to Asunción to receive medications and have their CD4 and viral-load exams,[25] and some even for consultations which should take place in the regional centers, because the health professionals are not qualified.According to a PRONASIDA

[24] Skill-building for health professionals are also included in the international cooperation program (PCI) that Paraguay signed with Brazil, as will be mentioned further ahead.

[25] Interval for carrying out exams: every six months.

report, there is planning for skills-building in order to enable decentralization (first in Ciudad del Este and Encarnación) and distribution of medication in other regions. With the process of decentralization, the country will have seven specialized-care centers for the purpose of offering the patient integral attention closer to their residence town. These centers, which will also deal with psychological care, will function inside the hospitals to guarantee better attention.

Skills-building activities will also deal with the theme of patients' adherence to treatment. According to staff of PRONASIDA, patients' observance to treatment is very low, both in adults and children. Many patients give up treatment, which is the reason why monitoring and evaluation of the anti-retrovirals is being programmed. The reason for abandoning medication is being investigated by an ongoing study across the country. The factors mentioned in interviews for giving up treatment have included stigma, discrimination, side effects, lack of family support, late detection and diagnosis of patients. Some NGOs have been working on the question of adherence with AIDS patients in order to respond to this situation.

5. Civil Society and NGOs in Paraguay

"The relationship with the State is that of brother and enemy. We sleep with the enemy, our eyes are never closed."
(Activist)

NGOs have played a fundamental role in the response to the AIDS epidemic in Paraguay. A document produced by about 50 non-governmental organizations from different areas gathered together at the "Paraguay without Excuses against Poverty"[26] evaluated the indicators of the millennium development goals. With regard to the objective of "combating HIV/AIDS", the document evaluates the tendency of the indicators as "worsening", and envisages no possibility of accomplishment.

Table 2. Objective 6. Combating HIV/AIDS, malaria and other diseases[27]

Aim 7:	By 2015, control and begin to revert the spread of HIV/AIDS
Indicator 18	Prevalence of HIV among pregnant women between 15 and 48 years old
Indicator 19	Rate of prevalence of the use of condoms
Indicator 20	Number of girls and boys orphaned because of HIV/AIDS
Aim 08:	By 2015, detain and begin to revert the incidence of malaria and other endemic diseases
Indicator 21	Rate of mortality associated with malaria (without deaths)
Indicator 23	Rates of incidence and mortality associated with tuberculosis

The Paraguayan NGOs are reflecting and intervening in the sphere of public policies, which shows the maturity and political advance of the social movement. As for

[26] The platform is part of the *Llamado Mundial a la Acción Contra la Pobreza*, a coalition of social organizations from over 70 countries across the world with the aim of sensitizing public opinion and pressuring governments to reconcile business with justice, cancellation of foreign debt, significant increase in the quantity and quality of help for development and efforts national to eradicate poverty.

[27] Plataforma Paraguay Sin Excusas contra la Pobreza. *ODM*, September 2005.

accompanying the millennium goals, the institutions gathered and made a diagnosis of the indicators used. The result of the discussions led to drawing up a list of challenges and priorities for assistance and development in relation to HIV/AIDS, which can be consulted in the publication *Platform Paraguay without Excuses against Poverty. ODM. Development Goals for the Millennium. Alternative report of civil society – Paraguay. 2000/2005*.

Among the NGOs that work on the theme of AIDS, eight are allied in a network whose secretariat is under the responsibility of the Vencer Foundation; there are other NGOs that are not members of this network. These entities, which work in different areas, were mentioned in the interviews:

- PROMESA – Its initial attention was in the area of sexual and reproductive health, later including in its agenda the theme of HIV/AIDS. It started as a social marketing project for male condoms, from 1998 to 2001, with the support of USAID. In the scope of this project it developed a research called "Knowledge, Attitudes and Practices in Sexual and Reproductive Health" of men and women aged between 15 and 35 (CAPS). At present the social marketing activities are not being carried out. Integral care, human rights, reproductive and sexual rights, and the community approach are this NGO's work themes, but its strong points are prevention and communication. For nine years it has run a radio program, a television program and produced 19 informational materials of different formats in the area of of HIV/AIDS. PROMESA is a member of networks such as LACCASO (the Latin-American and Caribbean Council of NGOs that Work with HIV/AIDS) and participates in the National Council of Reproductive and Sexual Health, the Network of HIV/AIDS NGOs of Paraguay, the Coordinating Committee for Children's and Adolescents' Rights (CDIA), the Extended Thematic Group ONUSIDA, the National Forum of Civil Society Organizations, which works with the rights of children and adolescents, and the Latin-American Consortium for Emergency Birth Control (CLAE).
- The VENCER Foundation – is composed of people who live with HIV/AIDS, and has been a leading NGO in the struggle for access to treatment and examinations. It works with advocacy, carrying out denunciations of the constant lack of supplies of ARV medicine and laboratory tests. It engages in political activism before Parliament in order to obtain more resources for treatment, medications and laboratory reactives. It is a member of networks and groups such as the ONUSIDA Thematic Group, forming regional alliances with countries of Latin America. It releases pronouncements, communiqués and denunciations in the media, and works on the preparation of projects. The NGO is also active in counseling couples and in treatment-adherence for people who live with HIV/AIDS. It does not distribute medications. In periods of lack of ARV medication supply it received the support of organizations from Brazil, Argentina and Chile when it requested donations for PVHA. The medications were donated enabling over 100 people not continue treatment without interruption.
- GAYLESBICO – Active in the area of human rights for sexual orientation, this

NGO carries out work at specific times (such as Gay Pride Day).

- EQUIDAD – Organization of people who live with HIV/AIDS.
- Marco Aguayo Foundation – The oldest Paraguayan organization in the struggle against the HIV/AIDS epidemic, it lends assistance and focuses on the theme of humanitarian support for infected people, in addition to developing educational prevention programs.
- ALTERNATIVA – An organization that works with children.
- PREVER – An organization that works to reduce damage due to the use of substances, including the use of injectable drugs, and on specific projects in the area of reproductive health.

Other NGOs that do not belong to the Network were also mentioned in the interviews:

- SIR Foundation – Develops the decentralization project called Alliance for Health, with the support of USAID.
- CEPEP (Paraguayan center for Population Studies) – Paraguay's oldest NGO, active in the area of health care, has private clinics and distributes condoms.
- TATARENDY – Its target public is made up of sex workers.
- Luna Nueva – Works with themes of integral health and HIV/AIDS, its target public being made up sexually exploited girls (there are no seropositive girls among those being assisted).

In November 2004, the first national encounter of people who live with HIV/AIDS was held in Paraguay, with the slogan "For a human, dignified life". The meeting was organized by the Vencer Foundation, and it gathered together people from different regions of the country to analyze the situation of people who live with HIV/AIDS regarding coverage and health care in Paraguay.

Paraguay took part in the II Joint Negotiations on Prices of Antiretroviral and Reactive Medicine in South America and Mexico, organized by PAHO/WHO/ONUSIDA and the Ministries of Health of Argentina, Bolivia, Brazil, Colombia, Chile, Ecuador, Mexico, Peru, Paraguay, Uruguay and Venezuela, and held in Buenos Aires on 2-5 August 2005.[28] The meeting was attended by the following community networks: REDLA+ (Latin-American Network of People Living with HIV and AIDS), RELARD (Latin-American Network for Harm Reduction), REDTRASEX (Latin-American and Caribbean Network of Sex Workers), LACCASO and the Latin ICW (International Community of Women Living with HIV/AIDS).

Beyond the topic of access to medication, emphasis should also be made in respect to the existence of stigma and discrimination suffered by people who live with HIV/AIDS in Paraguay since the occurance of these situations is substantial. The NGOs are tackling this situation, and Paraguay has a law that sets norms on control and prevention of AIDS (Law number 102/91).[29] This law, although only briefly commented on in the interviews, establishes provisions concerning the notification of HIV positive persons and

[28] Convoked by the LAC Community Networks, the meeting was supported by AMMAR/CTA, the International Center for Technical Cooperation (CICT) and Doctors without Borders.

[29] See the appendix.

of AIDS cases, on control and prevention for groups with added risk of infection, control of blood banks, transfusion and other services, laboratories, hospitals, care centers, international travelers, and education on control and prevention of AIDS and associated discriminations to HIV positive persons and AIDS patients

With regard to secrecy of information, the law establishes that the laboratories must notify the Ministry of Public Health and Social Welfare of all positive results of anti-HIV tests, the people infected must have clinical, epidemiological and laboratory follow-up through the proper service, but confidentiality must be respected as to the data on the people infected, as well as the subjects' right to privacy.

Although Law 102/91 prohibits "any type of discrimination against people who have HIV/AIDS, whenever conduct is observed that is free of the risk of proven transmission", at the same time it states that "any person who enters the country with the intention of establishing residence is obliged to take the anti-HIV test in the competent sanitary region; if the test is positive, he/she cannot settle in the country", and "all carriers of HIV are forbidden to practice prostitution". These articles of law touch on profound ethical questions and violate international guidelines and the rights of seropositive individuals.[30]

The law does not speak specifically of access to treatment or medication. There is intense mobilization of activists to change the text of the law with a view to contemplating universal access to medication, laboratory services, and so on.

[30] Law 102/91, articles 22 and 24, respectively.

According to interviewed representatives of civil society, the matter of discrimination and stigma is recognized as a national problem, and this is shown in all social spheres, including government. The problem of HIV/AIDS is minimized in the country and there are no TV campaigns for segments of the population such as men who have sex with men (MSM), transsexuals and sex workers. Prevention materials for PVHA for distribution in schools are sabotaged by some more conservative social segments.

It must be stressed that the presence of Paraguay's civil society still seems timid vis-à-vis the international scenario. Participation in events such as the recent III Latin-American and Caribbean Forum on HIV/AIDS/STI in El Salvador (November 2005), where no reference was found to the participation of Paraguayan NGOs, is important for the strengthening of civil society and its response to HIV/AIDS in the country.

6. Access and Distribution of Medications in Paraguay

The year 1996 saw the start of distribution of ARV medication in Paraguay. According to the interviews, from 1996 to 1998, PRONASIDA was a model program, offering medicine and exams to everyone. From 1996 to 1999, coverage was universal, with viral-load and CD4 exams, but two reasons led to universal distribution of drugs being discontinued, namely 1) the budget was cut in half, and 2) the number of patients increased.

A document of the Vencer Foundation describes the calendar of interruptions in the supply of drugs to people living with HIV/AIDS up to 2004. The first of these

interruptions dates from February 1999, the second occurred between October and December 1999, and the third from April to August 2000. In this period, PRONASIDA requested a donation of medications from Brazil to ensure treatment for AIDS patients. A substantial donation was obtained, but still not enough to meet the country's demand. In that year the laboratory exames on CD4 and viral load were suspended. When funds were supplemented by own government, the country decided to buy medication and supplies and commodities for laboratory exams. The fourth interruption in supplies began in October 2000, when the drugs donated by Brazil was exhausted. Interruptions lasted until January 2001. A request made to extend the resources was only granted in January 2002, when it was possible to obtain the medicine. The fifth problem with supply of medicine and laboratory follow-up occurred between February and April 2001, when the ARVs were resumed for three months, but without reactives for CD4 and viral load. With pressure from the Vencer Foundation and other NGOs and international networks, the budget for purchasing ARVs was re-programmed. From October 2002 to May 2003, Paraguay suffered the longest period without supply of ARVs and laboratory follow-up.

As of November 2003, another shortage: four months elapsed between the signing of re-programming, bidding and purchase of medications, until the medicine finally arrived in February 2004, but it did not last long. At that time there was also a lack of CD4 exams.The ninth interruption in supply occurred between 19 and 26 March 2004 – one week of interrupted medications such as Nevirapina, Lamivudina and others. Laboratory exams were also lacking at this time. During this period, only AZT was distributed, and PRONASIDA was only validating monotherapy, so most of the people living with HIV/AIDS were unable to buy the ARVs. From 3 to 13 May 2004, the supply of Ritonavir was interrupted.

From 17 May to 12 July 2004, the provision of Lamivudina was interrupted, and then all the ARV drugs. Supplies were resumed, but as of 5 August, once again the distribution of Lamivudina was interrupted until the end of October. As for the CD4 and viral-load laboratory exams, until the Vencer Foundation closed the calendar in 2004, these were not provided by PRONASIDA, according to the document, "due to omission on the part of the State to include these requirements in the PRONASIDA budget".[31]

Between 1998 and 1999, during the periods when the supply of medications were suspended, the condition of people who were under treatment since 1996 began to worsen; those who were under triple therapy moved to double therapy and later went without medicine, at the same time as the number of new cases grew larger and the budget grew smaller.[32] This situation violates the international criteria that recommend tritherapy and uninterrupted use of medication.

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[31] Fundación Vencer e BASE Investigaciones Sociales. Relevamiento de las principales debilidades en los Derechos de las Personas que viven con VIH/SIDS en el Paraguay. Documento de Trabajo nº 111. Asunción: Fundación Vencer e BASE Investigaciones Sociales, November 2004.

[32] One of the reasons why the budget diminished, according to one activist, was the belief that everything was under control. The actions and denunciations of civil society, inside and outside the country, were fundamental to political mobilization.

At present the country has two forms of acquiring ARV medication: by direct purchase and by supply via cooperation with Brazil. At the moment, 570 patients receive ARV medication in Paraguay, 70 of whom are children.

7. The Brazil-Paraguay International Cooperation Program (PCI)

In 2003, PRONASIDA, the Network of NGOs and ONUSIDA presented to the Brazilian Government a project that included among its activities the start of triple therapy for 100 people living with HIV/AIDS for the period of one year, in addition to capacity building and training health professionals in caring for and managing patients. The implementation of the International Cooperation Project (PCI) between Brazil and Paraguay began in 2004 with the purpose of transferring technology in assistance and clinical management of HIV/AIDS patients and promoting access to anti-retroviral (ARV) medication.[33] The PCI is being developed with the financial support of GTZ and covers the areas of 1) assistance to people living with HIV and AIDS; 2) planning and managing AIDS programs; 3) promoting human rights; and 4) strengthening civil society.[34] The PCI aimed to grant annual treatment with ARV medication from Brazil to 100 patients (and later on to 400) in Paraguay. The agreement also included training professionals in the area of assistance, surveillance, prevention and management for integral care of people living with HIV/AIDS, and projected strengthening the local programs and reference centers for assistance, with a view to making the actions sustainable. Another aim was to analyze the conditions for producing generic anti-retrovirals in the country.[35]

The specific objectives of the Brazil-Paraguay PCI:[36]

- To train Paraguayan health professionals from the National Health System to carry out treatment strategies for HIV infection, including anti-retroviral treatment;
- To strengthen the capacity for planning, managing and monitoring the actions of governmental and non-governmental responses to AIDS on the part of the Paraguayan Ministry of Health and the non-governmental organizations active in the combat against the epidemic;
- To create mechanisms with a view to strengthening civil society, especially the NGOs active in the area of AIDS, to engage in advocacy actions related to the epidemic.

The PCI includes the WHO "3 by 5" principles, furthering treatment and access to medication through its action. Among the more noticeable impacts would be promotion and functioning of the PCI, a 40% reduction of the national costs of ARV medication, and creation of a bank of medications between NGOs and GOs. According to the document *Universal Social Protection and Integral Response to HIV/AIDS: current challenges and perspectives of the health systems in Latin America and the*

[33] *Proteção Social Universal e Resposta Integral ao HIV/AIDS. Atuais desafios e perspectivas dos sistemas de saúde na América Latina e no Caribe.*

[34] Source: PN DST e Aids. Brazil, 2006.

[35] *Proteção Social Universal e Resposta Integral ao HIV/AIDS. Atuais desafios e perspectivas dos sistemas de saúde na América Latina e no Caribe.*

[36] Source: PN DST e Aids.

Caribbean, actions in the scope of the PCI are facilitating care for people living with HIV/AIDS in Paraguay.

Within the framework of the agreement with the Brazilian Ministry of Health to provide medications for patients in the Program, one of the points envisaged was adherence to treatment with ARV. According to a Program staff, a protocol was prepared

Chart 2. Principales números

Estimated number of people living with HIV/AIDS in need of ARV treatment (20% of the estimate for PVHA)[37]	3.000
PVHA identified by the PNLS to begin treatment	700
Number of patients receiving ARV in Paraguay[38]	571
Number of patients receiving ARV through the PCI agreement	100[39] 110[40] 261[41]
Number of patients receiving ARV through PRONASIDA	310
Number of children receiving ARV through PRONASIDA	74

Source: PN DST e Aids/Ministry of Health of Brazil, PRONASIDA, interviews and others.

[37] Source: Brazil, 2006.

[38] Source: Information obtained in field work.

[39] Source: Brazil, 2006.

[40] Id.

[41] Source: Information obtained in field work.

[42] Organization: Cíntia Pereira Nocentrini and Judit Lia Busanello (Brazil, 2006).

[43] The technicians Ana Maria Caballero de Arestivo and Ivan Allende took part (Brazil, 2006).

[44] The medication was delivered personally by Eduardo Filizzola (Brazil, 2006).

Chart 3. Calendar for the Brazil-Paraguay Cooperation Program

10/27/2003 to 11/07/2003	Course on Clinical Management for Paraguayan technical staff, São Paulo, Brazil.
03/16/2004	Shipment of the first medications, for 100 patients, to cover the period of 3 months.
05/31/2004 to 06/02/2004	Training Course for the Coordination of the Paraguayan Program on STD/AIDS in, Brasília/DF, to study the Brazilian response to HIV/AIDS. The agenda included visits to the Brazilian National Program for STD and Aids, health services and NGOs.
06/28/2004 to 07/02/2004	Mission conducted by Mauro Teixeira to (COOPEX, PN-STD/Aids) and Denise Lotufo (technical consultant in charge of the PCI Paraguay Project) to discuss extending the PCI, including the border region of Foz do Iguaçu and Ciudad del Este, and universal availability of ARV medications, increasing the number of treatment from 100 to 400. On this occasion, new activi ties were chosen for inclusion in the Work Plan.
07/21/2004	Shipment of the second lot of medications to Paraguay, sufficient for 100 patients for a period of 6 months.
09/30/2004 to 10/03/2004	Paraguay holds a course in Asunción on counseling skills- this activity being included following the mission to expand the PCI.[42]
11/21/2004 to 11/25/2004	Workshop held in São Paulo to train professionals in managing HIV infection in adults, adolescents and pregnant women.[43]
12/29/2004	Shipment of the third lot of medication to Paraguay for the treatment of 300 patients for a period of 3 months. Since the medication ofthe second shipment was depleted on 10 January 2005, according to information given by Mrs Águeda Cabello, authorization was given to use this medicine to follow up treatment of the 100 patients already under in therapy, as well as including 200 new patients.[44]
04/04/2005	Five Paraguayan doctors took part in theoretical-practical training in integral care, opportunistic infections and STD, in the São Paulo CRT.

Source: COOPEX (External Cooperation Unit), PN STD and Aids. Brazil, 2006.

Chart 4. Estimates for Shipment of ARV Medication from Brazil to Paraguay

Paraguay - (UNICEF sent 400 treatments)						
Medications	**1st shipment 16/3/2004 3 months coverage**	**2nd shipment 21/7/2004 6 months coverage**	**2nd compl. shipment 29/12/2004 3 months coverage**	**3rd shipment 26/5/2005 2 months coverage**	**4th shipment 2/9/2005 5 months coverage**	**5th shipment 1st- 2006 6 months coverage**
AZT+3TC (tablet)	5.520	11.040	47.220	0	126.600	164.700
AZT 100mg (capsule)	1.800	3.600	5.400	86.800	12.000	12.000
D4T 30mg (capsule)	2.640	5.280	7.920	3.540	17.640	17.640
D4T 40mg (capsule)	5.400	10.800	16.200	7.200	36.000	36.000
3TC 150mg (tablet.)	2.520	5.040	7.560	28.680	16.800	16.800
DDI 100mg (tablet.)	16.020	32.040	48.060	21.360	106.800	
DDI 25mg (tablet.)	2.040	4.080	6.120	2.760	13.620	
NVP (tablet.)	8.040	16.080	56.220	25.020	125.040	161.040
IDV (capsule.)	16.020	32.040	48.060	21.420	106.830	106.830
RTV (capsule.)		25.200*		4.200	25.200	29.400
Observación:	100 treatments	100 treatments	300 treatments	400 treatments	400 treatments	400 treatments

Fuente: Área de manejo logístico de medicamentos /AIDS, UAT/ PN-DST/AIDS. Brasil, 2006.

that consisted primarily in an interview to evaluate the start of treatment by means of semi-structured models and a questionnaire of symptoms. This instrument is used at the initiation of treatment and has been complemented by other instruments related to types of problems.

The continuity of the PCI agreement, is seen as a pillar to treatment adherence in the sense that it aims to prevent an interruption of the supply of medication in one hand, and on the other, to ensure production of drugs. However, according to activists, the question of adherence is mostly treated by the NGOs and there is no department within the AIDS Program that has a position on the matter.

Below we show the principal numbers relating to the HIV/AIDS epidemic in Paraguay, including epidemiological data on anti-retroviral medication for people living with HIV/AIDS. Note that in some cases we came across some divergence between the data according to the source quoted.

According to an evaluation of the Brazilian Ministry of Health, the Paraguay Project in the scope of the PCI has yielded satisfactory results: the activities have been carried out swiftly and efficiently and the patients have gradually been included in the treatment program. Two shipments of anti-retroviral medication were sent to Paraguay, the first to attend to 100 patients and the second to continue treatment of these patients and attend to another 200. Up to late February 2006, it was aimed to send medication to 400 patients, as established in

the recent agreements between the governments of Brazil and Paraguay.[45]

7.1. Assistance and access to medications in the context of the PCI: what the Paraguayans think

Activists have reported problems of supply and availability of medicine since the start of the epidemic. Civil society informs that while there is a conception of universal access (whereby all who need medication receive it), the current coverage is not universal because there is sub-registration of the number of people living with HIV/AIDS.[46]

According to some interviewees, thanks to the PCI, Paraguay is able to offer treatment without any therapeutic breaches, which is important for resistance and adhesion. For a certain time the medication arrived in Paraguay in fractioned form. Then there was a formalized shipment by the PCI, with the donation of medicine by Brazil to Paraguay. Previously, medication was received sporadically and through NGOs, and occasionally state governments. Some activists mentioned medications being obtained in private consulting rooms or even from persons living with HIV/AIDS, especially in the period when medication was scarce. Expanding the offer of medication is seen by some activists as a joint conquest of civil society and the AIDS Program. However, one of the flaws concerning implementation of the project by Paraguay is that with prophylaxis for opportunistic infections not being provided in the PCI, Paraguay should provide it as counterpart, but the activists claim that it does not do so.

In the assessment of some interviewees, the positive impact of the donation of medications by Brazil was very strong, because prior to that there were problems in providing anti-retroviral medication for the patients, which allows for universal coverage of treatment for patients. This did not happen before, which caused constant interruptions in the treatment, seeing that the budget corresponded to a third of what was necessary. The medications were supplied according to international criteria. When they were finished, a new purchase had to be made, which could take from two to three months, due to budget injunctions.

There are currently about 50 patients presenting resistance to the ARVs, and these need to undergo examinations such as genotying to evaluate their resistance. The test is costly (approximately US$ 300 per patient) and the patients have no means of paying. Such exams are not performed in Paraguay, but possibly in places like Brazil and Argentina. This is a fundamental point to be debated.

An investigation carried out by the NGO PROMESA stated that there are people in therapy using four and five drugs, and others are in bitherapy and monotherapy. According to one interviewee, some people are showing resistance to the ARVs, but there is also a great deal of controversy regarding the protocol for treatment and concerning clinical management and doctors' prescriptions (which medicine should be applied or not, which ones are appropriate for the specific situation of a certain patient). "I'm not a doctor, but I hear from

[45] Brazil, 2006.

[46] As mentioned at the beginning of the document, in Paraguay there is an estimated total of 15,000 HIV seropositive individuals.

PVHA and doctors that there are controversies. This information is not based on any research but on listening to patients and health professionals", says the interviewee. It was reported that there was possible influence from the pharmaceutical industry with regard to medical prescription for ARVs.

The PCI contemplates medication for the start of the therapy (first-line). However, about 30% of the people are under second-line treatment, for which no generics are produced in Brazil, meaning that these persons are not contemplated by the donations that come from Brazil, so they have to be included in the purchases from the Paraguayan Program. In addition, the PCI does not envisage treatment of AIDS for children.[47]

At the time when ARV medication was not available (prior to the PCI), some activists reported that Paraguay was purchasing medicine directly from other countries. At present the purchase of second-line medications is done by bidding, following the same model as in Brazil.

As mentioned by some of those interviewed, since the donation of medicine by Brazil to Paraguay, there exists the possibility of a first, second and even third combination of medicines being created; when it is necessary to make a change to a fourth scheme, the second-line medications bought directly by the State are used.

Besides the cooperation with Brazil and the allocation of own resources in the Government's proposal for the purchase of medications, Paraguay follows the "3 by 5" initiative proposed by WHO, initially agreed upon by the countries present at the Special Session of the General Assembly (UNGASS) in 2001 to promote treatment. Nevertheless, this initiative does not guarantee access to ARVs, but only strengthens the activities to promote treatment.

The end of the cooperation with Brazil is seen by those interviewed as the discontinuity of universal access to medication. One of the ways to keep the coverage would be to produce the medications internally, but at the moment Paraguay does not produce them. According to the evaluation of PRONASIDA, there is interest in producing the medicine locally, and this is even included in the original project established with Brazil. Private laboratories are interested in producing and selling the medicine to the State, but the demand (something around 2,000 generics) does not justify such an undertaking. Activists consider that there are no feasible conditions for such. This question is of the utmost relevance, and should be examined in more depth.

The country has a sanitary surveillance system for the regulation of pharmaceuticals. When the medicine arrives, a register has to be opened. There is a laboratory to examine the material and it takes between two and three months for the substance to be validated. However, as far as the medicine from Brazil is concerned, there is no quality control on the part of Paraguay, since the medications are sent with the proper international-level quality-control certificates.

Paraguay has participated in qualifications related to systems of monitoring the follow-up of patients under ARV therapy. The country aims to create a computerized reg-

[47] First-line medicine (AZT, 3TC, AZT + 3TC, DdI, D4T, Indinavir and Nevirapina) are generic medications produced in Brazil. Second-line medicine (for example, Efavirenz and Kaletra) are imported.

istration system like the system of logistical control for Brazilian anti-retroviral medicine.

Besides access to ARV medication, a segment of society feels insecure about a program showing signs of instability. For this reason, some people buy more medicine than they need and keep it in stock, fearing possible shortages or interruptions in supply. This procedure can cause damage to other people living with HIV/AIDS who need the medication. Facts such as this reveal people's worry about the direction of a health policy that is not presented with transparency.

Also reported was a kind of "commerce" of medications ("many people sell their medicine because they have nothing to eat", according to one activist). Such a situation speaks of a degree of poverty that contributes to the vulnerability of some groups to HIV/AIDS. It is not just a matter of ensuring the availability of medicine, but of considering the quality of assistance, in a broader sense, which is offered to the public (including social security).

The theme of intellectual property is only briefly discussed by the NGOs. "At the moment we are more concerned about the supply of medications than appealing for generics", said one interviewee, while another says that they are accompanying the Brazilian discussions. There is no patent law in Paraguay, but the country is joining the World Trade Organization (WTO). Despite the lack of technical conditions to produce generics, there is a segment of private initiative interested in outsourcing the service, which would also guarantee lower prices. The cooperation project with Brazil is viewed with interest, because this implies qualifying professionals and transferring technology so that one day Paraguay will also be able to produce its generic medicine.

Based on the interviews, it is possible to gather that while the activists see little chance of producing ARV medications locally, some of the Program staff claim that the country could become responsible for its own production in the near future, with private laboratories, stimulated by the PCI.

7.2. Recommendations for anti-retroviral therapy in Paraguay

The last reformulation of the norms and recommendations for anti-retroviral treatment in Paraguay dates from 2003.[48] The preparation of these norms involved a technical group assigned to review the notes, later on validated by members of scientific commities and then implemented.[49] According to information from civil society, the NGOs are not part of this technical group.

This protocol was based on international protocols from Brazil, Argentina and other countries. Activists mentioned in the interviews that in times of shortage of medication there were many denunciations against doctors prescribing medicine without using a protocol. This meant that some patients started their treatment with a certain medication when they should have been using another.

At the period when data was collected, the norms were being reformulated and the

[48] Data from the interviews with Nicolas Aguayo and Mirta Ruiz. However, the information that the first national.

[49] Workshops are conducted to diffuse the norms (skill-building workshops). Generally of a national character, they train capacitators who go to the interior of the country to train their colleagues.

country was preparing a new document. There is also a document for the prevention of maternal-infant transmission, based on high-efficacy therapy (triple therapy).

In this context, it is convenient to ask the following questions:

What is the space for action and possible intervention by civil society regarding preparing policies on access to treatment?

What is Brazil's role with regard to the norms and recommendations for anti-retroviral treatment in Paraguayan adults and adolescents?

7.3. The Proposal for the Global Fund

Paraguay is not a recipient of resources coming from the Global Fund. A 2004 document of the Vencer Foundation points out that the first proposal for the Global Fund against AIDS, Tuberculosis and Malaria was presented in 2002 by the Mechanism for Country Coordination, comprised of the Government, the Network of NGOs working with HIV/AIDS, grassroots organizations, organizations of people living with HIV/AIDS, international agencies, PAHO, WHO, the Military Forces, the Society of Infectology and other institutions in 2002, but it was turned down. There was contribution by external consultants financed by PAHO. In another proposal presented, approval was given only to the Project for Tuberculosis, with the AIDS proposal left for a fourth round of evaluation, when once again it was rejected, and then the country appealed to the Global Fund.

A new proposal presented for the fifth round of the Global Fund is awaiting the result. Paraguay presented four projects to the Global Fund, but so far these have not been accepted. The proposals were drafted with the help of consultants from GTZ, PAHO, WHO and ONUSIDA. As for the reasons for rejection, it was mentioned that the Global Fund had criticized the proposal for containing no reference to the participation of civil society or the way it works with the more vulnerable groups, such as MSM and sex workers. Those interviewed say that internally the proposal was considered good and that they did not know why it was not accepted, seeing that they really need the resources of the Fund.

According to one of the interviewees, prior to the project proposal to the Global Fund, one could see that the cause of mortality among the seropositive patients was pneumonia rather than tuberculosis. If people at least received prophylaxis for pneumonia, this would prevent at least some morbidity and mortality among the patients.

The last proposal planned for the purchase of medications (ARV and for opportunistic infections). Drs Ivan Allende, Maria Ines Lopez and Mirta Ruiz Dias were in charge of detailing the medication schemes that would be needed. According to some of those interviewed, there seems to have been a misunderstanding about whether the Global Fund was more dedicated to prevention or to integral care for people living with HIV/AIDS.

8. Final Considerations

One of the questions we faced in preparing this case study, and which certainly reflects the difficulties of setting up external cooperation programs, has to do with the need to map out and possess previous knowledge of the laws and socio-cultural

dynamics of the countries with which cooperation is to be established. We draw attention to the importance of a minimum understanding of the local society, that is, not only knowing its legislation but also understanding the current representation of the HIV/AIDS epidemic in the country and the political processes related to its response. This understanding means, for example, knowing the country's health structure, the configuration of the HIV/AIDS epidemic, the mapping of the social groups most vulnerable to the epidemic, the degree of articulation within civil society, and the interface between the social movement and public policies.

The considerations of those interviewed, among other information gathered by the study, lead us to the conclusion that the PCI represents a possibility of strengthening the Paraguayan responses to the AIDS epidemic. We speak of strengthening because in Paraguay the memory of the interviewees recalls a phase of responses, actions and policies for control and prevention of STD/AIDS prior to the PCI, despite the fact that they presented functional difficulties. In the case of Paraguay, which has indeed been implementing a program for STD/AIDS, the PCI can contribute towards re-structuring or strengthening the Program, unlike other countries that lack a governmental structure for an AIDS program and whose structure would be helped by the PCI and other cooperation programs. As a recommendation for the countries that sign the agreement, we note that the PCI, among other international cooperation agreements, should take into account different intervention approaches in accordance with the local historical and political situation and how structured the local responses are.

In the case of Paraguay, therefore, the PCI strengthened, extended and improved the access of seropositive persons to anti-retroviral treatment, as well as the array of possible combinations among ARVs. In addition, the PCI is also providential in relation to the technical training of health professionals in caring for people who live with HIV/AIDS. This training is important at a moment when the country aims to decentralize its actions and take them to the rest of the national territory. This fact should be taken into account in evaluating and following up on the PCI.

The principal challenges that we have identified in this study, after attempting to understand the Paraguayan system, are related to the sustainability of care for people living with HIV/AIDS, especially if we consider the current difficult situation regarding sustainability faced by Brazil in order to guarantee its own supply of ARV drugs.

Thus, we arrived at the following questions:

1) Occuring is an interruption in the Brazilian production of medications and subsequent interruption in sending medications from Brazil to Paraguay, and if Brazil does not manage to produce second-line medications, what will Paraguay do to maintain the access of seropositive persons to medication?

2) Does Paraguay envisage other sources to go on guaranteeing access of people living with HIV/AIDS to anti-retroviral medication, in addition to donations? We trust that the recommendations included in this study, which were discussed on the occasion of the interviews and the seminar held in Brazil, and which can be found annexed at the end of this publication, can

contribute to the public debate and find answers and alternatives to these questions.

9. Bibliographical References

BRASIL. *Situação do PCI Paraguai.* Documento PN DST e Aids. Assessoria de Cooperação Internacional (COOPEX). Ministério da Saúde. Programa Nacional de DST e Aids, fevereiro de 2006 [comunicação eletrônica, fevereiro de 2006].

FUNDACIÓN VENCER e BASE Investigaciones Sociales. Relevamiento de las principales debilidades en los Derechos de las Personas que viven con VIH/SIDS en el Paraguay. Documento de Trabajo nº 111. Asunción: Fundación Vencer e BASE Investigaciones Sociales, noviembre 2004.

_____. *Por una vida humana y digna. Memória del 1er. Encuentro Nacioanal de PVVS.* Fundacion Vencer. Paraguay, 2004.

HOLST, J. (org.) *Proteção Social Universal e Resposta Integral ao HIV/AIDS.Atuais desafios e perspectivas dos sistemas de saúde na América Latina e no Caribe.* Rede Setorial de Saúde e Proteção Social da GTZ na América Latina e no Caribe. OPAS, OMS, OIT, Ministério da Saúde do Brasil, setembro de 2005.

MESA-LAGO, C. *Las reformas de salud en América Latina y el Caribe: su impacto en los princípios de la seguridad social.* Comisíon Económica para América Latina y el Caribe (CEPAL). Naciones Unidas, diciembre de 2005.

ONUSIDA. *El SIDA em Paraguay. Situação Epidemiológica.* Junio 2005. www.onusida.org.ar/paraguay/docs/EpidemiologiaParaguay.doc. Acessado em 25 de janeiro de 2006.

PLATAFORMA Paraguay Sin Excusas contra la Pobreza. *ODM. Objetivos de desarrollo del milenio. Informe alternativo de la sociedad civil – Paraguay. 2000/2005*. Plataforma Paraguay Sin Excusas contra la Pobreza. Paraguay, septiembre de 2005.

ROJAS, Mer. *Situación en Salud. Paraguay 2003*. Ministerio de Salud Pública y Benestar Social. Dirección de Planificación y Evaluación. Centro de Documentación. Año VI. 2004. www.mspbs.gov.py. Acessado em 17/03/2006.

General Recommendations

During the Seminar "Cooperation, Social Mobilization and Decentralization of Public Policies on HIV/AIDS in Latin America" sponsored by ABIA in Rio de Janeiro on 7-9 February 2006, a set of observations and recommendations were pointed out by the participants based on the discussions held for the purpose of contributing the enhanced participation of civil society to the national and international responses to the AIDS epidemic, as well as establishing partnerships and participative South-South cooperation agreements between countries.

Regarding South – South cooperation agreements and processes, the need was seen to:

1 Create mechanisms for the involvement of representatives of civil society from the start of the process of preparing the proposals for cooperation projects, that is, involvement both in the planning phase and in the phase of execution and evaluation.
2 Promote advocacy and intercede so that free-trade treaties, as well as other cooperation agreements, do not overlay commercial interests on interests of public health.
3 Undertake diagnoses prior to preparing and implementing cooperation projects and their actions, including clarity as to the roles of the key actors and strategies in cooperation actions.
4 Document and lend more transparency to the reports and documents related to the processes and results of international cooperation, allowing for diffusion of information on the projects, both for government actions and those of civil society partnerships, with a view to more effective social control and continuity of actions.
5 Guarantee greater articulation and partnership among the various areas (government, education, research, communities affected by the epidemic, NGOs and networks) in order to favor the use of the existing diversity of methodological and operational strategies, thereby valorizing stronger interfaces between government and civil society.

6 Advocate with the government non-acceptance of violations of the human rights of groups vulnerable to HIV/AIDS (drug users, sex workers, homosexuals, etc) and people who live with HIV/AIDS in the countries where cooperation is practiced, so that they can participate effectively in actions in the various areas without suffering discrimination and persecution, with due preservation of the right to confidentiality.
7 Guarantee, within the terms of cooperation between the Brazil Government, UNAIDS and other Governments, the commitment of the Government that receives technical or financial cooperation to comply with professional ethical principles in prevention and assistance actions directed to those living with HIV/AIDS and the general population, with emphasis on the right to secrecy and confidentiality regarding serology for HIV.

With regard to universal access to AIDS treatments, proposals were made concerning:
1 Joining efforts (regional and international) directed towards reducing the prices of anti-retroviral medicine (ARV) and promoting strategies for expanding effective access to treatment and supplies and commodities for prevention, including monitoring by civil society of regional and bilateral treaties that refer to intellectual property and the use of trade-related aspects of intellectual property rights (TRIPS) flexibilities.
2 Carrying out studies on the legislation of the countries that sign the term of international cooperation during the phase of diagnosis prior to preparing and implementing cooperation projects, thereby enabling the establishment of different forms of partnership and cooperation in the area between the countries
3 Divulging the cooperation proposals, thus permitting greater clarity and transparency on the counterparts agreed upon on the part of the State in the international cooperation agreement so that the civil society organizations can enjoy greater control over the use of these agreements and the continuity of actions.

APPENDIX 1
Workshop Program

Cooperação, Mobilização Social e Descentralização das Políticas Públicas em HIV/AIDS na América Latina

07 a 09 de fevereiro de 2006 - Rio de Janeiro - Brasil

Programa

1º dia: 07/02

Painel:
O papel das ONG/Redes brasileiras na cooperação externa
Moderadores:
Eduardo Barbosa (SCDH - PN DST e Aids)
José Araújo Lima (AFXB)
Frei Lunardi (Pastoral da Aids)
Paulo Paes (ONG AZUL - Programa Fronteira Oeste)
Cláudio Pereira (GIV)
Comentários:
Narda Tebet (Pela Vidda Niterói)

2º dia: 08/02

Mesa de abertura
Veriano Terto Jr. e *Cristina Pimenta* (ABIA)

Apresentação da 1ª Versão do Estudo de Caso:
Acesso a medicamentos na América Latina: Experiência Paraguai
Moderador:
Veriano Terto Jr. (ABIA)
Expositora:
Ivia Maksud (ABIA)
Comentários:
Jorge Beloqui (GIV)
Mirtha Ruiz (Vencer)
Andrés Vargas (IDH)

Apresentação da 1ª Versão do Estudo de Caso:
Acesso a Medicamentos na América Latina: Experiência Bolívia
Moderador:
Julio César Aguilera (REDVIHDA)
Expositora:
Luciana Kamel (ABIA)
Comentários:
Juan Carlos Raxach (ABIA)
Aurora Gaona (Equidad)
Roberto Parra (RedBol)

3º dia: 09/02

Apresentação do Estudo de Caso
Descentralização das Políticas Públicas: Experiência do Rio de Janeiro
Moderadora:
Kátia Edmundo (CEDAPS)
Expositor:
Alcindo Ferla
Comentários:
Denise Pires (SES-RJ)
Ruben Mattos (IMS/UERJ)
Juliano Lima (Dir. Planejamento Estratégico - FIOCRUZ)

Apresentação do Relatório
Controle Social e Políticas Públicas de HIV/AIDS no Estado do Rio de Janeiro
Moderadora:
Cristina Pimenta (ABIA)
Expositora:
Alcinda Godoi
Comentários:
Maria Inês Bravo (FSS/UERJ)
Roberto Pereira (Fórum de ONG/AIDS/RJ)
Carlos Duarte (SCDH - PN DST e Aids/MS)
Roberto Pereira (Fórum de ONG/AIDS/RJ)
Carlos Duarte (SCDH - PN DST e Aids/MS)

APPENDIX 2
NGOs Participants List - Bolivia

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APPENDIX 3
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